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Disabling Menstrual Barriers

Investigating and addressing the barriers to menstrual hygiene management that young people with disabilities face in the Kavre district, Nepal

JANE WILBUR

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Department of Clinical Research

Faculty of Infectious and Tropical Diseases

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

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Research group affiliation: International Centre for Evidence in Disability

Declaration

I, Jane Wilbur, confirm that the work presented in this thesis is my own. Where data and information have been derived from other sources, I confirm that these have been indicated in the thesis.

Student signature: [redacted] Date: 8 December 2021

Abstract

Background:

People with disabilities face inequalities in many areas of life, so are likely to experience poor menstrual hygiene management (MHM). Evidence or interventions to support MHM for this population is lacking.

Study Aim:

To develop an MHM behaviour change intervention for young people with disabilities in Nepal and assess its feasibility.

Methods:

The Behaviour Centred Design's five steps were used to develop the MHM intervention. *Assess*: systematic review of MHM requirements of people with disabilities and coping strategies. *Build:* analysis of Nepal's MHM and water, sanitation and hygiene policies, and a qualitative study exploring MHM behaviours of young people with disabilities in the Kavre district. *Create:* The "Bishesta" campaign - an MHM behaviour change package for young people with intellectual impairments (hereto referred to as 'young people') and their carers. *Deliver:* Implementation of the Bishesta campaign to 10 young people and carers in Kavre. *Evaluate*: a feasibility study of the campaign.

Key findings:

The systematic review highlighted limited evidence about the barriers to MHM that people with disabilities and their carers face. People with intellectual impairments experienced the most negative outcomes, but only one MHM intervention was identified for this population. Within Nepal, disability was insufficiently addressed across policy, guidance and implementation. The qualitative study supported the findings of the systematic review, so people with intellectual impairments and their carers were targeted in the Bishesta campaign. The campaign was delivered through three group training modules and household visits; 'period packs' containing storage bags, a bin and MHM visual stories were distributed. The campaign was delivered with fidelity, and all target behaviours improved.

Conclusion:

People with disabilities in Nepal, particularly those with intellectual impairments, have large unmet MHM needs. The Bishesta campaign could support MHM for this group but requires efficacy testing before scaling up.

Format of Thesis

This thesis is formatted in the “**Research Paper Style**”.

Chapter One, An introduction to disability and menstrual hygiene management provides an overview of disability, how it is conceptualised, and how disability and poverty reinforce each other to increase vulnerability and poor health. It defines menstrual hygiene management (MHM), describes MHM interventions and delivery mechanisms, explains the importance of considering MHM and disability together, and sets out the original hypotheses held before conducting the PhD study. It details how disability and MHM are included explicitly and implicitly in the Sustainable Development Goals and international human rights. The chapter covers how the Government of Nepal has committed to being a disability-inclusive state and explores disability and MHM in the country.

Chapter Two, Methodology: Approaches, frameworks, and guiding principles frames the research conducted and presents the aim and objectives of the PhD study. This chapter introduces the study populations, the conceptual frameworks (Socio-ecological framework for MHM, the Behaviour Centred Design, and the Feasibility study framework) and the approaches applied. The PhD thesis is structured according to the Behaviour Centred Design’s five-step process for developing a behaviour change intervention: *Assess, Build, Create, Deliver* and *Evaluate* (ABCDE). The main researchers, implementers and their experiences relevant to the PhD study are introduced. My epistemological position is documented before explaining the qualitative data analyses methods applied. The specific methods are outlined in the respective chapters.

Chapter Three Paper One: Systematic review of menstrual hygiene requirements, its barriers and strategies for people with disabilities (1) (Assess step). This paper presents the systematic review of the global peer-reviewed literature on the MHM requirements, its barriers and strategies for people with disabilities and their carers. The chapter preamble includes a summary of articles produced on disability and MHM after Paper One was published and the key findings.

Chapter Four, Paper Two: Exploring the MHM policy and practice context in Nepal (2) (Build step). This article describes the result of the assessment of disability in Nepal's policy and guidance documents relevant to MHM and WASH, investigated through policy formulation and implementation in the Kavre district, Nepal.

Chapter Five, Paper Three: Investigating the barriers to MHM that young people with disabilities and carers face in the Kavre district, Nepal (3) (Build step). This paper reports the findings from the qualitative study, which describes the needs and barriers to MHM faced by individuals with disabilities and their carers in the Kavre district, Nepal.

Chapter Six, Paper Four: Developing an MHM behaviour change intervention for people with intellectual impairments and their carers (4) (Create step). Paper Four documents the process of developing an MHM behaviour change intervention for people with intellectual impairments and their carers, using the Behaviour Centred Design.

Chapter Seven, Paper Five: The Bishesta campaign: an MHM intervention for people with intellectual impairments and their carers (5) (Deliver step). This paper presents the content of the Bishesta campaign and how it was delivered to the target group of young people with intellectual impairments and their carers in the Kavre district.

Chapter Eight Paper Six: Feasibility study of an MHM intervention for people with intellectual impairments and their carers in Nepal (6) (Evaluate step). The findings from the feasibility study of the Bishesta campaign are presented in this chapter.

Chapter Nine: Discussion and conclusion summarises findings from the study, and critically appraises the conceptualisation of MHM using the adapted Socio-ecological framework for MHM, the application of the BCD and the Feasibility study framework in this PhD study. It reflects on participatory processes and how these fit within the existing literature. The intervention developed is considered and implications for future research and practice.

A ‘Preamble’ is included at the start of Chapters 4, 5, 6, 7, and 8, which include published papers. The Preamble presents the context for the paper, the aims of the research, an overview of the methods applied, and how findings from the preceding chapters informed the current research activities.

Appendices contain supporting materials for the published papers, and feasibility study data collection tools, which are referred to in the Discussion within Chapter Nine.

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Finally, Duncan and Maya, thank you for your love, unwavering support, encouragement, and always making me laugh.

List of Abbreviations

ABCDE	Assess, Build, Create, Deliver and Evaluate
BCD	Behaviour Centred Design
CBR	Community Based Rehabilitation
CEDAW	Committee on the Elimination of Discrimination against Women
CIUD	Center for Integrated Urban Development
DSSN	Down Syndrome Society Nepal
FGD	Focus group discussion
HBCC	Hygiene Behaviour Change Coalition
HIC	High income countries
ICED	International Centre for Evidence on Disability
ICF	International Classification of Functioning, Disability and Health
KIRDAC	Karnali Integrated Rural Development and Research Center
LMICs	Low- and middle-income countries
MHM	Menstrual hygiene management
NFCC	The Nepal Fertility Care Centre
NGO	Non-governmental organisation
NHRC	Nepal Health Research Council
OPD	Organisation of Persons with Disabilities
PMS	Pre-menstrual Syndrome
RTWS	The right to water and sanitation
SDG	Sustainable Development Goal
SRH	Sexual and Reproductive Health
ToC	Theory of Change
UN	United Nations
UNCRPD	United Nations Convention on the Rights for Persons with Disabilities
UNICEF	United Nations Children’s Fund
WASH	Water, sanitation and hygiene
WEDC	Water and Engineering Development Centre
WG	Washington Group
WHO	World Health Organization
YLD	Years of healthy life lost due to disability

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Chapter 1 An introduction to disability and menstrual hygiene management

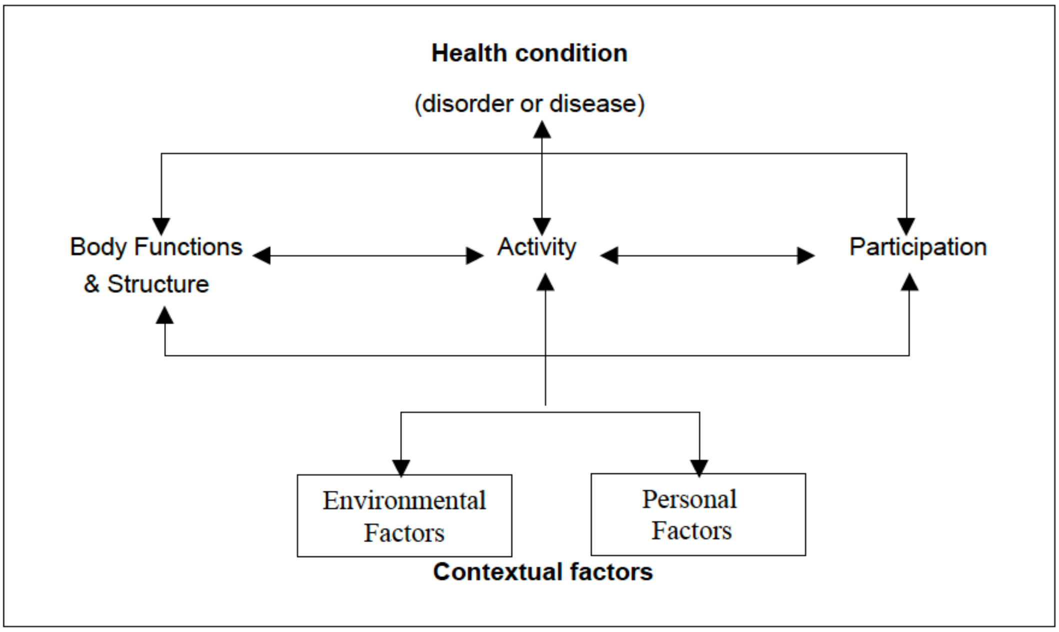
Chapter 1 frames the thesis by introducing disability and menstrual hygiene management (MHM), as well as explaining why MHM is important to disability globally and in the Nepal context. Subsequent chapters will explore these issues in greater detail.

1.1 Disability

A person with disabilities is defined by the UN Convention on the Rights of Persons with Disabilities (CPRD) as a person who has a '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' (7). This definition aligns with the International Classification of Functioning, Disability and Health (ICF), described below, and is an advancement upon the medical or social model conceptualisations of disability (8). The medical model of disability is based on the belief that a person's autonomy and ability to participate fully in society are limited by an impairment (9). Therefore, medical intervention is required to improve an individual's quality of life. The charity model of disability assumes that people with disabilities cannot contribute to society without external support provided by "good" citizens (10). This led to the abundance of poverty reduction efforts aimed at this population, such as income generation and 'special' schools for people with disabilities. Both the medical and charity models situate disability in the individual (11). The social model of disability states that a person is 'disabled' by environmental, attitudinal and institutional barriers that exist in society. If these are removed, people with disabilities can participate on an equal basis with non-disabled people (12). However, neither model is broad enough: a person's impairment, as well as addressing discrimination in society and medical interventions when required, are all important.

The World Health Organization's ICF is widely considered the most comprehensive framework for conceptualising disability, as it encompasses both medical and social aspects of disability and is applied in this PhD thesis (9, 12). According to the ICF framework Figure 1, disability and functioning are interactions between the health condition and environmental and personal contextual factors. For instance, a person with cerebral palsy (health condition) may experience pain, muscle weakness and coordination challenges (impairment, body functions and structures). This can lead to difficulties walking, grasping, washing, changing menstrual materials and dressing (activities), which can limit a person's ability to leave home (participation). However, the impact of the impairment on disability is not inevitable. If a person has access to an assistive product, such as a wheelchair, a bathing area with seat, hand and grab rails (environmental), as well as a supportive family member who understands the importance of MHM and provides menstrual care (personal), the person could participate in daily life.

Figure 1. The ICF Framework (8)



Approximately one billion individuals globally have disabilities, and 80% of those live in low-and middle-income countries (LMICs) (12). Disability increases with age and is more common in women than men, largely because of ageing (13). An estimated 110-119 million adults have significant difficulties functioning and rely on professional or informal carers (12). Different impairment types underly disability, including visual, hearing, physical, communication, psychosocial, cognitive and intellectual. The particular focus of this thesis is on intellectual impairment, described in more detail in the next section.

Intellectual impairment

Intellectual impairment is defined as having a 'significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development' (14). Learning disability is a common synonym for intellectual impairment. There is a dispute about the exact numbers. Still, recent estimates suggest that globally, 3.2% of children and adolescents have intellectual impairments, with the highest prevalence in South Asia (India), followed by the Middle East (Afghanistan and Yemen) (15). Analyses of the Global Burden of Disease Study 2017 data, which covered intellectual impairment, epilepsy, and hearing and vision loss in childhood and adolescence, showed that severe intellectual impairment and severe epilepsy had the highest years of healthy life lost due to disability (YLD) globally, and in all regions (15). Furthermore, people with intellectual impairments are at a significantly higher risk of experiencing diseases, including diabetes, epilepsy and asthma, than the general population (16).

People with intellectual impairments often experience functional difficulties and participation restrictions across the life course. Children with disabilities may take longer to achieve developmental milestones, such as crawling, sitting, walking, talking, reading and developing numerical skills (17-20). Daily activities that are difficult to carry out include personal hygiene, such as oral hygiene, bathing and cutting nails, grooming, dressing and doing laundry, and food hygiene and preparation (18). Independent problem solving, recalling information, and understanding social norms are also often challenging (20). Isolation and loneliness are major issues for people with intellectual impairments. In the UK, one in four people with learning disabilities spends less than one hour outside the home.

Approximately 50% of people with intellectual impairments report chronic loneliness compared to 15-30% of those without (21).

People with intellectual impairments tend to be more disadvantaged than people with physical, hearing or visual impairments, but few health promotion programmes target this group (12, 22) (this is explored in Chapter 3). The impacts of this can be profound: in the UK, females with intellectual impairments die an average of 20 years earlier than their counterparts without disabilities (23). People with learning disabilities were also six times more likely to die from COVID-19 than the general population in the UK (24). Reasons cited included a reduced ability to understand complex information and challenges communicating and identifying COVID-19 symptoms.

People with intellectual impairments are often supported by carers in their activities of daily living. Ideally, care is provided with dignity, which supports the individual's self-respect and recognises their capacities and ambitions. Still, even where policies and targets exist, such standards are not always met (25). For instance, in the UK, one-third of people with learning disabilities who died from COVID-19 lived in residential care, suggesting that some carers did not recognise or respond appropriately to symptoms (24). In the UK, healthcare staff working in hospitals for people with disabilities have been arrested for abuse, bullying, and neglect of residents (26, 27).

The positive outcomes of caring for a child with intellectual impairments include joy and family closeness, but it is also associated with higher depression and anxiety (28). Disability severity and lower household income were associated with higher levels of depression (29). In LMICs, many family members care for people with disabilities and receive minimal support and guidance about carrying out this role; this may negatively impact the care provided (30, 31). Results from a study sample of 25,048 children from 13 LMICs showed a correlation between the severity of developmental impairments and lower-quality parental care, including severe physical punishment and neglect (32).

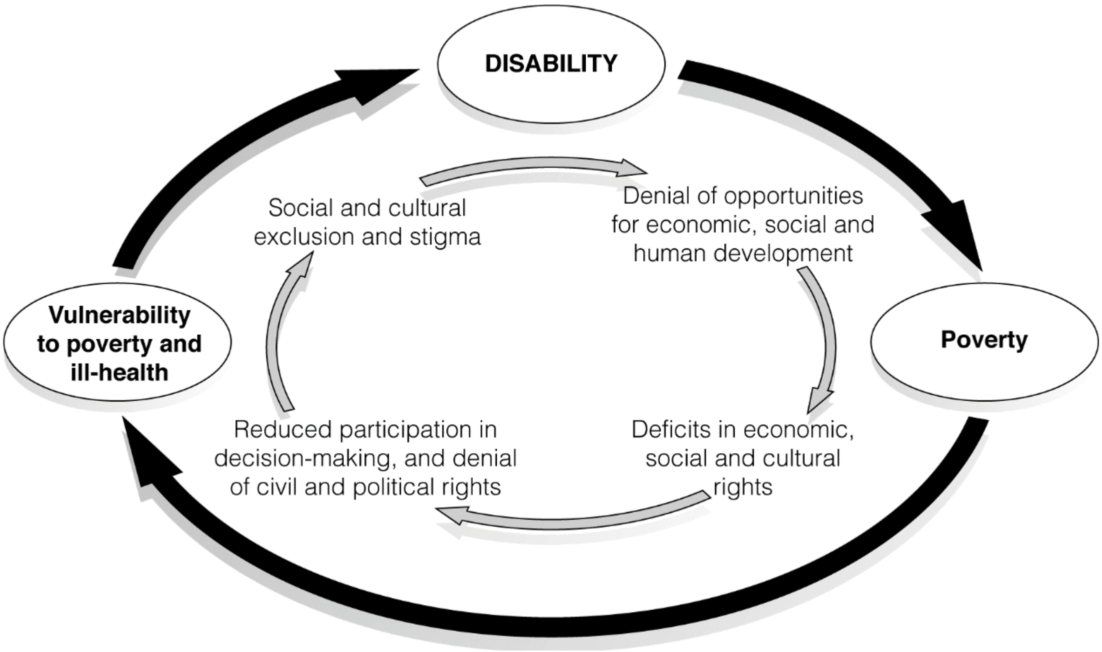
Disability, exclusion and global development

People with disabilities face widespread exclusion across different life domains because of the attitudinal, financial, accessibility and informational barriers they face. On a national or global scale, these exclusions will make it more difficult to reach the Sustainable Development Goals (SDGs) and other targets, given that there are at least one billion people with disabilities. Here, I describe the exclusions people with disabilities face with respect to poverty, education and work, health and water and sanitation, as it provides the context for the focus on menstrual hygiene.

1.1..1 Disability and poverty

Disability and poverty are cyclical and reinforce each other Figure 2 (33).

Figure 2. Disability poverty vulnerability cycle (34)



Poverty can be measured in different ways, but it is generally linked to inadequate access to healthcare, water, sanitation and hygiene (WASH) services, poor living conditions, and malnutrition, which can all lead to disability (35). Conversely, disability can result in exclusion from healthcare, education, and work and so deepen poverty. Stigma and discrimination are interwoven within the disability and poverty cycle. De Albuquerque defines 'stigma' as a 'process of dehumanising, degrading, discrediting and devaluing people in certain population groups' (36). Discrimination with respect to disabilities is defined in UNCRPD as 'any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others' (7). Stigma drives discrimination as it provides 'justification' for exclusion, making it appear natural and desirable (37).

People with disabilities may experience multiple grounds of discrimination, including disability, gender, age, impairment, health status, race, colour, language, and religion (38, 39). When inequalities intersect, they perpetuate discrimination. For instance, in the UK, data from 44,398 adults found that people with disabilities faced an increased risk of violence than those without disabilities, and people with intellectual impairments were at the most significant risk (40). In Australia, women with disabilities (aged 18 to 64) were twice as likely to experience sexual violence than non-disabled women of the same age (41). A study in India found that 11.4% of the study population were subject to 'elder abuse'; this increased for older adults with disabilities, and older women with disabilities were more likely to be abused than their male counterparts (40). Therefore, women with intellectual impairments living in LMIC may be among the most marginalised.

The following sections explain how the disability, poverty, and vulnerability cycle manifest in people's lives.

1.1..2 Access to education and work

A key mechanism by which disability and poverty are linked is through exclusion from education and employment. People with disabilities and their households, on average, have lower educational enrolment and attainment than their peers without disabilities, with disparities increasing from primary to secondary school (42-44). Differences are observed by impairment type: children with learning and communication impairments were least likely to attend school, whereas children with visual and hearing impairments were most likely (42, 43). Adults with disabilities are 50% less likely to be employed, and women with disabilities are less likely to be employed than men with disabilities (12). Estimating employment rates in LMICs is difficult due to widespread informal employment and livelihoods, but a study in Cameroon and India found that adults with disabilities were five times less likely to be working than non-disabled people (44).

1.1..3 Access to healthcare and sexual and reproductive health

Lack of access to healthcare may also be both a cause and a consequence of disability and can exacerbate poverty. People with disabilities have greater healthcare and rehabilitation needs, on average, but face barriers to accessing it, including financial, accessibility and attitudinal (35). For instance, compared to non-disabled people, those with disabilities are two times more likely to find healthcare services and staff skills inadequate; they are less able to understand information, 50% less able to afford healthcare and 50% more likely to suffer catastrophic health expenditure, which can push them further into poverty (45, 46). People with disabilities may require assistive products, such as wheelchairs or walking sticks, and support structures (e.g. raised toilet seats, seats in the bathing shelter and handrails) to use household toilets and bathing shelters independently and comfortably. However, only 5 to 15% of people have the assistive products they need (12).

Sexual and reproductive health (SRH) of people with disabilities is arguably particularly neglected (47). A recent systematic review of interventions to promote SRH for people with disabilities in LMICs found 400 articles that documented SRH for this population, but only 5% of those were interventions. This gap is partly driven by the widely held misconceptions that people with disabilities are asexual, do not have the same reproductive systems as non-disabled people, so they do not menstruate and cannot or should not have children (12, 48-50). The latter can result in ‘sterilisation abuse’, whereby control is exerted over the sexual and reproductive lives of people with disabilities (51). This differs by impairment group: historically, people with physical and intellectual impairments underwent forced sterilisation, but currently, it is predominantly the latter (50).

1.1..4 Access to water, sanitation and hygiene

The particular focus of this thesis is on MHM, which is a component of water, sanitation and hygiene (WASH) programming, and so WASH will be considered in more detail. People with disabilities frequently have additional WASH requirements. For example, in Vanuatu, this group were three times more likely to experience urinary incontinence than those without a disability (52). People who experience incontinence will require access to incontinence products (e.g., pads, bed protectors), accessible toilets including commodes and bedpans, water close to the home for drinking, bathing and laundry, and a private and accessible place to bathe (53). However, data from 34 countries reveal that people with disabilities are more likely to live in households without access to basic water and sanitation than a person without disabilities (54). An assessment of intra-household WASH access in Vanuatu, Bangladesh, Nepal, Malawi, Cameroon and India showed that people with disabilities experience difficulties collecting water and using the household toilet independently and challenges using the toilet without coming into contact with urine or faeces (55-57).

A key challenge is that information on WASH is not always communicated in ways that are accessible for people with all types of impairments, such as Braille, sign language and Easy Read. Visual representations of people in WASH communication materials do not consistently include people with disabilities (58, 59). The Social Representation Theory supports the belief that socially constructed realities are based on a shared understanding of what is ‘acceptable and unacceptable’; these are reinforced through communications (60, 61). This runs parallel to stigma, which is based on perceptions of what is ‘normal’ and ‘abnormal’ and leads to notions of ‘us’ and ‘them’. These processes lead to stereotypes, which can be positive or harmful: people with disabilities are capable and autonomous, or dependent on others and cannot fully participate in social life. By not representing people with disabilities in WASH communication materials, negative stereotypes can be reinforced, which can lead to discrimination.

Inclusive WASH is often considered an output, such as accessible water and sanitation facilities, but that is not a complete definition. As the term ‘inclusive

WASH' has not been outlined in peer-reviewed literature, I recently published the following definition (52):

> Inclusive WASH is a process that addresses the barriers to accessing and using WASH services faced by people who are vulnerable to exclusion, including people with disabilities, older adults, people living with chronic illness, women, girls, transgender, and non-binary people.
>
> For disability, inclusive WASH means people with disabilities effectively participate in and inform WASH-related research, policy and programme design and implementation. All persons with disabilities, regardless of their impairment and where appropriate, including their caregivers, can access and understand the information provided, which is also made relevant for their specific WASH requirements. Information dispels harmful misconceptions that perpetuate disability discrimination. All people with disabilities can reach water points, latrines and bathing shelters safely. Public and private WASH facilities, including disposal mechanisms for menstrual and incontinence materials, are safe and accessible for everyone to use with dignity. Caregivers are supported to provide WASH-related care that promotes the self-respect, dignity and autonomy of the person with a disability.
>
> WASH-related policies and guiding documents include activities and indicators that support the progressive realisation of the right to water and sanitation for people with disabilities. Service providers understand policy commitments and are supported to realise them. Progress and exclusion are monitored and reported on, with persons with disabilities central to the process.

Inclusive WASH is still frequently considered an 'add on' to WASH interventions, as demonstrated by a recent review of the Hygiene Behaviour Change Coalition (HBCC) funded interventions (62). The HBCC was set up and funded by Unilever and the Foreign, Commonwealth & Development Office to contain and limit the spread of COVID-19 in LMICs. Twenty-one organisations received funding for 74 projects across 37 countries to raise awareness of and promote personal hygiene behaviours, such as handwashing with soap and disinfecting surfaces to disrupt COVID-19 transmission routes (62). People with disabilities and older adults are at greater risk of contracting COVID-19 and dying from it. They may also face challenges carrying out the recommended hygiene behaviours to disrupt COVID-19 transmission routes, so it is vital to proactively include these groups in hygiene promotion programmes (63). The evaluation aimed to understand the extent to which HBCC grantees included disability and ageing in their hygiene promotion programmes. In terms of disability, results showed that 90% of HBCC grantees identified people with disabilities as target groups in their interventions, but only 49% of those identified targets, indicators, and monitored progress (62). This means more than half of the organisation's statements about disability inclusion appear to be tokenistic.

1.2 Menstrual hygiene management

Within WASH, the particular focus of the thesis is on MHM, which is described in more detail in this section.

A working definition of MHM

Menstrual hygiene management is increasingly recognised as an important public health, educational, and social issue because effective and hygienic management of menstruation is vital for women and girls' ability to participate fully in society (64, 65). Almost two billion people globally are of menstruating age, yet a substantial proportion lacks the supportive services, knowledge and materials to manage their menstruation hygienically and with dignity (66-68). Effective MHM means having a basic understanding of the menstrual cycle and how to manage it hygienically and with dignity, access to a clean menstrual management material, facilities to change it in privacy, disposal mechanisms, and access to soap and water for washing the body and material used (69). It also involves challenging addressing harmful societal beliefs and taboos surrounding the issue (70). This definition implies personal hygiene (using clean menstrual materials, handwashing, changing menstrual materials and washing reusable materials) and public hygiene behaviours (safe disposal of used menstrual materials). These behaviours are identified as targets in the Bishesta campaign: an MHM behaviour change intervention for people with intellectual impairments and their carers in Nepal, which was developed through this PhD (presented and discussed in Chapters 6 and 7).

Recently, MHM has been expanded to “menstrual health”, which is defined as ‘a state of complete physical, mental, and social well-being and not merely an absence of disease or infirmity, in relation to the menstrual cycle’ (67). This concept encapsulates MHM, human rights, empowerment, health and wellbeing. It depends on informed professionals, access to health services (including sexual and reproductive health), positive social norms, and advocacy for policy change. The term MHM is used in this thesis because the definition of menstrual health was released after all the PhD papers were published. Moreover, the thesis primarily focuses on achieving effective MHM, rather than on menstrual health more broadly.

MHM: a public health issue

Inadequate MHM is driven by discriminatory social norms, gender inequality, cultural taboos and a lack of water, sanitation and hygiene (WASH) facilities and services. Evidence from LMICs shows that poor MHM can result in limited educational attainment as girls may drop out of school when they reach menarche (64, 71, 72); increased risk of sexually transmitted diseases (if adolescent girls engage in transactional sex to obtain menstrual materials) (73), absence from the workplace (74), as well as negative psychosocial consequences including shame, fear, and anxiety (75-78). Poor menstrual hygiene practices, including an inability to wash the body and materials used thoroughly and not changing the menstrual material regularly enough, can lead to urinary tract infections and lower reproductive tract infections, such as Candida, Bacterial vaginosis and Trichomonas vaginalis (79-82). Furthermore, discriminatory cultural beliefs and norms related to menstruation contribute to misinformation, unhygienic use and disposal of menstrual materials, and restrictions on bathing, accessing water, and participating in social activities during menstruation (83-86).

Types of MHM interventions and delivery mechanisms

There is a range of factors that support the achievement of MHM (Table 1), including:

- Appropriate policies, strategies, and training
- Availability of water and sanitation facilities and menstrual hygiene materials
- Appropriate knowledge, attitudes, and social supports to achieve MHM

A range of MHM interventions are available to put in place these enabling factors, which vary in their activities, focus population group, and mode of influence. According to Hennegan and Montgomery's (87) systematic review, MHM interventions can focus on the provision of 'hardware' and 'software'. The former includes the provision of menstrual materials and WASH facilities. Software interventions focus on increasing knowledge for MHM through providing education. All the interventions included in the review were delivered directly to the person who menstruates, thus demonstrating an implicit assumption that people who menstruate manage independently.

A second systematic review by Hennegan et al.'s (65), which covered 35 countries and over 6,000 participants across 76 included articles, found that 72% of studies focused on adolescent girls (mainly school age), and 28% on adult women, including university students. As adolescent girls are a primary target for MHM interventions, many are delivered through schools and include hardware and software components (71, 88-90). Those intended to reach adults are delivered in public settings, such as MHM facilities in public toilets and prisons (91, 92), and through community-wide approaches (93-95). As gender inequalities drive inadequate MHM, some interventions include men and boys so that they can support MHM in the household, school, community, and work through their roles as fathers, brothers, teachers, community leaders, and employers (96).

Another avenue for intervention is to hold media campaigns on MHM to promote positive social norms, including Period Poverty in the UK, Menstrual Hygiene Day, and including MHM in soap operas on television and radio (97-99). Finally, policy and advocacy campaigns encourage States to prioritise MHM in public health (64, 100, 101). However, MHM is not consistently recognised as an essential element of development and so is often overlooked and underfunded (67).

In LMICs, MHM interventions are delivered through a range of stakeholders, including peer and healthcare providers (102, 103) and government departments (104). International Government Organisations, such as UNICEF, also support governments in integrating MHM education into school curricula, non-government organisations deliver MHM interventions directly (e.g. World Vision(105)), and fund local implementing organisations to deliver programmes (e.g. WaterAid (106) and Plan International (107)).

1.3 Disability and MHM

Section overview

This section presents my original hypotheses on the potential barriers to MHM faced by people with disabilities, which were assumed before conducting the PhD study. These largely correlate to the different physical and social environmental factors that influence MHM, presented in the socio-ecological framework for MHM (described more fully in Chapter 2). Chapter 3 (Paper One) presents the existing global evidence on MHM and disability and explores these assumptions. These are further investigated through analyses of Nepal’s WASH policies and guidance documents (Chapter 4, Paper Two) and with young Nepalis with disabilities and their carers (Chapter 5, Paper Three). In the discussion (Chapter 9), I revisit these hypotheses and explore their accuracy by drawing on findings from this PhD study.

Original hypotheses

I propose the following hypotheses for this research:

1. There is a lack of evidence on MHM in relation to disability in LMICs. Though attention to MHM globally has gained momentum over the last two

decades, consideration of the requirements for people with disabilities, and the potential differences between impairment groups, is largely absent (108).

2. People with disabilities receive inadequate information and support on MHM. People with disabilities are less likely to be in school, particularly in secondary school, when menarche often occurs (109). As most MHM interventions are delivered through school platforms to adolescent girls, people with disabilities who are out of school might not benefit. Moreover, community-based interventions may not be accessible for all people across impairment types as WASH information is not always delivered in accessible formats (110).
3. The risks and impacts of inadequate MHM are greater for people with disabilities. People with disabilities already face barriers to participating fully in daily life, which could be curtailed further during menstruation (83). The impacts of inadequate access to WASH facilities faced by this population may also worsen during menstruation. As disability and poverty are cyclical, people with disabilities may be less able to afford menstrual materials. Finally, negative socio-cultural beliefs and norms related to disability and menstruation may overlap to intensify discrimination.
4. Programme staff lack awareness and skills to deliver MHM to people with disabilities. Attention to disability and MHM is also dependent on staff's understanding of disability and their competence to include disability in interventions. These will likely be limited due to the inadequate attention given to the topic. These issues were highlighted in Uganda, Zambia and Malawi studies, which evaluated the inclusion of people with disabilities in community-led total sanitation (CLTS) interventions (58, 111). Training and mentoring on facilitation, disability awareness, and how to encourage meaningful participation of target groups were provided for community mobilisers as part of the intervention. Evaluation findings noted that WASH practitioners struggled to mobilise a diverse range of people, including those with disabilities, to participate in CLTS programmes because staff lacked general facilitation skills essential for CLTS interventions (58, 112).

5. Drawing on the Socio-ecological framework for MHM, Table 1 presents the enablers for achieving MHM, MHM behaviours, the potential barriers that people with disabilities may face in adopting these with reasons why, and proposed strategies to address these challenges (113). Specifically, people with disabilities may face additional barriers to different aspects of MHM, and so they require additional interventions. As one example, people with physical impairments may find menstrual materials uncomfortable, so new products are needed.

Table 1. Framework for achieving MHM for all people who menstruate

Overarching enablers for MHM	MHM behaviours	MHM for people with disabilities		
		Potential barriers to MHM faced	**Rationale**	**Enablers for MHM for people with disabilities**
Policies, strategies, curriculum, training standards include MHM; harmful traditional norms, practices and cultural beliefs are challenged and addressed.	Does not follow harmful traditional norms and practices.	Misconceptions about people with disabilities, e.g. dirty, contagious, do not have the same sexual and reproductive systems as non-disabled people. Policies and training do not include disability content.	Disability discrimination is widespread.	MHM information dispels misconceptions related to disability. Visual MHM information includes people with disabilities.
Water and sanitation facilities including for solid waste management; availability of affordable, and culturally appropriate sanitary protection materials; access to soap and water for washing the body and materials used.	Use a clean menstrual material.	Inability to afford menstrual materials.	Disability is related to poverty: people with disabilities tend to have less access to employment opportunities, have additional healthcare requirements that might not be met.	People with disabilities can access menstrual materials at a reduced cost, or for free; taxation on menstrual materials is abolished.
		Lack of prioritisation of the person's MHM requirements in the household budget.	People with disabilities face discrimination in the household and their WASH needs are not prioritised (114).	MHM information dispels misconceptions related to disability. Visual MHM information includes people with disabilities.
		Menstrual materials are not comfortable.	Wheelchair users may find it uncomfortable wearing a menstrual material and being seated most of the time (115).	A new menstrual product is developed with end users that is effective and comfortable for people with physical impairments.
	Change the menstrual material regularly.	Unable to access MHM information.	MHM information provided is not accessible for people with hearing and visual impairments.	MHM information is provided audibly and visually, as well as in Braille and sign language.

	Wash reusable menstrual materials with water and soap.	Inability to access and use water point or bathing/laundry area to wash the menstrual material.	Distance to facility, inaccessible route to the facility, inaccessible infrastructure (e.g. steps into the facility, handpump physically difficult to pump, no hand or grab rails, no space for a person with a disability and carer to enter the facility together and turn with ease, incinerator out of reach). People with disabilities not involved in the design, construction and evaluation of water and sanitation facilities (116). Unable to afford soap. Misconceptions related to disability, e.g. disability is contagious, a person with a disability is 'dirty'.	People with disabilities meaningfully participate in the total WASH programme cycle, can reach WASH facilities with ease and infrastructure is accessible. The cost of soap is reduced for people with disabilities and misconceptions related to disability is dispelled through WASH information and communication.
		Unable to afford soap.		
		People with disabilities may be stopped using WASH facilities because of negative stereotypes.		
	Dry reusable menstrual material in direct sunlight.	Inaccessible water and sanitation facilities, including disposal.		
	Dispose of single use menstrual materials in a bin with lid, an incinerator, or by burying or composting.			
Positive relationships with family, teachers and other people in authority; relationships with peers,	Communicate about MHM.	May have limited ability to interact with others; might be out of school and/or reliant on a carer.	Limited physical mobility, limited ability to leave the home and participate fully in daily life, face barriers to accessing education.	The human rights-based approach is applied to all MHM interventions.

positive perceptions of changes in gender roles post-menarche.				
Information and knowledge about the biology of menstruation and MHM exists.	N/A	Unable to access MHM information.	MHM information provided is not accessible for people with hearing and visual impairments.	MHM information is provided audibly and visually, as well as in Braille and sign language.
People are skilled in coping with menstruation and pain relief options are available.	Use pain relief options.	Commercial pain relief options are unaffordable.	People with disabilities and their households are more likely to be financially worse off than households without.	Home remedies and traditional forms of pain relief are promoted (e.g. drink warm water, put a hot water bottle on the stomach, back; rest).
Positive attitudes, beliefs and feelings about menstruation.	N/A	Unknown.	Unknown.	Unknown.
Widespread understanding of menstrual variations due to age and features of menstrual cycle (regular, irregular, heavy, light) and any other biological changes related to menstruation; intensity of menstruation (pain) and influences on behaviour, health and concentration; biological issues that impact on MHM	N/A	Have additional WASH requirements.	May experience urinary and/or faecal incontinence.	Menstrual materials are provided at a reduced fee or free for people with disabilities who experience incontinence. Taxation on menstrual and incontinence materials is abolished.

Importance of disability and MHM

There are three core arguments why focusing on disability and MHM is important. First, as explained above, people with disabilities face greater difficulties in achieving MHM and this has impacts on their participation and poverty. Second, this issue is also important from a development perspective and, third, for the fulfilment of human rights, as explained below. Subsequently, mechanisms for the delivery of disability interventions are presented in this section.

MHM and disability in the Sustainable Development Goals

The Sustainable Development Goals (SDGs) are the main global development framework for 2015-2030, and they include 17 goals, 169 targets and 232 indicators. The SDGs commit to ‘Leave no one behind’, thereby recognising that there are groups who may be likely to be excluded from development and may have additional needs. People with disabilities are one such group. ‘Disability’ and ‘people with disabilities’ are specifically mentioned 11 times across six SDGs, targets and indicators for education, growth and employment, inequality, accessibility of human settlements, data collection and monitoring progress against the SDGs (117). The UN Department of Economic and Social Affairs argue that SDG 6 (clean water and sanitation) ‘has created an unprecedented opportunity to [….] realise the right to safe water and sanitation for persons with disabilities’ (54).

Gender equality has a standalone Goal 5, with half of all the other goals including gender dimensions and indicators (118). Regular menstruation is a valuable indicator of good reproductive health. Ensuring MHM for all is vital for SDGs that include targets for women’s and girls’ participation, safety, dignity and well-being (67, 119). MHM is relevant to ensure healthy lives and promote well-being for all at all ages (Goal 3), ensure inclusive and equitable quality education and promote lifelong learning opportunities for all (Goal 4), achieve gender equality and empower all women and girls (Goal 5), and ensure availability of water and sanitation for all (Goal 6). However, menstruation is not explicitly mentioned in any of the 17 goals or indicators (67). Under SDG 6 (clean water and sanitation), only indicator 6.2 infers menstruation: ‘paying special attention to the needs of women and girls’ (120).

Achievement of MHM for people with disabilities is therefore an implicit target within the SDGs, especially given the emphasis on ‘leave no one behind’. However, data about the specific MHM requirements of people with disabilities and how to address these are lacking. This PhD study contributes to filling this evidence gap.

Human rights and MHM by people with disabilities

The ability to manage menstrual hygiene can be considered a human right, as well as being important to individuals and in the achievement of SDGs and other development goals. Human rights are universal and inalienable, meaning everyone is equally entitled to human rights without discrimination and that these rights cannot be removed. International human rights outline the connection between the state (or government) as a ‘duty-bearer’ of rights and the citizens as ‘rights-holders’. The state is responsible for ensuring that the citizens’ rights are fulfilled, and the rights holders should demand these rights. Governments voluntarily sign up for certain human rights and thereby accept the obligations within the international human rights treaties.

Several UN human rights are relevant to MHM. The Rights to Water and Sanitation ‘entitles everyone to have access to sufficient, safe, acceptable, physically accessible, and affordable water for personal and domestic use’ (7). Progressively realising these rights for every woman and girl is an important requirement for enabling effective MHM (121). The human right to health is also relevant to MHM, as it entitles everyone to access healthcare services, health-related education and information, including sexual and reproductive health (7).

The UNCRPD was the first UN human rights treaty in the 21st century (122). It is fundamental to supporting the rights of persons with disabilities. It aims to ‘promote, protect and ensure the full enjoyment of all human rights and fundamental freedoms by all persons with disabilities’ (7). In July 2021, 164 countries had signed the Convention and 182 had ratified its Optional Protocol

(117). The Rights to Water and Sanitation and Health are relevant to and consistent with the UNCRPD, and this is reflected in UNCRPD Articles 25 and 28:

> ‘States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation’ (Article 25) (7).
>
> ‘To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs’ (Article 28) (7).

The Convention on the Elimination of Discrimination against Women (CEDAW) is also relevant to addressing menstrual taboos, and harmful practices as MHM and gender equality are interrelated. For instance, CEDAW necessitates that states must take steps to address abusive gender norms to eliminate ‘prejudices and customary and all other practices, which are based on the idea of the inferiority or the superiority of either the sexes or on stereotyped roles of men and women’ (Article 5) (123). Menstrual taboos are based on and perpetuate such stereotypes, and this is explored in more detail in Chapter Three, Paper One.

On 5 July 2021, the United Nations Human Rights Council momentously adopted the first resolution on MHM, human rights and gender equality (124). The resolution calls upon States to prioritise MHM in relevant policies, ensure MHM facilities in public and private spaces, accurate MHM information and education, and address stigma and discrimination. It highlights that the human right to water and sanitation, the UNCRPD and CEDAW are central to MHM and highlights that women and girls with disabilities face ‘compounding levels of discrimination’ and inequalities, which worsen during economic, humanitarian and health crises (124). Notably, the resolution includes the following references to disability (page 3):

> (d) To ensure that women and girls, including those with disabilities, have access to separate and adequate basic sanitation facilities in public and private spaces, including affordable and accessible disposal options for used menstrual hygiene management products

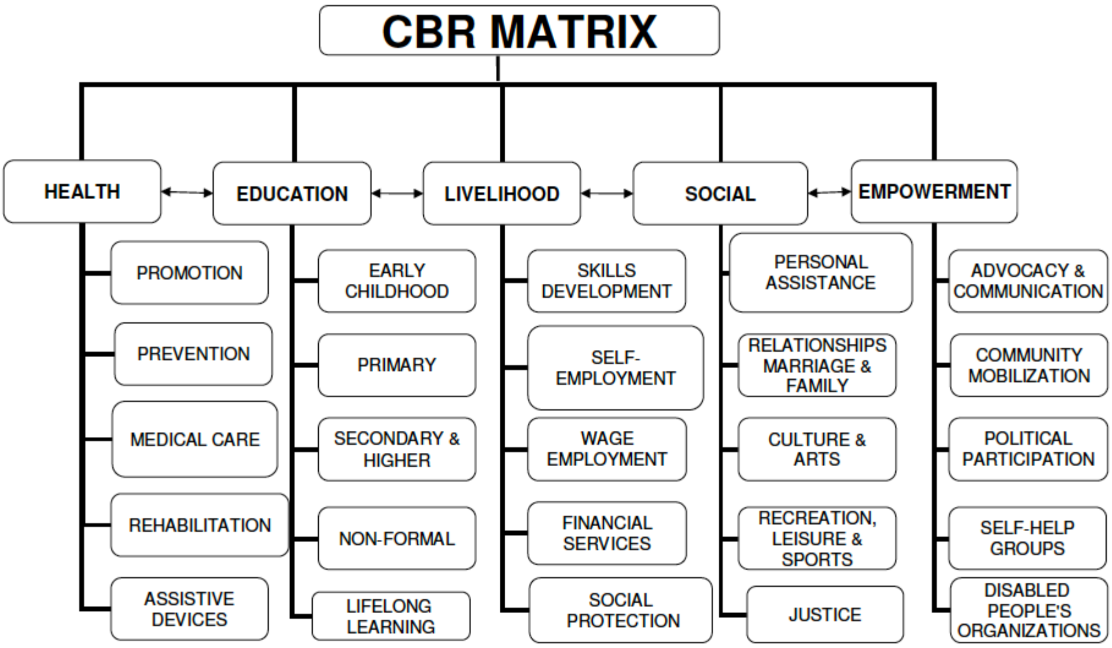
> (e) To ensure that women and girls with disabilities and those in vulnerable situations have free access to medical care and medicines to prevent, identify and treat health issues relating to menstrual hygiene

The resolution also states that ‘access to adequate and accessible information and education on menstrual hygiene management, including within family units and out-of-school settings’ are required (124). Papers One, Two, and Three in this PhD thesis argue that people with disabilities who do not attend school and their carers must be targeted and reached through MHM outreach programmes.

Mechanisms for delivering disability interventions

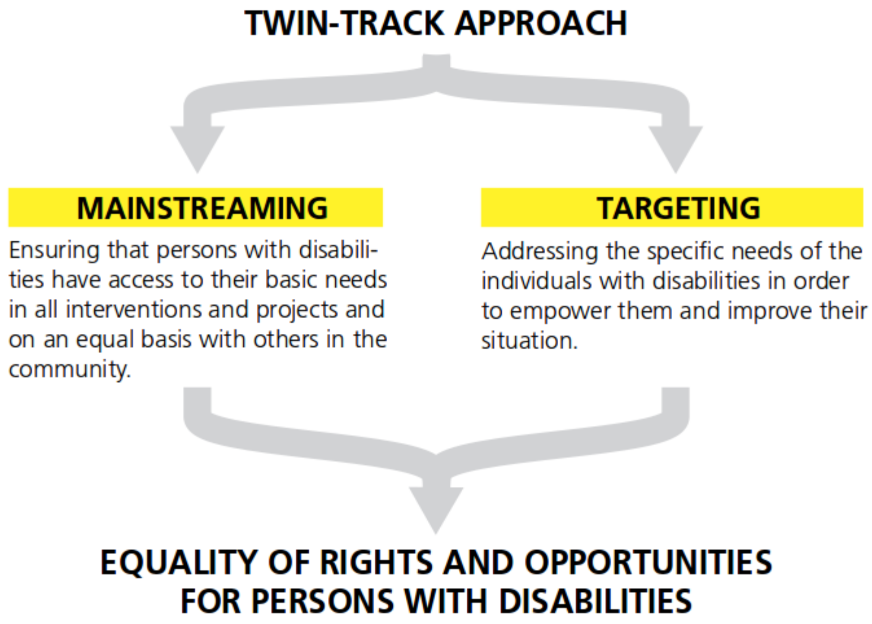
Therefore, there are strong arguments to support MHM for people with disabilities to improve the lives of individuals and their carers, meet development goals, and realise fundamental rights. However, currently, mechanisms for delivering MHM interventions for people with disabilities are lacking, as described in detail in Chapter Six. As people with disabilities face a broad range of exclusions and barriers, multi-focal interventions are needed to improve their participation. The World Health Organisation developed the community-based rehabilitation (CBR) matrix, which incorporates the principles of the UNCRPD and aims to include people with disabilities in all development efforts (Figure 3). These include access to health, education, livelihood and social sectors, and enhancing their and their family’s quality of life (125). In 2010, Khasnabis et al. estimated that CBR was being implemented in over 90 countries by people with disabilities, their families and communities, and health, education, employment and social services across governmental and non-governmental organisations (125). WASH and MHM are not explicitly included in the CBR matrix but are implicit within the ambitions to achieve good health and social inclusion. CBR offers one approach for delivering MHM working primarily through grassroots organisations, using locally appropriate approaches from the bottom-up.

Figure 3. The CBR Matrix (126)



MHM delivery to people with disabilities should be through the twin-track approach. This sets out a process to enable inclusive development, whereby disability-specific WASH interventions are delivered alongside mainstreaming disability within WASH programmes and policies (Figure 4). This modality is reflected upon in Chapter 9, Discussion and conclusion. For example, this could combine inclusive delivery of MHM at schools (mainstream programme) with additional targeting of people with disabilities in the community through CBR.

Figure 4. Diagram of the twin-track approach (127)



1.4 Spotlight on Nepal

The research in this thesis was conducted in Nepal, a country in Southern Asia with a population of around 30 million people, which is ranked 142 (out of the 189 states) in the Human Development Index (128, 129). The Government of Nepal aims to be an inclusive state, ensuring that all citizens have the right to equality, including MHM-related activities. Consequently, the State has pledged Gender, Equality and Social Inclusion (GESI) within poverty reduction (130). The Government of Nepal is a signatory of the Right to Water and Sanitation, the UNCRPD and the CEDAW (117, 131). It has also set out a road map toward universal health coverage (132).

Figure 5. Map of Nepal, with the Kavre district, marked red (133)

Disability in Nepal

The policy framework of Nepal supports the rights and inclusion of people with disabilities. After ratifying the UNCRPD in 2010, Nepal replaced the Disabled Persons Welfare Act 2039 (1982) with the Disability Rights Act (2017), which marks a shift from the welfare to a rights-based approach (134, 135). The definition of disability in the Act matches that used in the UNCRPD (see section 1.1 Disability). The Act is the legal framework for providing disability services at the village, district and national levels (136). Nepal has also implemented the National Policy and Plan of Action on Disability (2007), which aims to empower people with disabilities. It includes objectives across seventeen priority sectors, including national coordination, public awareness and advocacy, information and research, training and employment, education, health, transport, rehabilitation, poverty alleviation, assistive products and support services (136). Finally, the National Penal Code (2017) criminalises disability discrimination (135) and the National Health Policy (2014) and the Safe Motherhood and Reproductive Health Rights Act of Nepal state that healthcare services must be disability-inclusive (137, 138).

Disability-targeted programmes, including CBR, are also in place to provide practical support and promote inclusion. A part of the Government of Nepal's poverty reduction strategy includes social protection entitlements for groups at risk of poverty and exclusion, including people with disabilities (139). Social protection comes in the form of social assistance (cash or in-kind), educational scholarships, employment support, or healthcare discounts (57). People with disabilities are assessed to assign them into four categories of severity. Those categorised as having a 'complete disability', or 'severe disability' (difficulty performing daily activities with or without support from others) are eligible for the Disability Allowance (57). However, many people with disabilities do not access the Allowance for a variety of reasons, including inadequate training for those who carry out the assessments and a reliance on medical records of impairments when many people with disabilities face barriers in accessing healthcare services (136).

In Nepal, disability prevalence estimates are unreliable as they use different definitions for disability and various measurement tools. For instance, prevalence estimates vary from 1.94% in the 2011 census, 3.6% in the 2011 National Living Standards Survey report, and 14.5% from a survey of 18,223 households screened using the Washington group questions (140, 141). Additionally, disability discrimination and stigma, such as the belief that disability is a result of sins in a past life, is widespread and could inhibit disclosure (140).

A growing body of evidence shows that people with disabilities in Nepal are left behind in core development outcomes, as they are in other parts of the world. A study in 2014-2015 found that people with disabilities are financially worse off, and households containing a person with a disability had poorer living standards than those without (141). Fewer children with disabilities access education in Nepal than those without disabilities. Across a data set of 2,123 people with disabilities and 2,000 without, only 36% of children with disabilities accessed formal education in Nepal. This compares to 50% of children without disabilities, showing that overall access was low (141). Data also reveal disparities across impairment types: 46% of people with physical impairments accessed formal education, compared to only 15% of people with visual and hearing impairments. People with disabilities are also less likely to be employed than those without. In a survey of 4,121 people with and without disabilities, 36% of people with disabilities were employed, compared to 55% without (141). In terms of accessing healthcare services, studies show that people with disabilities face barriers including staff's negative attitudes and lack of understanding of their needs, inaccessible information and high transport costs (142, 143). People without disabilities reported the latter, inadequate staffing and limited medicine, so challenges accessing healthcare services exist for everyone (143). Findings from Banks et al.'s study, reveal that almost 25% of people with disabilities in the sample spent over a quarter of their income on healthcare, which puts their households at high risk of incurring catastrophic health expenditure (136).

WASH and MHM in Nepal

Menstruation is often shrouded in stigma and taboo in Nepal. Socio-cultural norms forbid menstruating people to enter a place of worship, kitchens, touching food, cooking, touching males in the family, and sleeping in their beds; these practices are internalised and widely followed (144). A recent cross-sectional survey of 1,342 women and girls from three urban districts in the Kathmandu valley found most participants were Hindu, 83% of participants did not pray whilst menstruating, and almost three quarters were encouraged by mothers to follow restrictions (144). In some of the poorest areas, Chhaupadi is practised, where people are banished to makeshift huts outside the home during menstruation, even though it was outlawed by the Supreme Court of Nepal in 2005 (145, 146). Data from Nepal's 2019 Multiple Indicator Cluster Survey (MICS) revealed that women from the poorest households were 20% less likely to participate than those from the richest during menstruation (146). For instance, 30% of people in the poorest households stay in a separate room in the same house when menstruating, compared to 8% of the richest households. Similar trends are observed across eating and bathing in a separate place and attending social gatherings. However, regardless of wealth, over 91% of households stayed away from temples and religious work when menstruating (146).

Knowledge about the biological factors related to the menstrual cycle is low in Nepal. A survey of 150 adolescent girls in the Chitwan district found that 59% did not have adequate knowledge about menstruation (147). Accurate information on the menstrual cycle and how to manage it hygienically is likewise limited. MHM information is predominantly shared between family members and focuses on using menstrual materials and maintaining socio-cultural norms. The use of menstrual materials is relatively high, with 94% of women and girls (aged 15-49) reporting use (146). Nearly three-quarters of women in rural areas used reusable menstrual materials (146), but prevailing socio-cultural norms can encourage unhygienic menstrual practices. For instance, people may be reluctant to dry their re-usable menstrual materials in the sunlight because there is a belief in Hindu society that the sun is a god and soiled products should not be shown to a god. Hygienic disposal of sanitary pads is also problematic because people who are menstruating do not want men and boys to see them (147). These practices are discussed in more detail in Chapter 5, Paper Three.

WASH access is also limited in Nepal, which is a barrier to effective MHM. The Joint Monitoring Programme (JMP) reports that 90% of the population has access to basic water, with 18% of those accessing safely managed drinking water services (146). Overall, 77% have basic sanitation; 49% have safely managed sanitation and open defecation levels reduced from 24% in 2015 to 10% in 2020, marking remarkable progress towards eliminating open defecation, shifting social norms and improving public health (146). The majority (62%) of the population has access to basic handwashing facilities at home, but 36% of those had limited water or soap.

MHM has gained attention in the last decade in Nepal. This is demonstrated by the inclusion of policy statements on MHM in the Water Supply Sanitation and Hygiene Sector Development Plan, a training package on integrating MHM in school health programmes, and establishing a task force to develop a national policy on menstruation (148, 149). Attention to MHM in Nepal’s policies and the extent to which they include the rights of people with disabilities is discussed in more detail in Chapter 4, Paper Two.

Disability and MHM in Nepal

Scant evidence exists on MHM for people with disabilities in Nepal, but one mixed-methods study does cast some light on the issue (57). A population-based survey of disability in the Tanahun district of Nepal explored people's experiences of accessing WASH, which included one question on MHM. Quantitative data found that women with disabilities were more likely to get menstrual blood on their clothes than women without disabilities (62% and 24%, respectively) (57). The qualitative findings (currently being analysed) reveal that people with cognitive impairments rejected menstrual materials, which led to blood on their clothes and surfaces (150). Carers who supported individuals in managing menstruation and the individuals themselves found the menstrual care tasks 'embarrassing'. Finally, those with and without disabilities reported additional bathing needs during menstruation, which increased the time spent on WASH activities. Though this study is valuable, it primarily explores WASH experiences that include MHM instead of focusing solely on the latter, meaning MHM data is not extensive in relation to disability in Nepal.

1.5 Terminology

Inclusive or non-discriminatory language is important as it recognises diversity and expresses respect for all people (151). Language is a political tool that is a powerful driver for shaping social norms and behaviours.

Gender refers to the socially constructed characteristics of women and men, which is non-binary and encapsulates norms, behaviours and roles (152). In this PhD thesis, I refer to 'people' who menstruate as a gender-neutral and inclusive term, which recognises that not all women menstruate and not everyone who menstruates identifies as a woman. However, I refer to women and girls if reflecting on existing evidence that uses this term. Menstruation has historically been considered within women's health, and the terms used can be controversial. This was demonstrated by the furore caused when J.K. Rowling said women menstruate on Twitter to respond to an opinion piece in Devex that referred to 'people who menstruate' (116).

Persons with disabilities, disabled person, person or people with disabilities are all accepted terms. The first is the term used in the UNCRPD, and ‘disabled person’ is preferred in the UK. However, person or people with disabilities tends to be more widely used globally. In this PhD thesis, disabled person or people are used in Chapter 3, Paper One, and person or people with disabilities are used throughout the rest of the thesis.

1.6 Conclusion

MHM is a global public health issue which contributes to improvements in health (sexual and reproductive and psychosocial wellbeing), education and gender equality. People with disabilities face stigma and discrimination in all these realms. Still, discourse and evidence on the needs of people with disabilities, their current menstrual behaviours, and barriers to MHM are largely absent. Without evidence, it is difficult to design inclusive MHM policies and interventions. Therefore, I hypothesise that people with disabilities face barriers to adopting MHM behaviours that enable menstrual health.

Owing to the practice of Chhaupadi, Nepal is often cited as a country where socio-cultural norms surrounding menstruation are the most harmful (65, 153-155). Within this setting, the impacts of disability and menstrual-related stigma and discrimination may be significant and therefore warrants exploration.

This PhD thesis aims to contribute to filling these important gaps by generating evidence on the needs of people with disabilities, their current menstrual behaviours, and barriers to MHM faced by this group, as well as developing and testing an inclusive MHM behaviour change intervention in Nepal.

Chapter 2 Methodology: Approaches, frameworks, and guiding principles

Chapter 2 describes the choice of research approaches and methods and key conceptual frameworks applied.

2.1 Research design, study aim and objectives

This is a mixed-methods study to develop a complex, evidence-based intervention and assess its acceptability and feasibility. The full methods of each section are presented in the published papers.

The study aims to develop an MHM behaviour change intervention for young people with disabilities in Nepal and assess its feasibility. It will achieve this by achieving the following study objectives:

1. Systematically review the literature on the MHM requirements of people with disabilities in different settings, and the barriers that they face (Chapter 3, Paper One)
2. Assess the inclusion of disability in Nepal's policies and guidance relevant to WASH and MHM, and explore the implementation of policy commitments in the Kavre district (Chapter 4, Paper Two)
3. Undertake qualitative research to understand the specific MHM requirements of a) young people with disabilities and the barriers they face in managing their menstruation hygienically and with dignity in the Kavre district, Nepal, and b) carers who support these people during menstruation (Chapter 5, Paper Three)
4. Develop an MHM behaviour change intervention that enables young people with intellectual impairments to manage their menstruation more independently (Chapter 6, Paper Four)
5. Pilot-test the MHM behaviour change intervention in the Kavre district and evaluate its feasibility and acceptability (Chapter 7, Paper Five and Chapter 8, Paper Six)

2.2 Study population

Young people

In this PhD thesis, I focus on ‘young people’. The World Health Organization defines ‘young people’ as those aged 10-24 years and states that this group is at a high risk of negative health outcomes (156). For instance, almost 5,000 young people died every day in 2019 for reasons including SRH issues, violence, diarrhoeal disease, poor nutrition, and suicide (157). However, this group is often neglected in public health interventions (157). Within its Global Action Plan to Achieve its Global Strategy for Women’s, Children’s and Adolescent’s Health (2016-2030), the World Health Organization (WHO) recognises the importance of MHM for young people’s health (123, 158). This commitment is demonstrated by the inclusion of three recommendations on MHM (recommendation 70, 128b, 141 on pages 106, 115, and 117, respectively) (158).

Efforts should be made to ensure all participants fully understand the study and can give informed consent. Those aged 18 years and younger are considered too young to provide consent, so their assent (where affirmative agreement to participate is provided (159)) must be sought, with consent requested from a parent, carer or guardian (160). The participant must be given the option to have an adult present during the data collection, and the young person should identify the adult. Researchers must also consider the inherent power differences between the researcher, who is likely to be older, and the participant and attempt to manage potential researcher bias. Identifying appropriate settings for the interaction and data collection tools are important considerations for this. For instance, a private setting might be more appropriate to explore sensitive topics than a group setting. Participatory methods have also been trialled with this population in medical and non-medical settings and elicited meaningful responses from young people (161).

As regular menstruation was an inclusion criterion for the study population, I set the age range from 15-24 years to increase the likelihood that menarche had been reached. Further details of the study population, sample size and inclusion criteria are presented in Chapter 5, Paper Three.

People with intellectual impairments

The core focus of the PhD is on people with intellectual impairments (definition and prevalence are documented in Chapter One, section 1.1).

Conducting research with people who have intellectual impairments brings ethical and practical challenges. These begin with the informed consent process, as the participant may not fully understand what is being asked of them (162). It may be difficult for this group to understand abstract concepts, such as using their quotes in a report, or that they might not get any direct benefit from being part of the study. It may also be difficult for participants to maintain focus throughout the informed consent process, or they may be unresponsive (163). This will be managed by ensuring the carer is present during the informed consent process. In this study, a ‘carer’ is defined as a paid or unpaid person who provides significant support (including during menstruation) to people with disabilities over long periods of time (164). Carers who participated in this PhD study were professionals working in a residential home and female family members. During the Qualitative study (Chapter 5, Paper Three), the majority were family members, whilst in the Bishesta campaign (Chapter 7, Paper Five), most were professional carers. Some participants may face challenges communicating verbally or might only be understood by those who know them well, such as carers (163). Additionally, participants may feel unsettled in an unfamiliar interview setting and become distressed or unresponsive (163).

Many studies with people who have intellectual impairments use proxy responses (165). This approach is critiqued as one can never fully understand another’s lived experiences, so some academics argue that interviewing by proxy is theoretically uncredible (166, 167). It also means that the ‘direct voice’ of the participant is unheard (165). Instead, personal experiences are expressed by the carer, who holds power to tell the individual’s ‘story’ in their own way and perhaps selectively.

2.3 Conceptual frameworks

Conceptual frameworks guide empirical studies from inception to completion. Ravitch and Riggan (2016) define conceptual frameworks as “an argument about why the topic one wishes to study matters, and why the means proposed to study it are appropriate and rigorous” (p. xv) (168). Therefore, conceptual frameworks connect different aspects of interest, each of which informs and influence each other, as well as specifying how the methods will answer the research questions. The conceptual framework may change as new evidence and knowledge are generated through the study (169).

In this study, I will apply three conceptual frameworks: the Socio-ecological framework for MHM to explore what barriers are and why they exist, the Behaviour Centred Design to understand how to overcome these barriers and improve MHM through a behaviour change intervention, and Bowen et al.’s Feasibility study framework to assess if the intervention can, will and does work (69, 170, 171). These frameworks were selected through reviewing the literature and in consultation with the PhD supervisory and advisory committees. Each framework is introduced in this section and discussed in more detail in Chapters 3, 6 and 8.

The Socio-ecological framework for MHM

Negative consequences of a lack of MHM related to education, health and psychosocial wellbeing are presented in Chapter 1, section 1.2. These outcomes relate to factors and sub-factors that affect MHM, presented in the Socio-ecological framework for MHM (69). For instance, evidence shows that if affordable menstrual materials are unavailable (which is a sub-factor within the environmental and resource availability factor), people may engage in sex to obtain sanitary pads and therefore be at risk of sexually transmitted infection (78). Until 2021, the Socio-ecological framework for MHM was the only recognised MHM framework tested in different LMIC settings (172-175).

The Socio-ecological framework for MHM was applied in this PhD study to inform the collection and interpretation of qualitative data on MHM and identify targets for the intervention. This framework describes the key factors that influence MHM, structured by the level at which they are experienced (e.g. societal, interpersonal). Though it considers MHM holistically, it was designed for children in school without disabilities, so does not include the specific needs of people with disabilities or their carers. Therefore, I adapted it for this research. Table 2 presents the Socio-ecological framework for MHM, with adaptations italicised. For instance, ‘interpersonal factors’ have been expanded to include people with disabilities; within this, the sub-factors include their relationship with a carer. This is because some people with disabilities may be unable to manage menstruation independently, so their relationship with a carer who supports MHM is integral to the individual’s menstrual experiences. This is explained in greater detail in Chapter 3.

Table 2. Socio-ecological framework for MHM, adapted for disability	
Factors that support MHM	**Sub-factors**
Societal and government policy factors	Policies, strategies and curriculum; training standards and practices; traditional norms, practices and cultural beliefs
Environmental and resource availability factors	Water and sanitation facilities including for solid waste management; availability of affordable, *usable* and culturally appropriate sanitary protection materials
Interpersonal factors – *person with disabilities*	Relationship with family, *carer (family and / or professional); relationships with healthcare workers,* teachers and other people in authority; relationships with peers; perceptions of changes in gender roles post-menarche
Interpersonal factors – *Carer*	Relationship with family, *the person with disabilities; relationships with healthcare workers* and other people in authority; *relationships with the wider community;* perceptions of changes in gender roles post-menarche
Personal factors – *person with disabilities*	Knowledge about the biology of menstruation and MHM, information on menstruation and MHM; skills in coping and behavioural adaptions (including pain relief); attitudes, beliefs and feelings about menstruation *(including sterilisation / long-term contraception); ability to manage menstruation independently, and support required*
Personal factors – *Carer*	Knowledge about the biology of menstruation and MHM, information on menstruation and MHM; skills in coping and behavioural adaptions (including pain relief); attitudes, beliefs and feelings about menstruation *(including sterilisation / long-term contraception); ability to manage another person's menstruation independently, support required, and caring tasks related to MHM*
Biological factors	Menstrual variations due to age and features of menstrual cycle (regular, irregular, heavy, light) and any other biological changes related to menstruation; intensity of menstruation (pain) and influences on behaviour, health and concentration; biological issues that impact on MHM, *such as incontinence*

The Behaviour Centred Design

While the Socio-ecological framework focuses on structural factors that influence MHM, the Behaviour Centred Design approach is applied in this PhD study to enhance the behaviours needed to achieve MHM. As explained in Chapter 1, practising good personal and public hygiene behaviours is vital for MHM. These behaviours include using clean menstrual materials, handwashing, changing menstrual materials regularly, washing reusable materials, and safe disposal of used materials. To encourage the adoption of these behaviours, accurate information about the menstrual cycle and how to manage it, menstrual materials, WASH facilities and a positive environment that is free from stigma and discrimination must be provided and supported (175). Consequently, developing a behaviour change intervention that considers these enablers is key for improving MHM.

Choosing target behaviours on which to intervene and how to do so should be sensitive to context. Behaviour Centred Design (BCD) applies a theory of change, behavioural determinants, and a programme design process (170). In relation to MHM, the BCD, therefore, facilitates the exploration of the behaviours practised by the study population before the intervention, the drivers for these, and any barriers to MHM that exist. This selection is also guided by the factors and sub-factors identified in the Socio-ecological framework for MHM. For example, traditional norms, practices and cultural beliefs (sub-factors within the societal and government policy factors in the Socio-ecological framework) correlate to context, behaviour-setting, and norms within the BCD. The BCD also supports the identification of target behaviours for improved MHM and how to design an intervention that dismantles barriers and encourages the adoption of specific behaviours by the target groups. Appendix 1 presents a more detailed comparison of both approaches.

The BCD has been applied to develop public health interventions, including handwashing behaviour change campaigns (176, 177). Drawing on the example of hand hygiene, historically, interventions focused on educating target groups about the links between an activity (e.g. handwashing with soap) and disease prevention (e.g. diarrhoeal disease) (178). Though knowledge often increased, it did not always lead to sustained behaviour change (178). Consequently, the BCD recognises that interventions cannot directly affect behaviour; instead, behaviour change results from a learning process based on human motives and changes in the behaviour settings. Triggers for behaviour change are generated by the automatic, motivated and executive behavioural control mechanisms (170).

Figure 6. BCD Handwashing with soap campaign (Image: Dreibelbis et al., 2016)

BCD interventions are designed to surprise, reassess behaviour and disrupt performance in the behaviour setting. Figure 6 gives an example of a BCD handwashing campaign. The image shows how the intervention aims to disrupt the environment, brain and body with memorable and surprising 'nudges' to encourage the adoption of the target behaviour (handwashing with soap and water after using a latrine). These nudges include the coloured path with footprints from a latrine to a handwashing station, which has pictures of hands on the tank.

The BCD follows five steps to develop a behaviour change intervention, and this PhD thesis is structured according to these:

1. *Assess* - existing evidence about the behaviours of interest and target groups are gathered (Chapter 3, Paper One)
2. *Build* – formative research is conducted to understand the behaviours within the study setting, fill any information gaps and draft a Theory of Change (Chapter 4, Paper Two and Chapter 5, Paper Three)

3. *Create* – drawing on findings from the *Assess* and *Build* steps, an intervention is developed with creative professionals (Chapter 6, Paper Four)
4. *Deliver* – intervention is rolled out, and process monitoring data is gathered (Chapter 7, Paper Five)
5. *Evaluate* – intervention outcomes and processes are assessed (Chapter 8, Paper Six)

These steps, referred to as 'ABCDE', are similar to the Medical Research Council's framework for developing complex interventions: 1) identify the desired outcome, 2) identify how to bring about change based on theory and evidence, 3) test the feasibility of the intervention to ensure that it is acceptable and can be delivered as intended and 4) evaluate the intervention through both impact and process evaluation (179, 180). The key difference between the Medical Research Council's framework and the BCD is that the latter focuses explicitly on targeting and changing behaviours (discussed further in Chapter 6), so I applied the BCD instead of the Medical Research Council's framework. The BCD was also designed by environmental health researchers, specifically for developing WASH behaviour change interventions. It has been applied in different settings, including Nepal, with promising results (176, 177, 181-185). Furthermore, the Socio-ecological framework for MHM and the BCD are complementary. The Socio-ecological framework for MHM gives structure to exploring key issues, and the BCD applies a process to develop a behaviour change intervention.

The Feasibility study framework

Bowen et al.'s Feasibility study framework guided the assessment of the feasibility of the MHM intervention developed in this thesis (171). This framework systematises the evaluation of interventions by identifying eight focus areas for assessment: acceptability, demand, implementation, practicality, adaptation, integration, expansion, and limited-efficacy testing. As Duttine et al. (186) suggests, these focus areas correspond to three key questions: 1) can the intervention work (acceptability, demand)? 2) Will the intervention work (implementation, practicality)? 3) Does the intervention work (adaptation, integration, expansion, limited-efficacy testing)?

In this PhD study, I explored the first four focus areas: acceptability, demand, implementation, and practicality. With finite resources, I wanted to pilot-test the intervention to understand if it is feasible within a small sample size (study objective six). If it is deemed feasible and therefore warrants further investment, funding for a comprehensive impact evaluation of the intervention will be sourced to explore the remaining focus areas - adaptation, integration, expansion, and limited-efficacy testing. This is discussed in Chapter 9, section 9.5.2. Table 3 presents the areas of focus, topics to investigate, and outcomes of interest that I explored in this PhD study. The feasibility study methodology and findings are discussed further in Chapter 8, Paper Six.

Table 3. Bowen's Feasibility Study Framework areas of focus applied in this study

Area of focus	Topics to investigate	Outcomes of interest
Acceptability	How the participants and implementers react to the intervention	• Satisfaction • Intent to continue use • Perceived appropriateness • Fit within organisational culture • Perceived positive or negative effects on organisation
Demand	Estimated or actual use of intervention activities in a defined target group	• Actual use • Expressed interest or intention to use • Perceived demand
Implementation	The extent, likelihood, and manner in which an intervention can be fully implemented as planned and proposed	• Degree of execution • Success or failure of execution • Amount, type or resources needed to implement • Factors affecting implementation ease of difficulty • Efficiency, speed, or quality of implementation
Practicality	The extent to which an intervention can be delivered when resources, time, commitment, or a combination of these are constrained in some way	• Positive / negative effects on target population • Ability of participants to carry out intervention activities • Cost analysis

The areas of focus in Bowen et al.'s Feasibility study framework are consistent with the issues the BCD recommends monitoring and evaluating (170). These are presented in Table 4. However, the Feasibility study framework facilitates a more nuanced identification of the outcomes of interest, which in turn supports the development of research questions.

Table 4. Consistency between the recommended areas of focus across the Feasibility study framework and the BCD

Feasibility study framework	**BCD**
Acceptability	Acceptability of the programme offerings to the target population
Demand	Brand recognition, sustainability
Implementation	Coverage, dosage of exposure, fidelity
Practicality	Cost-effectiveness (with respect to behaviour change or impact) and security (from competing campaigns, risk of misinterpretation and uncontrollable factors)

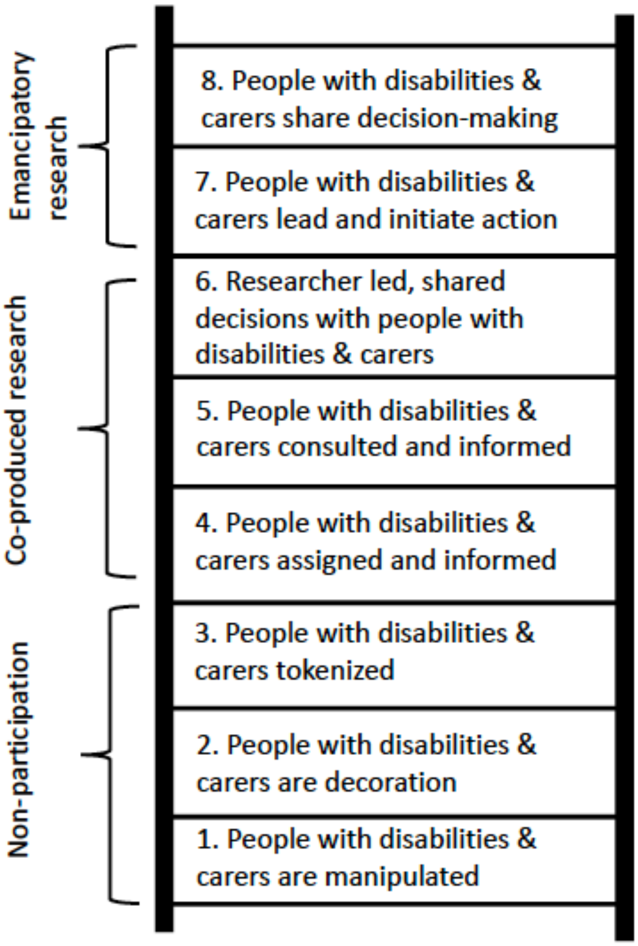
2.4 Data collection approaches

Participatory approaches in collecting qualitative data

Research, policies and interventions that aim to be disability-inclusive must meaningfully involve people with disabilities to ensure any outputs address their requirements. This imperative is stipulated in Article 3, Clause 3 of the UNCRPD: the generation of evidence on disability through research must ensure the 'full and effective participation and inclusion of disabled people' (7). Full participation is at the core of human rights. Still, traditionally research has been carried out 'on' people with disabilities rather than 'with' or 'by' them, which can be disempowering, exploitative and harmful.

Participation is conceptualised in different ways, but one that is often cited as a way of describing the different levels of participation in the 'ladder of participation', which was initially developed for citizen participation by Arnstein (187) (Figure 7).

Figure 7. Ladder of participation for people with disabilities and carers (adapted from Hart's Ladder of Young People's Participation (188))



In Figure 7, the first three rungs relate to non-participation: the ladder's lowest rung is 'manipulation' when people with disabilities do not understand the study or their role in it. 'Decoration', on the second rung, is when people with disabilities are 'put on display' at an exhibition or awareness-raising event. The third rung is 'tokenism', for example, where people with disabilities are present at a meeting about the research, but their contribution is not listened to or enacted upon; they have no agency, and the participation is not meaningful. The upper rungs represent degrees of meaningful participation. This range starts with active participation, where people with disabilities are partners in the research; they are engaged in designing the research, gathering data and voicing opinions. This is referred to as 'co-produced' research (189). The upper levels are effective participation, or ‘emancipatory’ research, which is when people with disabilities have full ownership of the research and make the majority of decisions (190).

In this PhD study, I aim to achieve co-produced research, so I apply several participatory processes and methods in collecting qualitative data. Participatory research methods that aim to reduce power differentials and recognise, value, and integrate the lived experience of participants with disabilities throughout the research cycle may lead to more ethical, equitable and higher-quality studies (191). Examples of participatory methods include Body Mapping (192), Cue Cards (193), Talking Mats (194), PhotoVoice (195, 196), the Mosaic Approach (197), Emotion Dice (198), Story Boards (199), Collage (200), and Participatory Video (201). These art-based methods have been used with children, people with disabilities, including intellectual impairments, and survivors of abuse. They can be applied to discuss sensitive topics as they reduce reliance on verbal communication (163, 194, 195, 197, 202-205). These methods are discussed further below and in Chapters 5, 6, 7 and 8.

I also set up an Advisory Committee in Nepal, whose role was to ensure the research and its outputs were credible, rigorous and relevant for WaterAid, the Government of Nepal, and the health and WASH sectors. Members included people with disabilities from the National Federation of Disabled in Nepal, the Nepal Disabled Women Association; professionals focusing on MHM, WASH and health from the Association of International NGOs in Nepal, the national MHM Policy Task Force, Nepal Fertility Care Center, and the Center for Integrated Urban Development (CIUD) and Karnali Integrated Rural Development and Research Centre (KIRDAC).

I recruited a qualitative research team (through an open and competitive process) which included Shubha Kayastha (a Nepali woman), Anita Sigdel (who has a visual impairment) and Amrita Gyawali (who has a mobility impairment and uses a wheelchair). The research team completed a week-long training that I delivered with an ICED colleague, an experienced qualitative researcher. The training covered conducting ethical research with people with disabilities, applying participatory methods, and discussing 'private' topics sensitively. More details are provided in Chapter 5, Paper Three. During the formative research, Anita and Amrita contributed their lived experiences to design the topic guides, data collection, analysis of the findings, and dissemination. Anita and Amrita had limited research experience, so they were mentored throughout the study by Shubha and me. Anita Sigdel gathered data with me for the feasibility study (Chapter 8), and I am continuing to mentor her.

Carers of people with intellectual impairments were involved in creating the campaign and its delivery. The Down Syndrome Society Nepal (DSSN) founder, Shila Thapa, joined the creative team. The DSSN is a disability service provider offering education for young people with Down syndrome. Shila is a mother of a young man who has Down syndrome, and she advocates for the rights of people with Down syndrome and other intellectual impairments in Nepal. Shila's input was invaluable and included advising on the visuals to ensure Bishesta looked like a young person with Down syndrome. I recruited four professional carers from the DSSN (including Shila) and one person from the CIUD, a WASH implementation partner of WaterAid, to deliver the campaign so that disability service providers were central to the intervention. The campaign components were piloted with five members of the DSSN (people with Down syndrome and their carers), and their input and recommendations were incorporated before production for implementation.

Qualitative data analyses

Thematic content analysis was applied to transcriptions of voice recorded interviews. This type of analysis is helpful when exploring relevant issues for particular groups, such as common barriers to MHM, behaviours, and reasons for these across a study population (206). The process followed was, firstly, familiarisation with the data, whereby transcripts and fieldnotes were re-read. Then, first-level thematic analysis was applied, in which participants' accounts were grouped into broad themes which corresponded to the sub-factors in the Socio-ecological framework for MHM, such as knowledge about the biology of menstruation and MHM. This structured the data and the extent to which sub-factors were discussed across the study population. Broad themes were then broken down into sub-themes, such as ‘hiding menstrual materials’, which would include drying menstrual materials where they cannot be seen rather than in direct sunlight, within the ‘menstrual restriction’ theme as this is related to menstrual stigma and taboos. Sub-themes were compared, and relationships between each were identified and analysed using analytic memos in Nvivo 11. This is discussed in more detail in Chapter 5, Paper Three.

Research collaborators

I am committed to decolonising global health, including facilitating learning across the global south and north to reduce poverty and inequalities. This is reflected in the partnerships and approaches developed and applied in this PhD study. Research collaborators are WaterAid, KIRDAC, the CIUD and the DSSN. All these organisations are committed to achieving MHM globally and in Nepal. This section provides an overview of each organisation and its relevance and commitment to the study topic.

WaterAid was one of the first WASH organisations to give attention to MHM. Since 2010, it has been a pivotal player on the global MHM stage, has contributed to the generation of evidence on the topic, and encouraged key decision-makers and practitioners to ensure MHM for people living in LMICs (64, 74, 96, 207-209). WaterAid’s current global strategy has four strategic aims, two of which are relevant to disability and MHM: *Reduce inequality* and *Improve hygiene behaviour* (210). WaterAid works in partnership with civil society, government and private sector actors to deliver WASH programmes and influence change. Within the South Asia region, WaterAid Nepal has four objectives and ‘flagship programmes’, which demonstrate best practices. Two of these are relevant for disability and MHM: *Reaching the Unreached* and *Hygiene*. Consequently, WaterAid Nepal is a key actor within the WASH sector and works to influence stakeholders to prioritise MHM in national policies and practices (211).

KIRDAC is a rights-based Nepali NGO registered in 1999 with 16 staff. It focuses on human rights, accountability, and livelihood improvements across 12 programmatic areas, including health and wellbeing, resilient WASH (including MHM), and gender equality. KIRDAC operate in the Sudurpachhim, Karnali, Lumbini and Bagmati Provinces (the Kavre district is in the latter) and in 2019, they supported 31,459 Nepalis across these provinces (212).

The CIUD has 23 staff and advocates for sustainable urban development and urban service delivery through community participation (213). Their focus areas are WASH, including MHM, disaster management, transport planning and information systems. CIUD has programmes in Kathmandu, Bhaktapur, Lalitpur, and the Kavre district.

The DSSN, established in 2010, is a disability service provider operating in Kavre and the Kathmandu Valley (214). Through daycare centres and networks of groups, the DSSN offers educational, information, physical and health support to young people with Down syndrome and intellectual impairments across 250 families. The DSSN also advocates for the rights of people with Down syndrome and intellectual impairments within Nepal.

Within the PhD study, WaterAid Nepal, KIRDAC and CIUD supported identifying the study population for the formative research (Chapters 4 and 5) and joined the team that created the Bishesta campaign, along with DSSN (Chapter 6). DSSN and CIUD delivered the Bishesta campaign and were interviewed as part of the feasibility study (Chapters 5 and 7).

2.5 Ethical issues and approval

The main ethical issues in this PhD study include conducting research with young people, people with intellectual impairments, ensuring PhotoVoice participants fully understand the informed consent process, and taking photos during the in-depth interviews and observation. These issues and strategies applied to ensure the study is ethical are presented in this section, with more details provided in Papers Three and Six.

Informed written consent was sought from all participants over the age of 18 years by the research team before respondents were enrolled in the study. If the participant was illiterate, a thumbprint was requested. Assent from young people under 18 and people with intellectual impairments were sought, followed by consent from an adult carer via the same mechanisms as above. Participants were asked if they wanted their carer to be present during the interview. The carer also supported the researchers in understanding the participant's responses. If the participant became distracted or distressed, the interview was ended.

If there were concerns that the participant did not fully understand what they were consenting to, the carer was interviewed as a proxy. Interview questions encouraged carers to report on behalf of the participant and relay their own experiences carrying out menstrual care tasks for the individual. As recommended by Caiels et al. (215), I ensured proxies were very familiar with the participant (including their MHM), before recruitment, and I also asked exploratory questions on these topics during the interview. Additionally, I used participatory methods and applied methods triangulation to support the consistency of findings.

Consent for PhotoVoice included two consent processes. Initially, consent was sought for the participant's agreement to carry out the method. A second consent was sought after the photos were printed. This ensured participants were fully aware that they owned the images and what they were consenting to; it also allowed them to opt-out of specific aspects, such as showing their photos at public exhibitions related to this study. The initial and secondary informed consent process for PhotoVoice is included in Appendix 9.

Data collection for the qualitative study (Chapter 5, Paper Three) involved taking photos of the menstrual materials used, ranked according to the participant's preference, for data management purposes only. A camera was used during the accessibility and safety audit to capture any challenges participants faced using the WASH facilities. These photos ensured that researchers not present during the interview could fully understand the infrastructure used. No identifying data were included in any photos, such as the person's home or face, and only the research team saw the images. The topic guides in Appendix 4 provide instructions on the process.

Ethics approval for the study components within the Build step (Chapters 4 and 5) was granted by the Research Ethics Committee at the LSHTM (reference: 12091) and the Nepal Health Research Council (reference: 102/2017). The same Ethics bodies gave approval for the research activities in the Create, Deliver, and Evaluate steps (Chapters 6, 7, and 8), references 15703 and 39-2018, respectively.

2.6 Lead researcher's epistemological position and researcher reflexivity

The epistemological position for this doctoral research project is interpretivism: people interpret the world they inhabit rather than working in a patterned way, and human's world view influences their behaviours (216). From this viewpoint, menstruation is regarded as a physiological and social phenomenon, and socio-cultural factors shape a person's experience of menstruation. Therefore, menstrual-related behaviours and beliefs are influenced by external and individual factors. These factors must be considered when reflecting on how the position and role of the lead researcher may have influenced the data collected.

I am a white, British, middle-class, non-disabled woman, so I may have attracted attention in a low-income rural setting in Nepal. People with disabilities in such settings are often socially excluded and may not have interacted with people outside their community or seen a foreigner before (12). They may be unused to answering questions about themselves and might find it difficult talking about menstruation. To minimise these potential biases, I worked with a Nepali research team of women, including women with disabilities, and was not present at all interviews. I provided direction and guidance before and after interviews so that interviews could be conducted without the disruption of translation.

Before my current position as Research Fellow at the International Centre for Evidence in Disability (ICED), I was the Equality, Non-discrimination and Inclusion Advisor at WaterAid (UK). I have developed resources for practitioners on how to make WASH programmes more inclusive (59, 217, 218) and contributed to the production of Menstrual Hygiene Matters, a seminal resource for practitioners to improve MHM (108). These resources infer barriers to MHM that people with disabilities face, but there is limited guidance on addressing these in practice. My professional history led me to initially hypothesise that people with disabilities would find it physically difficult to access MHM facilities and that they might not be able to access MHM information as it is rarely communicated in ways that people with hearing and visual impairments can easily absorb.

Before this PhD study, I reviewed WaterAid Nepal's equality and inclusion work and enjoyed a positive working relationship with WaterAid staff (219). These afforded me access to key stakeholders and organisations in Nepal. For instance, WaterAid Nepal arranged several meetings with high-level government officials for me, which may have been difficult otherwise. However, these existing relationships and WaterAid Nepal's reputation may have biased policy makers' responses during the interviews. This is because WaterAid runs policy influencing campaigns and activities to encourage the relevant government ministries to prioritise WASH and MHM in national poverty reduction efforts and ensure that people with disabilities benefit equally. Two policy makers interviewed during the policy analysis were aware of WaterAid's work and policy influencing agenda (Chapter 4, Paper Two). Representing WaterAid during interviews with people with disabilities and carers gave the research team legitimacy, which might have positively enhanced levels of rapport with participants. However, this also meant that some participants expected to benefit from partaking in the study. This was managed by having a detailed informed consent process explaining the compensation level offered. I reflect on these dynamics with policy makers, people with disabilities, and carers in 'The interview process' section within Chapter 9. Appendix 8 includes the Feasibility study information sheet for carers.

A potential risk of collaborating with WaterAid within this PhD study was that I could have felt pressured to demonstrate that the intervention is effective and relevant. However, having worked for WaterAid for many years I was fully aware that the organisation embraces learning and is open to failure. This is evidenced by WaterAid's organisational value, 'always learning' and its evaluation strategy (210, 220). The latter sets out the types of mandatory evaluations and reviews at WaterAid, including the global strategy evaluation, thematic reviews (e.g. Equality, Non-Discrimination and Inclusion), advocacy priorities review, and country programme and project mid-term review and evaluations (220). These evaluations and reviews are often published online to enable transparency and accountability (112, 219, 221, 222). Consequently, I did not feel influenced by my connection with WaterAid to demonstrate positive project outcomes.

2.7 Conclusion

In this PhD study, I focus on young people aged 15-24 years because this population often experience adverse health outcomes and is likely to have reached menarche. A substantial focus of this PhD is on people with intellectual impairments, which brings practical and ethical challenges. These are managed by following informed consent processes developed specifically for this group, applying participatory methods and approaches, and methods triangulation. Three complementary conceptual frameworks are applied in this PhD thesis. Certain issues were identified that could influence the collection of data and development of the intervention, such as the epistemological position of the researcher, and mitigating strategies were put in place (e.g. the Advisory Committee). The discussion chapter will reflect on whether these choices and frameworks were appropriate and what consideration may be needed in future research.

Chapter 3 Paper One: Systematic review of menstrual hygiene management requirements, its barriers and strategies for people with disabilities (Assess step)

Preamble

Consideration of the MHM needs of people with disabilities, and the potential diversity across impairment groups, has been lacking in menstrual-related discourse and development over the last 20 years (108). At the time of publication of Paper One, no systematic review exploring disability and MHM existed.

Within the *Assess* step of the Behaviour Centred Design approach, a systematic review of the MHM requirements, its barriers and strategies for people with disabilities across all countries was conducted to fill this gap. This chapter presents findings from the review.

Searches were conducted across four databases (MEDLINE, PubMed, EMBASE and Global Health) and were completed in April 2018. Eligible articles included analyses relevant to people with disabilities who menstruate and/or how their carers support their MHM. Twenty-two studies, published after 1976 were included. The majority were published after 2010 (n=12); 15 were from high-income countries, one study was quasi-experimental, and the remaining 21 were observational. Seventeen articles focused on people with intellectual impairments, three on people with multiple impairments, and two on people with mobility impairments. Nine studies included professional and familial carers of people with disabilities.

Since April 2018 (when the search was undertaken), only nine more peer-reviewed papers have been published on disability and MHM, and five of these are included in this thesis (223-226). Table 5 summarises the articles published outside this PhD thesis after Paper One. Two focused on people with visual impairments and two on intellectual impairments. The following key findings from these articles reflect those in Paper One: people with disabilities had limited knowledge about MHM (223, 224), some relied on carers (223, 226) who lacked MHM information and support (224, 225). Menstruation was viewed negatively by people with disabilities and carers (226); the latter did not like MHM tasks, and some would prefer it if the individual did not menstruate (224, 225). Hysterectomy to manage menstruation for people with intellectual impairments was considered acceptable and was unregulated in LMICs (225).

Table 5. Characteristics of published papers on disability and MHM after April 2018, and summary of key findings

Author, date, title	Study design	Impairment group	Study sample	Summary of key findings
Dündar T, Özsoy S. (2020) *Menstrual hygiene management among visually impaired women* **(223)**	Quantitative	Visual	187	• Over half of participants were dependent on carers for MHM • Limited knowledge about MHM • Infrequently changed the menstrual material • Identified the start of menstruation by smell • Used the calendar to track the menstrual cycle
Harvey K, Mano P, Lakshminarayana I, Gupta S. (2019) *G480(P) Menstruation matters: the impact of menstruation on girls and young women with severe learning difficulties and their families. Archives of disease in childhood* **(224)**	Quantitative	Intellectual	20	• Severe menstrual pain and menstrual associated behaviour change • Physical challenges keeping clean, changing the menstrual material, inadequate knowledge about how frequently to change a menstrual material and leaking menstrual blood • Limited information on medical management of menstruation provided to carers • Nearly half of parents 'wished their child did not have periods'
Márquez-González H, Valdez-Martinez E, Bedolla M. (2018) *Hysterectomy for the Management of Menstrual Hygiene in Women with Intellectual Disability. A Systematic Review Focusing on Standards and Ethical Considerations for Developing Countries* **(225)**	Mixed methods systematic review	Intellectual	28 articles	• In LMICs carers were not supported to provide MHM for people with intellectual impairments and felt 'excessively burdened' • Medical professionals viewed hysterectomy as a safe solution for women with intellectual impairments who experience menstrual issues • Medical professionals and carers thought informed consent or assent from women with intellectual impairments was possible and necessary • In high income countries, authorization from the Court is required for a menstrual related hysterectomy. In LMICs, the State is not involved
Wea LD, Hepilita Y, Fachry ME. (2020) *The experiences of visually impaired teenage girls on menstrual hygiene management: a qualitative study* **(226)**	Qualitative	Visual	6	• Most participants received MHM information from teachers • Menstruation was viewed negatively • Some participants were reliant on carers for MHM

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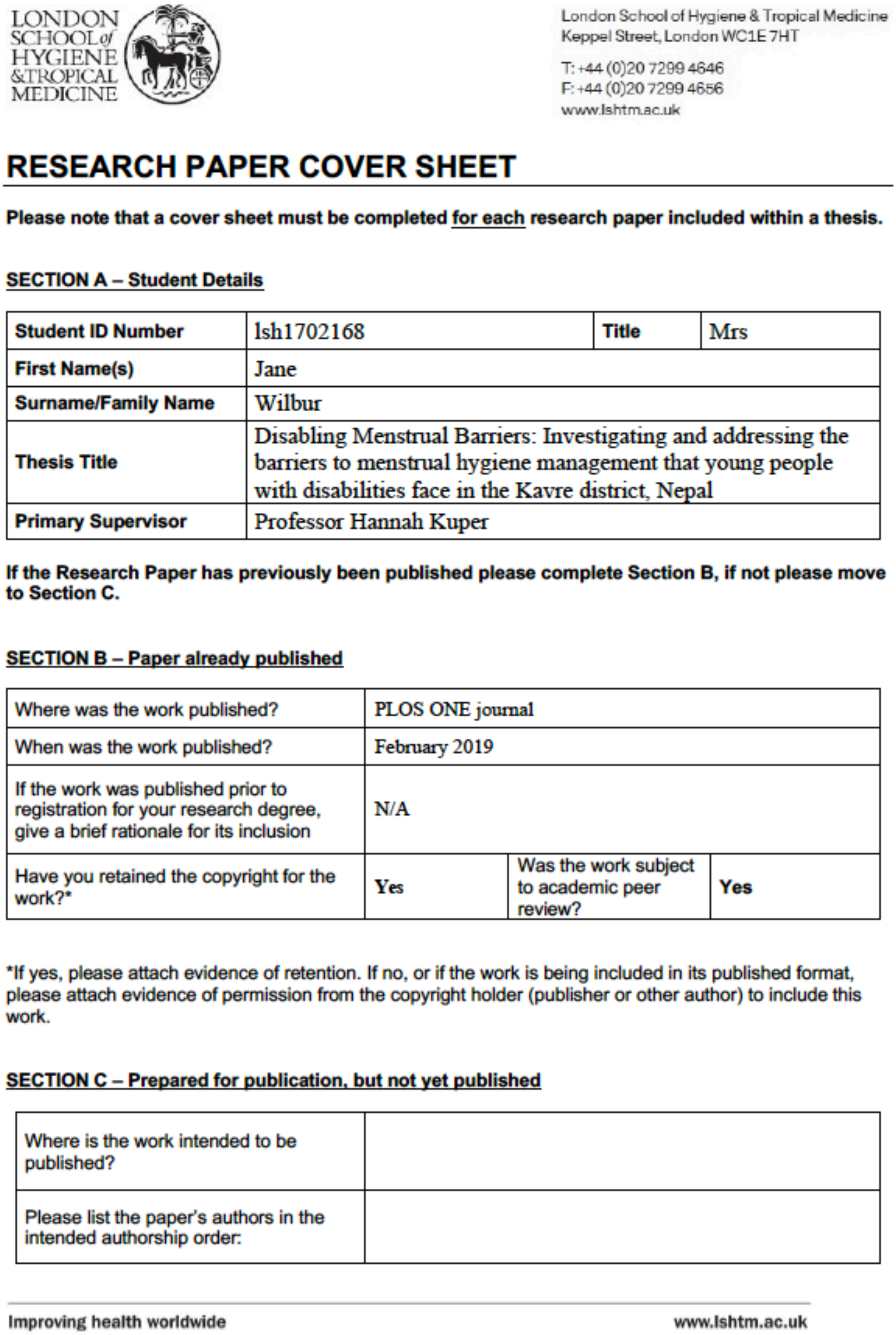

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

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SECTION A – Student Details

Student ID Number	lsh1702168	**Title**	Mrs
First Name(s)	Jane		
Surname/Family Name	Wilbur		
Thesis Title	Disabling Menstrual Barriers: Investigating and addressing the barriers to menstrual hygiene management that young people with disabilities face in the Kavre district, Nepal		
Primary Supervisor	Professor Hannah Kuper		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	PLOS ONE journal		
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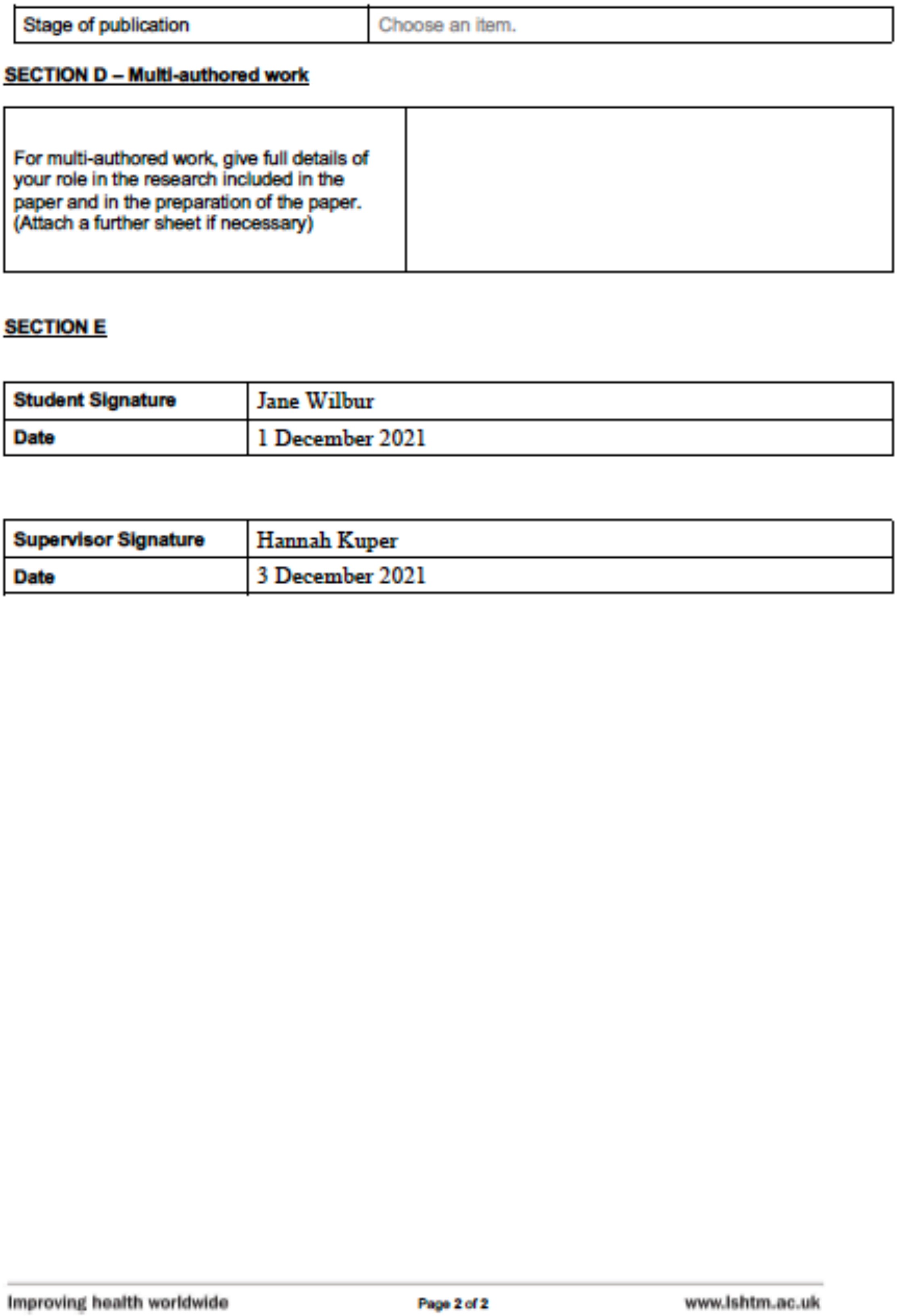

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Date	1 December 2021

Supervisor Signature	Hannah Kuper
Date	3 December 2021

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RESEARCH ARTICLE

Systematic review of menstrual hygiene management requirements, its barriers and strategies for disabled people

Jane Wilbur[1]*, **Belen Torondel**[2], **Shaffa Hameed**[1], **Thérèse Mahon**[3], **Hannah Kuper**[1]

1 International Centre for Evidence in Disability, Department of Clinical Research, London School of Hygiene & Tropical Medicine, London, United Kingdom, **2** Environmental Health Group, Department of Clinical Research, London School of Hygiene & Tropical Medicine, London, United Kingdom, **3** Wateraid, London, United Kingdom

* jane.wilbur@lshtm.ac.uk

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Abstract

Background

One quarter of the global population is of menstruating age, yet menstruation is shrouded in discrimination and taboos. Disability also carries stigma, so disabled people may face layers of discrimination when they are menstruating. The objective of the review is to assess the menstrual hygiene requirements of disabled people, the barriers they face, and the available interventions to help them manage their menstruation hygienically and with dignity.

Methods

Eligible studies, gathered across all countries, were identified by conducting searches across four databases (MEDLINE, PubMed, EMBASE, Global Health) in May 2017, with alerts set on each database to highlight new titles added until April 2018. Eligible studies incorporated analyses relevant to menstruating disabled people and/or how their carers provide support during their menstrual cycle.

Results

The 22 studies included were published since 1976; the majority after 2010 (n = 12; 55%). One study was a quasi-experiment; all others were observational. Most studies (n = 15; 68%) were from high income countries and most (n = 17; 77%) focused on people with intellectual impairments, so the review findings focus on this group and their carers. Outcomes investigated include choice and preference of menstrual product, ability to manage menstrual hygiene and coping strategies applied. Barriers faced included a lack of standardised guidance for professional carers; a lack of menstruation training, information and support provided to people with intellectual impairments and their carers; a lack of understanding of severity of symptoms experienced by people with intellectual impairments, the high cost of menstrual products and lack of appropriate options for people with physical impairments. Few interventions were found, and strategies for menstrual hygiene management applied

Competing interests: The authors have declared that no competing interests exist.

by carers of persons with intellectual impairments include limiting the disabled person's movements when menstruating and suppressing their menstruation.

Conclusions

Little evidence was identified on the requirements of disabled people and their carers in managing their menstruation, and only one intervention, but a range of barriers were identified. This gap in evidence is important, as the consequences of failing to meet menstrual hygiene needs of disabled people includes shame, social isolation, and even sterilisation.

Systematic review registration

PROSPERO CRD42018095497.

Introduction

Globally, 663 million people lack access to safe water and 2.4 billion people lack access to adequate sanitation [1]. There is extensive literature showing that disabled people face barriers in accessing appropriate water, sanitation and hygiene (WASH) services in low and middle income countries (LMICs) [2–4]. WASH services are vital for effective menstrual hygiene management (MHM).

UNICEF and the WHO define menstrual hygiene management as *"Women and adolescent girls using a clean menstrual management material to absorb or collect blood that can be changed in privacy as often as necessary for the duration of the menstruation period, using soap and water for washing the body as required, and having access to facilities to dispose of used menstrual management materials. They understand the basic facts linked to the menstrual cycle and how to manage it with dignity and without discomfort or fear"* [5]. Menstrual hygiene management also involves addressing harmful societal beliefs and taboos surrounding the issue [6].

Approximately 75% of people experience premenstrual syndrome (PMS), which includes emotional and physical symptoms that occur between one and two weeks before menstruation [7]. Regular menstruation is a sign of health and fertility; it is inherently female. However, drawing on feminist theory, femininity is linked to beauty, freshness and cleanliness [8]; these are opposed to the qualities associated with menstruation: dirty, bloody and smelly. This means menstruation does not conform to the gender stereotypes, is linked to inferiority and contributes to the devaluation of females [9]. This dichotomy may begin to explain menstrual taboos [9]. These points are demonstrated through the 'Tampon Experiment', which aimed to understand how a menstruating woman is perceived by others [8]. When an informed research participant dropped a tampon (a visible reminder than women menstruate) on the floor, she was viewed more negatively by men and women than when she dropped the hair clip (considered a feminine item that is not linked to bodily functions) [8].

Menstrual taboos are rooted in, and drive gender inequality. In some settings menstruating people are viewed as impure, so they are separated from men and banned from using the same water sources in order not to contaminate them [10, 11]. These taboos and social beliefs have led some people to internalise this stigma, reporting that they feel dirty when menstruating and are ashamed of it [12, 13].

Menstruation is not widely spoken about [14, 15]. Many pre-pubescent girls do not receive information about menstruation, so their first menstrual cycle can be a frightening experience. In India, a cross sectional study of 387 school going girls reported that only 37% of them were aware of menstruation before menarche [16].

Affordability of menstrual products is an issue in many countries, especially for people from lower socio-economic groups. In many LMICs, people use bark, paper, sand, mud or cloth to absorb menstrual blood [9]. Evidence exists that some adolescent girls in western Kenya engage in transactional sex to obtain sanitary pads [17–20], contributing to exposure to sexually transmitted diseases [21], pregnancy and school dropout [22].

Attention on MHM has increased over the last decade. Examples include the socio-ecological framework for MHM (developed for school girls and their families) to guide research and interventions in LMICs [23] and the inclusion of MHM in the Sustainable Development Goal 6 [24].

This shift is encouraging, but MHM efforts must be inclusive of disabled people.

This review applies the UN Convention on the Rights of Persons with Disabilities' (CRPD) definition of disability: *'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'* [25].

Like menstruation, disability often carries stigma [26]. Research in Uganda and Zambia demonstrate that disabled people are considered 'dirty' and contagious, so can be banned from using public latrines and water points [27]. It is likely that disabled people face layers of discrimination when they are menstruating, which will vary for people with different impairment types. Inaccessible latrines means disabled people who cannot stand or see often have to crawl, or sit on dirty latrine seats to change their pads or cloths [10]. People with visual impairments may be unable to identify when their period started and finished [3]. People with hearing, communication or intellectual impairments may be less able to communicate when they are in pain or need support [10]. There is a widespread misconception that disabled people are asexual, so do not receive information on sexual and reproductive health, or menstrual hygiene [10, 26, 28].

Objectives

The objective of the review is to assess the menstrual hygiene requirements of disabled people, the barriers they face, and the available interventions to help them manage their menstruation hygienically and with dignity. A review protocol is registered online with PROSPERO; registration number: CRD42018095497.

Disclaimer

This review recognises that gender is a social construct, non-binary and fluid. People who menstruate may identify themselves as male, female, or neither. Therefore, this review uses the terms 'person', or 'people' who menstruate rather than 'female', 'women' or 'girl', unless these terms are pertinent to the study or theory referenced. The authors also chose to use the terminology 'disabled people' rather than 'people with disabilities'.

Materials and methods

Search strategy

The search strategy was designed to identify peer reviewed published studies researching disability and MHM. The review covered all countries; no date limit was set to ensure the widest range of articles could be identified. The searches were conducted in May 2017, with alerts set on each database to highlight new titles added since then. Four online databases were used: MEDLINE, PubMed, EMBASE and Global Health through Ovid SP. Additional relevant studies were identified by reviewing references of included studies and scanning the internet for relevant studies after the database searches were completed. Search terms were generated to encapsulate three main concepts: disability, menstruation and hygiene management. Disability included both specific impairments and broad assessments (e.g. self-reported functional or activity limitations) (S1 Table).

Inclusion / Exclusion criteria

To be eligible, papers had to in English, published in a peer reviewed journal; be original primary research including experimental, observational and qualitative studies, but excluding economic analyses, systematic reviews, project reports, and policy analysis. No exclusion criteria were set on world region or date of publication. Studies were excluded if they reported no empirical qualitative or quantitative data on MHM and if they analysed disability without the inclusion of MHM and vice versa.

Eligible participants were menstruating disabled persons and/or the carers of disabled persons who provide support during their menstrual cycle. Carers were professionals or family members working in institutions or at home. Disabled persons had specific impairments, activity limitations or self-identified as disabled.

Papers were required to investigate the extent to which disabled people and their carers are able to understand and manage their menstrual cycle hygienically and with dignity. The relevant outcomes explored were purposefully broad as there were anticipated to be limited published studies on the issue. Example outcomes include choice of menstrual management material and preference, ability to manage menstrual hygiene and the menstrual cycle; challenges experienced during menstruation and coping strategies applied; changes in behaviour through the menstrual cycle and its management.

Study selection

All studies identified through the search process were exported to EndNote version X7. Duplicates were removed. Two authors independently double screened the titles, abstracts and key words against the eligibility criteria. Results were compared and contrasted and full-text records of potentially relevant publications were obtained and screened using the inclusion criteria for final selection of studies for the systematic review.

Data extraction

Data was extracted from the final selection of studies using pre-designed tables and the socio-ecological framework for menstrual hygiene management [23]. Through the data abstraction process for this review, a number of gaps in the socio-ecological framework in relation to the MHM requirements of disabled people and their carers were identified and additions were made to fill these gaps (Table 1, with changes marked in italic).

Data was extracted into Microsoft Excel against the following study and framework components:

1. Publication details: author/s, year, title
2. Study location: low, middle or high-income country, country name
3. Methods: study design

Table 1. Socio-ecological framework for menstrual hygiene management [23].

Factors that support MHM	Outcomes
Societal and government policy factors	Policies, strategies and curriculum; training standards and practices; traditional norms, practices and cultural beliefs
Environmental and resource availability factors	Water and sanitation facilities including for solid waste management; availability of affordable, *usable* and culturally appropriate sanitary protection materials
Interpersonal factors–*disabled person*	Relationship with family, *carer (family and / or professional); relationships with healthcare workers*, teachers and other people in authority; relationships with peers; perceptions of changes in gender roles post-menarche
Interpersonal factors–*Carer*	Relationship with family, *the disabled person; relationships with healthcare workers* and other people in authority; *relationships with the wider community;* perceptions of changes in gender roles post-menarche
Personal factors–*disabled person*	Knowledge about the biology of menstruation and MHM, information on menstruation and MHM; skills in coping and behavioural adaptions (including pain relief); attitudes, beliefs and feelings about menstruation *(including sterilisation / long-term contraception); ability to manage menstruation independently*, *and support required*
Personal factors–*Carer*	Knowledge about the biology of menstruation and MHM, information on menstruation and MHM; skills in coping and behavioural adaptions (including pain relief); attitudes, beliefs and feelings about menstruation *(including sterilisation / long-term contraception); ability to manage another person's menstruation independently*, *support required and caring tasks related to MHM*
Biological factors	Menstrual variations due to age and features of menstrual cycle (regular, irregular, heavy, light) and any other biological changes related to menstruation; intensity of menstruation (pain) and influences on behaviour, health and concentration; biological issues that impact on MHM, *such as incontinence*

https://doi.org/10.1371/journal.pone.0210974.t001

4. Participants: source of participants (household, institution), disability type (e.g. intellectual impairments, physical impairments), means of assessing disability, carer type (family member, professional), sample size
5. Aspect of MHM considered
6. Quality assessment

A meta-analysis was not conducted due to the lack of consistency in study designs, population types and outcomes included. The review was conducted to meet the requirements of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement (PRISMA) [29].

Quality assessment

Studies were assessed for their potential risk of various types of bias, by applying an approach used by Banks et al. [30]. This quality scoring used modified versions of the assessment tools STROBE and RATS for quantitative and qualitative studies [31, 32]. Assessment focused on the risk of potential biases stemming from study design, sampling methods, data collection, data analysis and interpretation. As study methodologies varied widely, papers were evaluated to assess their overall risk of bias instead of applying a rigid cut off criteria. Studies were graded as having a low risk of bias when all or almost of the criteria were fulfilled, and those that were not fulfilled were thought unlikely to alter the conclusions of the study; medium risk of bias when some of the criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study; and high risk of bias when few or no criteria were fulfilled, and the conclusions of the study were thought likely or very likely to alter the conclusions of the study [30] (S2 Table).

Results

Study selection

8026 records were identified through database searches. An additional 3 records were sourced through the authors' knowledge of the available literature. 2999 duplicates were found and removed. An additional 4902 studies were excluded in the title screening process and a further 87 records were excluded through screening the abstracts. 41 full text articles were assessed and 19 were excluded. The remaining 22 studies were included. No additional studies were sourced through database alerts (Fig 1).

Study characteristics

A summary of the characteristics of included studies are presented in Table 2. Data extracted from all studies against study framework components is captured in Table 3. Studies were published between 1976 and 2017, with the majority published after 2010 (n = 12; 55%). Most of the studies were conducted in high income settings (n = 15, 68%), including Northern Europe (UK, Netherlands and Denmark) (n = 6; 27 Eastern Asia (Taiwan, n = 4, 18%) Northern America (USA and Canada, n = 4, 18%) and Australia and New Zealand (n = 1, 5%). Only seven were conducted in LMICs (32%), including in Southern Asia (India, n = 3, 14%); Eastern Europe (Turkey, Bosnia and Herzegovina, n = 2, 9%); Eastern Africa (Malawi, n = 1, 5%); and South Africa (n = 1, 5%). The majority of studies were quantitative (n = 14; 64%); one study was a quasi-experiment; all others were qualitative.

Description of studies

Of the 22 studies, disabled persons were the primary research participant in the majority (n = 13; 59%), followed by the carer (n = 6; 27%), or the carer and the disabled person (n = 3; 14%) (Table 4). These participants were sourced through institutions (n = 13; 59%), such as hospitals and residential homes; households (n = 6; 27%) and households and institutions (n = 3; 14%). The means of assessing disability ranged from clinical (n = 8; 36%), self-reported (n = 4; 18%) to government lists (n = 2; 9%). Seventeen (77%) studies focused on people with intellectual impairments, followed by multiple impairments (n = 3; 14%) and physical impairments (n = 2; 9%).

The quality assessment identified 13 (59%) studies as having low, seven (32%) as medium and two (9%) as high risk of bias. The main reasons for potential bias was the limitations in generalisability of results due to a small sample and response rate being lower than 70%.

Impacts of menstruation

Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments. Nine papers (41%) covered pre-menstrual symptoms (PMS) [33–41]. Eight reported PMS symptoms and related behaviour, including menstrual cramps, mood swings, fatigue, irritability, anger, social withdrawal, decreased concentration, increased hyperactivity, self-injury and inappropriate handling of menstrual blood or hygiene products experienced by people with intellectual impairments [34–41]. Six papers assessed the frequency and severity of pain [36–41], three of which compared these between disabled and non-disabled people [37, 38, 41].

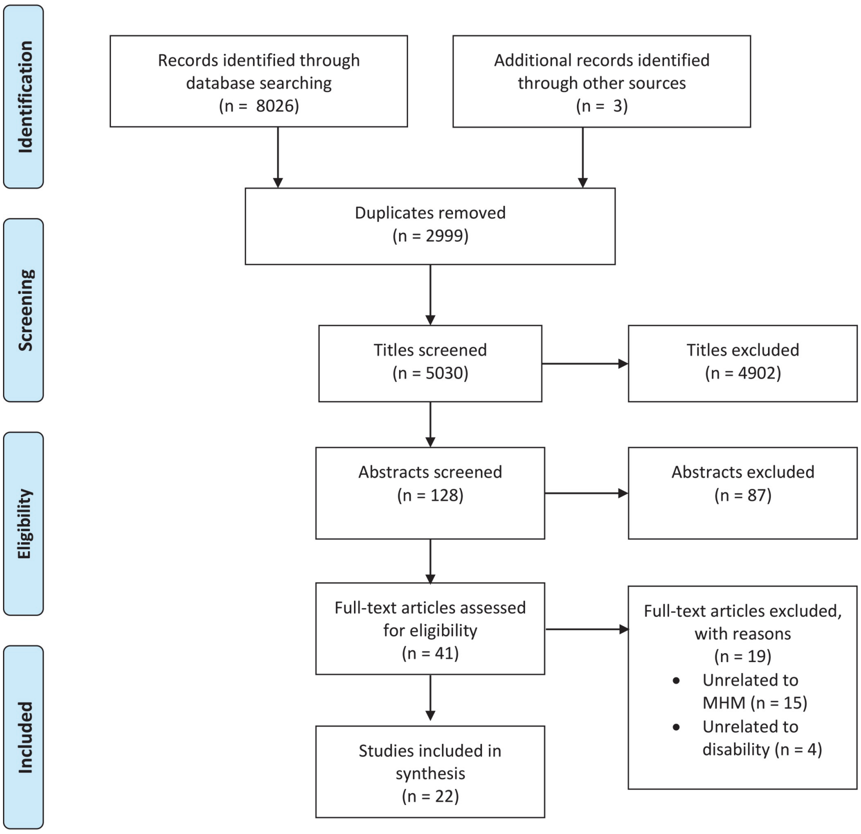

Fig 1. Search strategy with PRISMA flow diagram.

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Obaydi and Puri stated that PMS was experienced by 92% of the group of people with autism, compared to 11% in the control group of non-disabled people [38]. This study had the lowest risk of bias. Kyrkou also concluded that people with Down syndrome or autism experienced higher rates of pain than the general population [37]. Due to the challenges in communicating the extent and location of pain, Kyrkou deduced this through changes in behavior [37]. However, Ibralic et al. [41] and Ranganath and Ranganath [39] contradicted this finding. Ibralic et al. reported that PMS symptoms were almost equally distributed between non-disabled people and people with an intellectual impairment [41]. Ranganath and Ranganath reported that no one with Down syndrome experienced menstrual pain or premenstrual

Table 2. Characteristics of included studies.

Variable	Detail	Number	%
World Bank region	Low-middle income country	7	32
	High-income country	15	68
Location	Northern America	4	18
	Northern Europe	6	27
	Eastern Europe	2	9
	Eastern Africa	1	5
	Southern Africa	1	5
	Eastern Asia	4	18
	Southern Asia	3	14
	Australia and New Zealand	1	5
Decade of publication	1970	1	5
	1980	2	9
	1990	1	5
	2000	6	27
	2010	12	55
Study design	Qualitative	7	32
	Quantitative—Cross-sectional survey	11	50
	Quantitative—Case-control	3	14
	Quasi-experimental	1	5

https://doi.org/10.1371/journal.pone.0210974.t002

tension, but the authors did not include an assessment of the participant's communication abilities or factor this into the results [39]. Ranganath and Ranganath's study was marked as having a high risk of bias [39].

Three studies investigated the severity of PMS symptoms by disability type [34, 37, 40]. All studies concluded that there is divergence within groups. Kyrkou [37] and Hamilton et al. [40] recognised that the ability to report and locate pain was a determining factor. For instance, within the intellectual impairment group, Kyrkou found that 67% (n = 8) of the research participants with Down syndrome were able to say that they were in pain or point to where they had pain, even those with limited communication abilities [37]. Only one of the nine participants on the autistic spectrum was able to point to, or state when she was in pain, even though all participants had good communication skills.

Three studies stated that the inability of some people with an intellectual impairment to understand the source of pain and communicate affected their behaviour [34, 35, 37].

> *"She gets short tempered. But it's not her fault. She can't speak very well, so I think that's how she expresses herself"* (carer from India) [35].

Concerns of carers of people with intellectual impairments. Six (27%) studies investigated the key concerns of carers who support people with intellectual impairments [34–37, 42, 43].

Carers (mothers) of people with an intellectual impairment in Thapa and Sivakami's study in India reported that difficulties with communicating to daughters, and vice versa, were a major challenge [35]. Challenges with communication lead mothers to rely on observing changes in their daughter's behaviour to anticipate menstruation [34]. Predictors include irritability, restlessness, crying, self-harm, decreased appetite and disruptions in sleeping patterns [34].

Table 3. Data extracted against study framework components.

First author	Year	World Bank region	Country	Study Design	Disability sub-group	Disabled person (n)	Carer (n)	Main focus
Carnaby, S.	2002	HIC	UK	Qualitative	Intellectual	0	Number not specified in paper	Carers' KAP*
Charlifue, S.W.	1992	HIC	USA	Quantitative	Physical	231	0	Menstrual product
Chou, Y. C.	2009	HIC	Taiwan	Quantitative	Intellectual	92	0	PMS
Chou, Y. C.	2012	HIC	Taiwan	Qualitative	Intellectual	13	12	Carers' KAP
Patage, D.P.	2015	LMIC	India	Quantitative	Multiple	198	0	Menstrual product
Goldstein, H.	1988	HIC	Denmark	Quantitative	Intellectual	15	0	Menstrual cycle
Hamilton, A.	2011	HIC	USA	Quantitative	Intellectual	124	Number not specified in paper	PMS
Ibralic, I.	2010	LMIC	Bosnia and Herzegovina	Quantitative	Intellectual	31	0	PMS
Kirkham, Y. A.	2013	HIC	Canada	Quantitative	Multiple	300	Number not specified in paper	Menstrual suppression
Kyrkou, M.	2005	HIC	Australia and New Zealand	Quantitative	Intellectual	24	0	PMS
Lin, L. P.	2011	HIC	Taiwan	Quantitative	Intellectual	0	1152	Menstrual suppression
Lin, L. P.	2011	HIC	Taiwan	Quantitative	Intellectual	0	1152	Carers' KAP
Mason, L.	2007	HIC	UK	Qualitative	Intellectual	6	53	Training for disabled persons
Obaydi, H.	2008	HIC	UK	Qualitative	Intellectual	26	Number not specified in paper	PMS
Perrin, J. C.	1976	HIC	USA	Qualitative	Intellectual	20	Number not specified in paper	Menstrual suppression
Ranganath, P.	2012	LMIC	India	Quantitative	Intellectual	0	10	PMS
Rodgers, J.	2005	HIC	UK	Quantitative	Intellectual	452	217	Training for disabled persons
Altundağ	2015	LMIC	Turkey	Quasi-experimental	Intellectual	54	0	Training for disabled persons
Thapa, P.	2017	LMIC	India	Qualitative	Intellectual	0	23	Menstrual suppression
Van der Merwe	1987	LMIC	South Africa	Quantitative	Multiple	152	0	Menstrual suppression
van Schrojenstein Lantman-deValk	2011	HIC	Netherlands	Quantitative	Intellectual	234	0	Menstrual suppression
White, S.	2016	LMIC	Malawi	Qualitative	Multiple	36	15	Barriers and outcomes

*Knowledge, attitudes and practices

https://doi.org/10.1371/journal.pone.0210974.t003

Other challenges reported by carers included an aversion to wearing a menstrual product, a lack of adherence to social and cultural norms, such as inappropriate handling of menstrual blood and product, talking to others about their menstruation and changing the used menstrual product in front of others [35–37, 43].

> *"She will leave the door open while changing her pad, and doesn't understand that her elder brother is at home. So I tell her, 'Always bolt this door from inside.' Sometimes she understands, but sometimes she starts changing in front of them"* (carer from India) [35]*"*.

One of these six studies investigated professional carers' levels of satisfaction of intimate care tasks, finding that menstrual care was the second most disliked aspect for residential staff

Table 4. Characteristics of participants and quality assessment.

Variable	Detail	Number	%
Primary research participants	Carer	6	27
	Disabled person and carer	3	14
	Disabled person	13	59
Source of participants	Household	6	27
	Institution	13	59
	Household and institution	3	14
Means of assessing disability	Clinical	8	36
	Self-reported	4	18
	Government list	2	9
	Not given	8	36
Disability type	Multiple	3	14
	Intellectual	17	77
	Physical	2	9
Quality assessment: risk of bias	Low	13	59
	Medium	7	32
	High	2	9

https://doi.org/10.1371/journal.pone.0210974.t004

(after giving enemas), and the most disliked aspect for day unit staff (who do not give enemas) [42].

Strategies for menstrual hygiene management

Menstrual product acceptability for people with physical impairments. Four studies (18%) investigated the menstrual product used and preference [34, 35, 44, 45]. Two of these studies considered the product used [44, 45]. One [44] explored the product acceptability from the perspective of people with spinal cord injuries, and the remaining two [34, 35] investigated the carers' product preference. 19% of the sample in the study focusing on people with spinal cord injuries (conducted in the USA), reported discomfort and difficulty in positioning the menstrual product to ensure its maximum absorbency, as well as increasing difficulties with catheters and urinary management during menstruation [44].

Menstrual product acceptability for people with intellectual impairments. Three of the 22 studies explored the disabled person's preference through the carer [34, 35, 43]. The studies reported that the people with an intellectual impairment often refused to wear the menstrual product, leading to stress felt by the carer and constant negotiation with the disabled person.

> *"My biggest problem was that she didn't want to wear a pad. The understanding isn't there* (carer from England) [43]."

In a study, undertaken in India, mothers limited their daughter's physical movements during menstruation so that she would not go outside with blood stained clothes [35]. Another coping mechanism applied by carers in Taiwan, was sewing the pad into the underwear or buying adult sized nappies for their daughters [34].

In two of the four studies, mothers were caring for daughters with incontinence [34, 35]. These carers felt that menstruation added another layer of complication [35], and that the cost of nappies and pads were a major concern [34]

MHM training and support for people with intellectual impairments. Five studies (23%) investigated MHM training given to people with intellectual impairments [35, 37, 43, 46, 47]. One study highlighted a lack of training and support provided to this group because carers did not believe that the individual would understand MHM information [35]. The authors hypothesised that some people with intellectual impairments refused to wear a menstrual product because they were not given any MHM information, including being shown a menstrual product, or practice wearing it prior to their first menstrual cycle. Consequently, they did not understand the purpose of a menstrual product, did not feel comfortable wearing it and associated it with menstrual cramps [35].

One of these fives studies explored the teaching on MHM provided to people with intellectual impairments in institutions [47]. It highlighted a lack of correlation between training provided and the person's level of understanding [47]. Three studies showed positive correlations between providing MHM training to people with intellectual impairments and an increased ability to manage menstruation independently [35, 37, 46]. In Kyrkou's study, conducted in Australia and New Zealand, people with Down syndrome who had been given MHM information prior to puberty were better able to cope with their menstrual cycle than those who were not [37]. Altundağ and Calbayram showed in their study in Turkey, that using a doll to practice changing and disposing of a used menstrual product, was an effective way to increase the MHM skills of people with intellectual impairments [46].

MHM training and support for carers. Five studies investigated the level of training and support provided to carers (professionals and mothers) on how to manage menstruation of a person with an intellectual impairment [34, 35, 42, 48, 49]. Three of these studies [42, 48, 49] focused on professional carers working in institutions and two studies on mothers at home [34, 35]. The three studies conducted in institutions highlighted limited MHM training and standards for intimate and personal care tasks; that the task's importance was under-recognised by management; understanding of the menstruation of people with intellectual impairments was low, and support provided on menstrual issues was lower than sex education, but higher than menopause [42, 48, 49].

The mothers in the two studies focusing on care provided within the family were given no guidance, information or support on how to manage their daughter's menstruation, leaving them feeling overwhelmed and unsupported [34]. In the Indian and Taiwanese settings, mothers believe that menstruation is a private issue so did not discuss their daughter's menstrual cycle with anyone else, including professionals [34, 35].

Menstrual suppression. Six papers included an analysis of menstrual suppression of people with intellectual impairments [34–36, 50–52]. Menstrual suppression includes long-term contraception (i.e. oral contraceptive pill and the patch) and sterilisation (i.e. hysterectomy, tubal ligation). Two of these six studies were from the LMIC and the remaining four studies were from HICs [35, 50]. Two studies [50, 52] were published before 2000 and four after 2010 [34–36, 51].

Of these six papers, five reported that people with intellectual impairments were sterilised or on long-term contraception. Reasons for sterilisation cited by carers including a perception that menstruation care is a "burden", a fear of unwanted pregnancies [35, 36, 50–52], difficulties related to the menstrual care tasks; the perceived lack of benefit for the person with an intellectual impairment, as well as mothers' desire not to "burden" an older daughter with the menstrual care tasks when she is no longer able to undertake these tasks [35, 50, 52].

> *"I used to do everything–changing the pads every three–four hours, taking her to the toilet. But she was not aware at all; there were no feelings in her. Then when she was 16 years old, I realised that I could not do it anymore, and it was not benefitting her in anyway. Then we got her operated upon. We got her surgery done, and got her uterus removed"* (carer from India) [35].

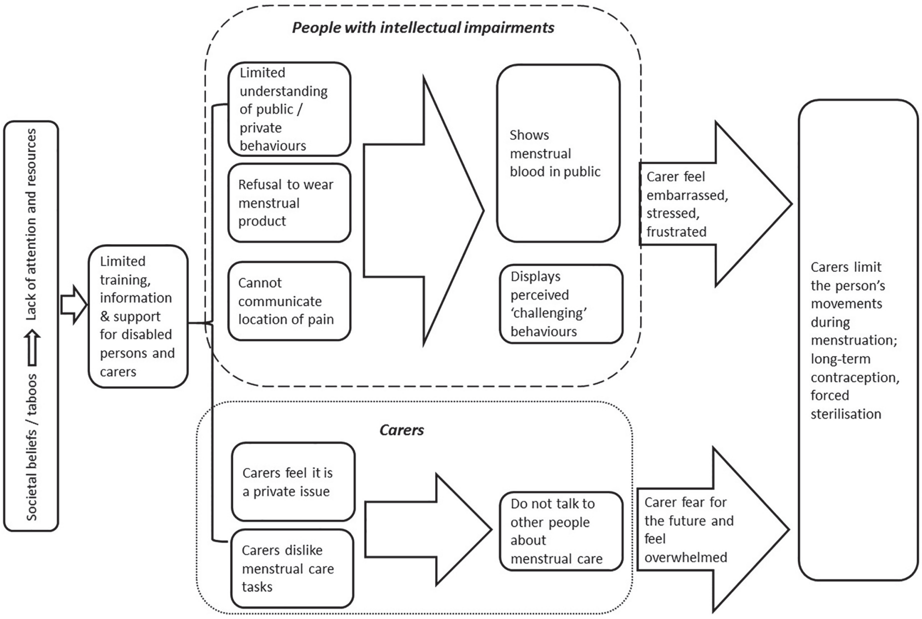

Fig 2. Flow diagram of review findings.

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Three studies included satisfaction levels of carers post sterilisation [35, 50, 52]. All of these reported high levels of carer satisfaction. One study from Taiwan challenged this trend of menstrual suppression [34]. In this study, regular menstruation was seen as an indication of good bodily health and daughters with an intellectual impairment were given medicine to help regulate their cycles. However, almost all mothers in this study were advised by relatives and medical professionals to sterilise their daughters in order to eliminate the 'tedious' menstrual care, for better hygiene and to prevent unwanted pregnancies [34].

Discussion

Our search sought to identify studies exploring the MHM requirements of disabled persons, but only found 22 studies that met the inclusion criteria. The majority of studies focused on people with intellectual impairments and their carers.

Fig 2 summarises the key findings in this review that relate to people with intellectual impairments and their carers. It shows that societal beliefs and taboos around menstruation and disability means the issue is shrouded in silence, and that it lacks attention and resources. The silence surrounding disabled people's menstrual hygiene requirements is demonstrated by the limited number of peer reviewed studies gathered for this review. Without rigorous evidence from different contexts, it is difficult to advocate for greater attention and resourcing to meet the MHM requirements of disabled people and their carers. The subsequent dearth of MHM training, information and support tailored to meet disabled people and their carers requirements means some people struggle to manage. Strategies for MHM applied by carers include limiting the disabled person's movements when menstruating and suppressing their menstruation.

The top box in Fig 2 focuses on people with intellectual impairments. This review has shown that some people with intellectual impairments do not always understand or follow social and cultural norms [35–37, 43], or wear a menstrual product [34, 35]. This group face challenges in understanding PMS and communicating when in discomfort [33–41]. Carers reported subsequent 'menstrual behaviours' make them feel stressed, embarrassed and they coped by not letting their daughters leave the home or sought ways to supress their menstruation [35]. The authors propose that if repetitive, accessible MHM information and training is provided regularly to the persons with intellectual impairments, they may get a deeper understanding of cultural and social norms and be better able to manage their menstruation more independently.

The bottom box in Fig 2 focuses on findings related to carers, which highlights an absence of standards and training on providing menstrual care in the institutions covered in the studies [42, 48, 49]. Findings show that professional carers dislike providing menstrual care [42]. If combined, these two factors might mean that a disabled person's dignity and personal hygiene is compromised in these institutional settings.

The review found that MHM training and support is not provided to family members who care for daughters with intellectual impairments [34], and that mothers also dislike providing menstrual care [35, 50, 52]. Mothers reported an inability to see how menstruation benefit their daughters [35], which is intertwined with the societal belief that disabled people should not be parents or sexual beings [53]. Disability and menstruation related taboos discourages open dialogue, meaning mothers do not seek advice or support, because they view the provision of menstrual care as a private issue [34, 35].

In addition to the findings captured in Fig 2, included studies also investigated the disabled person's preference of menstrual product [34, 35, 44, 45]. Research participants, with a physical disability, reported low levels of satisfaction with the menstrual product used (sanitary pads with and without tampons), stating that they find the products uncomfortable, difficult to place and use with catheters [44].

Implications for future research

There is limited evidence about the MHM requirements of disabled people, interventions to meet these and an assessment of their impact. This is particularly stark in LMICs, so research to investigate these topics must be carried out in these settings. Another key research gap is around the development of standardised measurements of MHM related outcomes for disabled people and their carers [54], and here the socioecological framework for MHM, adapted to include disabled persons and their carers (Table 1), could be a start. It is useful as the framework recognises MHM outcomes have individual, social and environmental influences that affect menstrual experiences and MHM among the target population.

More research is required to explore the severity of PMS experienced by disabled people compared to non-disabled people, and compared within disability groups with the view of developing mechanisms that enable disabled people to better locate and communicate pain. Finally, research on menstrual product preference and effectiveness for people with different impairments, to understand if the current products on the market are suitable and acceptable, should also be conducted.

Review strengths and limitations

To the authors' knowledge, this is the first systematic review of the MHM requirements of disabled people and their carers. This review restricted the search to studies in the English language and the number of datasets (such as excluding the CINAHL database), so some relevant studies may have been missed. Few studies met the inclusion criteria and across those, there was no standardised measurement of outcomes, meaning an outcome assessment across the studies was difficult. For instance, only seven (32%) studies defined symptoms and practices associated with menstruation, and only 12 (55%) studies identified the means for assessing disability.

There were not enough studies with consistent methods for a meta-analysis. The authors mitigated this by using Banks et al.'s [30] quality assessment that combines the STROBE and RATS assessment tools for quantitative and qualitative studies [31, 32]. The main reasons for risk of bias are due to a sample size being smaller than 100 and the response rate being less than 70%, or not reported. This could lead to an over estimation of impacts. However, there are no great divergences between the findings in papers that have a high risk of bias and those with a medium or high risk of bias, which alleviates concerns.

Conclusion

In conclusion, limited evidence was identified on the MHM requirements of disabled people and their carers, though a number of barriers were identified. This evidence gap is important and must be filled with future research. MHM interventions that address these barriers must be developed, tested and scaled up in partnership with disabled people. If the inaction continues, disabled people's rights will continue to be violated; they will continue to face social exclusion and potentially sterilisation.

Supporting information

S1 Checklist. PRISMA checklist.
(PDF)

S1 Table. Search string for PubMed.
(PDF)

S2 Table. Quality assessment for all studies.
(PDF)

S3 Table. Summarised data extraction table.
(PDF)

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Author Contributions

Conceptualization: Jane Wilbur, Hannah Kuper.

Data curation: Jane Wilbur, Hannah Kuper.

Formal analysis: Jane Wilbur.

Funding acquisition: Jane Wilbur, Thérèse Mahon.

Investigation: Jane Wilbur.

Methodology: Jane Wilbur, Hannah Kuper.

Project administration: Jane Wilbur.

Resources: Jane Wilbur.

Software: Jane Wilbur.

Supervision: Belen Torondel, Shaffa Hameed, Hannah Kuper.

Validation: Jane Wilbur, Hannah Kuper.

Visualization: Jane Wilbur.

Writing – original draft: Jane Wilbur.

Writing – review & editing: Jane Wilbur, Belen Torondel, Shaffa Hameed, Hannah Kuper.

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Supporting information [see Appendix 2]

S1 PRISMA 2009 Checklist

S1 Table. Search String for PubMed

S2 Table. Quality Assessment for all studies

S3 Table. Summarised data extraction table

Chapter 4 Paper Two: Exploring the MHM policy and practice context in Nepal (Build step)

The research team (left to right): 1) Anita Sigdel and Amrita Gyawali, 2) Amrita, Shubha Kayastha and the author, 3) the author and Amrita

Photographs taken by the research team.

Preamble

Findings from the systematic review completed in the *Assess* step informed the *Build* step. For instance, by adapting the Socio-ecological framework for MHM and applying it in the systematic review, findings highlighted a lack of strategies and training standards for MHM for people with disabilities. Therefore, a deeper exploration of the 'Societal and government policy factors' that influence MHM behaviours practised by people with disabilities in Nepal was warranted and undertaken in this formative research.

In the *Build* step of the Behaviour Centred Design approach, formative research was carried out with: 1) key informants to understand the wider policy and practice context which could influence the MHM behaviours practised (Chapter 4, Paper Two), and 2) a sample of the target population to explore the specific MHM behaviours and their drivers (Chapter 5, Paper Three).

While menstruation is gaining increasing attention in policy-making (101, 121, 227-229), there is a risk that the needs of marginalised populations are not addressed. This chapter examines the extent to which policies in Nepal address the WASH and menstrual hygiene needs of persons with disabilities. It does so at the policy formulation and implementation level, using the Kavre district as a case study. This was achieved by adapting the EquiFrame framework for disability and gender, WASH and MHM across 21 core concepts of human rights (230). Ten Nepali policies and guidance documents were reviewed and scored for quality with the adapted EquiFrame. We also interviewed 12 government officials and service providers who had a professional focus on WASH, MHM, health and disability and worked in Kathmandu or Kavre. In Paper Two, the first two factors that support MHM in the adapted socio-ecological framework were investigated: 1) societal and government policy factors and 2) environmental and resource availability factors.

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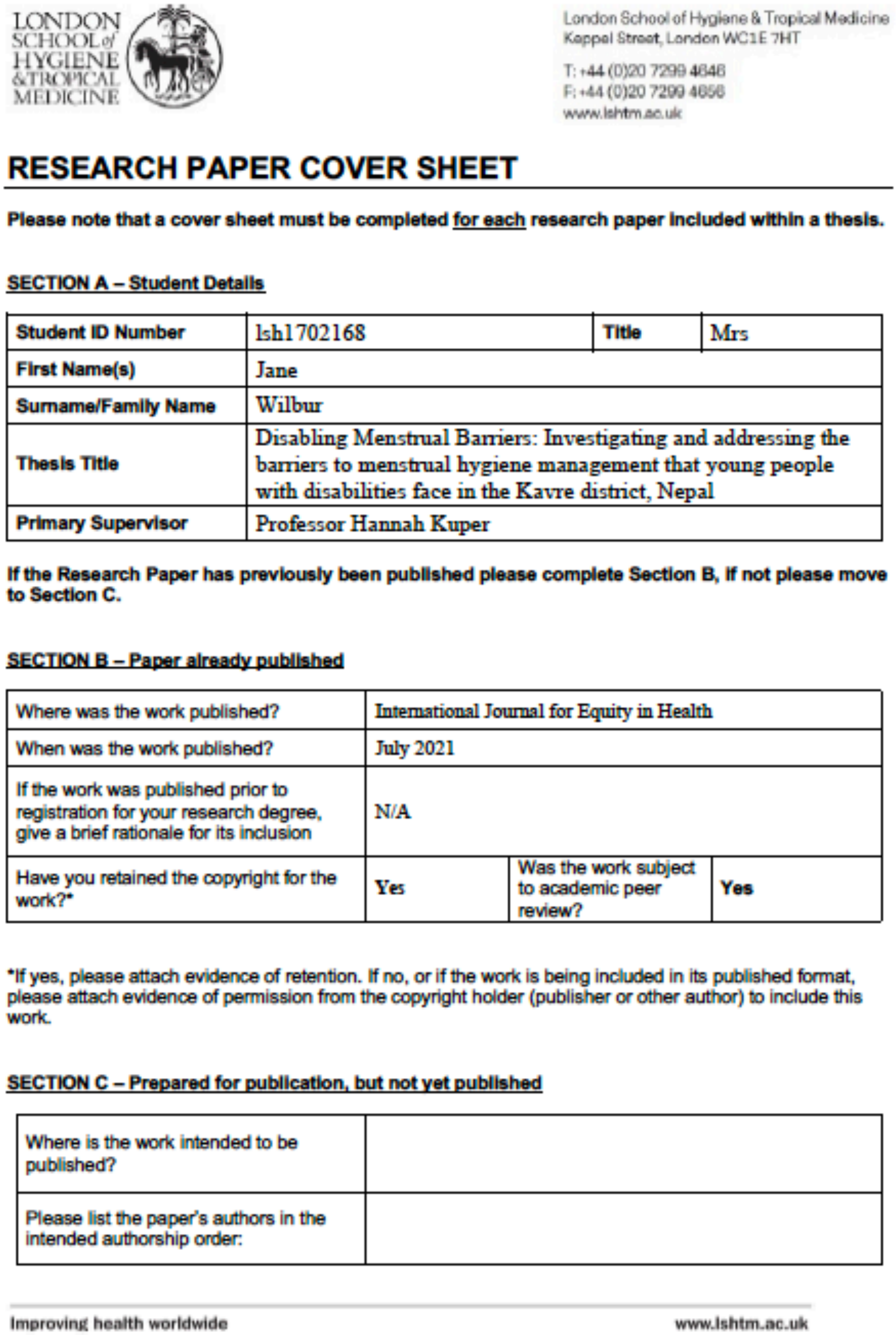

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

RESEARCH PAPER COVER SHEET

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SECTION A – Student Details

Student ID Number	lsh1702168	**Title**	Mrs
First Name(s)	Jane		
Surname/Family Name	Wilbur		
Thesis Title	Disabling Menstrual Barriers: Investigating and addressing the barriers to menstrual hygiene management that young people with disabilities face in the Kavre district, Nepal		
Primary Supervisor	Professor Hannah Kuper		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	International Journal for Equity in Health		
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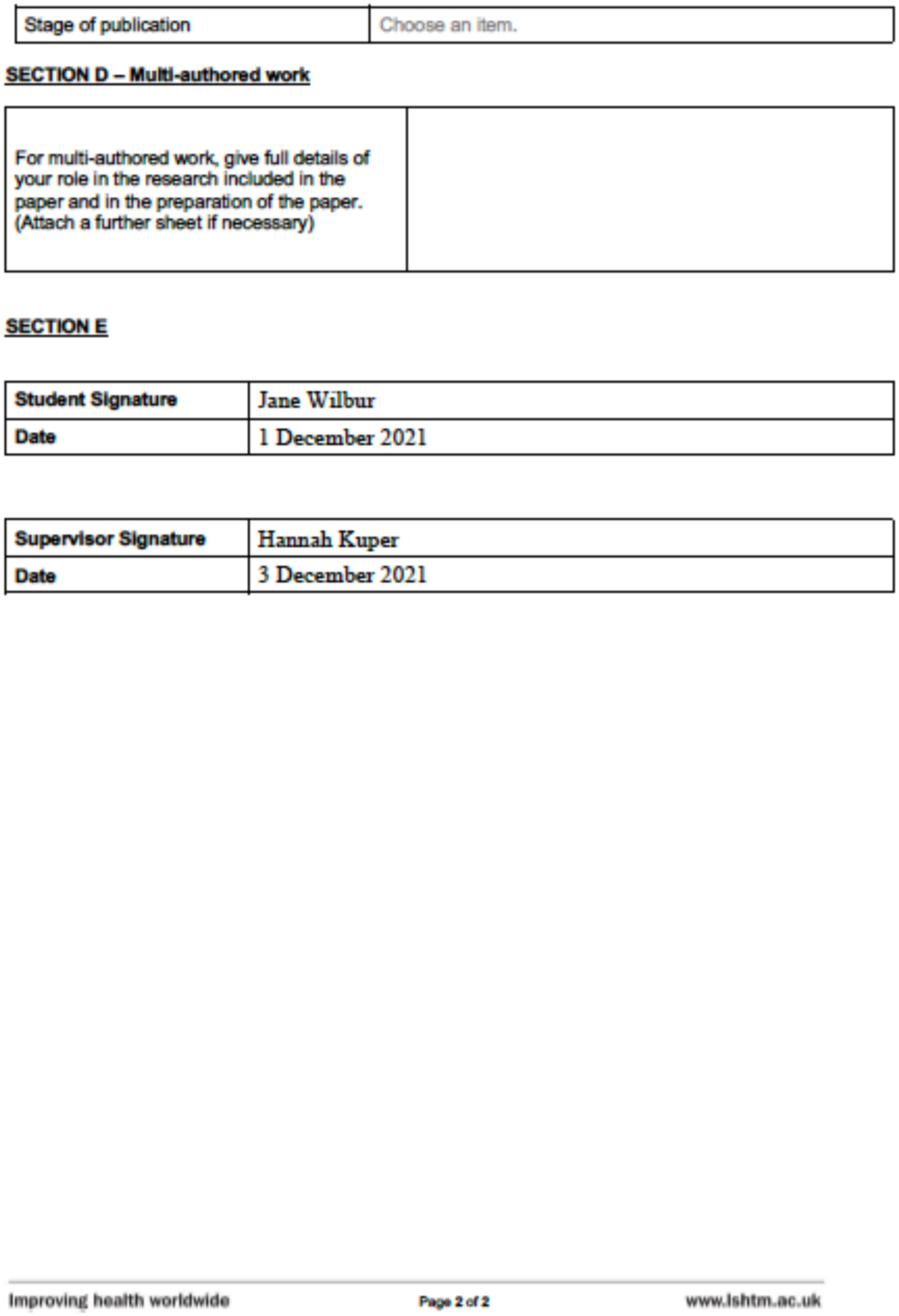

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For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	

SECTION E

Student Signature	Jane Wilbur
Date	1 December 2021

Supervisor Signature	Hannah Kuper
Date	3 December 2021

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International Journal for
Equity in Health

RESEARCH **Open Access**

Are Nepal's water, sanitation and hygiene and menstrual hygiene policies and supporting documents inclusive of disability? A policy analysis

Jane Wilbur[1*], Nathaniel Scherer[1], Islay Mactaggart[1], Govind Shrestha[2], Thérèse Mahon[3], Belen Torondel[1], Shaffa Hameed[1] and Hannah Kuper[1]

Abstract

Purpose: This study assesses the inclusion of disability in Nepal's policy and guidance relevant to water, sanitation and hygiene (WASH), and menstrual hygiene management (MHM) in comparison to gender. We investigated both policy formulation and implementation, using the Kavrepalanchok district as a case study.

Materials and methods: We used the EquiFrame framework, adapted for disability and gender, and focusing on WASH and MHM. Ten Nepali policies and guidance documents were reviewed and scored for quality against the framework, which included 21 core concepts of human rights. We also interviewed key informants to consider the inclusion of disability in the implementation of MHM interventions. We applied stratified purpose sampling to 12 government officials and service providers working in Kathmandu and the Kavrepalanchock district; conducted in-depth interviews and analysed data thematically using Nvivo 11.

Results: Disability was inadequately covered within the policy documents, and MHM policy commitments for disability were almost non-existent. Participation of people with disabilities in policy development was limited; within Kavrepalanchok, policy commitments were not implemented as intended and disability service providers were unable to allocate government resources. Inadequate data on disability and MHM resulted in limited professional understanding of the issues, as service providers had no training. A narrow WASH infrastructure approach to improving MHM for people with disabilities was prioritised. MHM interventions were delivered in schools; these failed to reach children with disabilities who are often out of school. Finally, there were indications that some caregivers seek sterilisation for people with disabilities who are unable to manage menstruation independently.

(Continued on next page)

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* Correspondence: jane.wilbur@lshtm.ac.uk
[1]London School of Hygiene & Tropical Medicine, Keppel Street, London WC1E 7HT, UK
Full list of author information is available at the end of the article

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Conclusion: Though the Constitution of Nepal enshrines gender equality and disability inclusion, there are consistent gaps in attention to disability and MHM in policies and practice. These omit and exclude people with disabilities from MHM interventions. Investment is required to generate evidence on the MHM barriers faced by people with disabilities, which would then be drawn on to develop training on these issues for professionals to improve understanding. Subsequently, policy makers could include more concepts of human rights against disability in relevant policies and service providers could implement policy commitments as intended.

Keywords: Equiframe, Disability, Gender, Menstrual hygiene management, Policy analysis, Qualitative research

Introduction

In 2017, approximately 26% of women globally (1.9 billion) were of menstruating age [1]. However, many of these people – particularly those living in low- and middle-income countries (LMICs) – have poor menstrual hygiene management (MHM) (Table 1).

Inadequate MHM can negatively affect girls' education [4] and employment [5, 6], and increase the risk of sexual violence and coercion, as well as sexual and reproductive diseases [7, 8]. A growing body of evidence highlights the additional barriers to MHM that people with disabilities face, including inaccessible water, sanitation and hygiene (WASH) facilities, lack of relevant MHM information, and inappropriate menstrual hygiene products [9, 10]. Additionally, where people with disabilities require support from others to manage their menstruation, caregivers receive limited guidance or support about how to do this [11–15]. Consequently, caregivers may feel isolated and stressed, which can result in poor MHM outcomes for the individual they support [9]. These concerns are important, as approximately 15% of the global population live with a disability [16]. However, there is a dearth of MHM interventions for people with disabilities and their caregivers, and this topic is still largely absent from global discourse on MHM. Similarly to WASH more broadly, addressing the issues around MHM requires a multi-sectoral response across health, education and disability [4, 17, 18].

The definition of MHM in Table 1, focuses on the knowledge and behaviours necessary for adequate menstrual hygiene, including personal hygiene (using clean menstrual materials, and changing and washing them when needed) and public hygiene behaviours (safe disposal of used menstrual materials). Consequently, MHM tends to be referenced within WASH policies, strategies and plans, which are vital to align national priorities with the health and wellbeing needs of the population. These documents stipulate how government, development partners, civil society and the private sector should collaborate and utilise available resources effectively and efficiently. However, in many low-and middle-income countries WASH policies are not always implemented as intended for a variety of reasons, including limited capacity of service providers to absorb allocated funds, inadequate monitoring of service provision by the government and a lack of demand from citizens [19]. Additionally, women and girls with and without disabilities commonly experience discrimination and inequalities in relation to WASH and MHM [20]. Discriminatory processes must be identified and understood and then addressed in policies and programmes.

Table 1 Definition of Menstrual Hygiene Management

In 2012, the WHO and UNICEF Joint Monitoring Programme (JMP) for drinking water, sanitation, and hygiene defined MHM as: 'Women and adolescent girls using a clean menstrual management material to absorb or collect blood that can be changed in privacy as often as necessary for the duration of the menstruation period, using soap and water for washing the body as required, and having access to facilities to dispose of used menstrual management materials. They understand the basic facts linked to the menstrual cycle and how to manage it with dignity and without discomfort or fear' [2]. MHM also involves addressing harmful societal beliefs and taboos surrounding the issue [3].

In many parts of Nepal, menstrual behaviours are shaped by socio-cultural restrictions and taboos, which inhibit MHM [21, 22]. To combat this, Nepal has worked to integrate gender within WASH policy development and implementation, such as ensuring gender segregated toilets that include MHM facilities are constructed in schools, and ensuring women hold leadership positions in WASH management structures. However, there has not been an assessment of the extent to which the MHM needs of people with disabilities are included in the Government of Nepal's relevant policies and supporting documents, and how they are implemented. This study aims to fill that gap.

Methods

Study aims and objectives

Our study sits within the wider Disabling Menstrual Hygiene Barriers research which aims to investigate and address the barriers to MHM that young people with disabilities face in the Kavrepalanchok (hereafter referred to as Kavre) district, Nepal [23].

This study aimed to review the extent to which the needs of people with disabilities are included in Nepal's policy documents related to MHM and WASH, and explore how these policy commitments are implemented, using the Kavre district as a case study. It will meet this aim by answering two linked research questions: 1) are Nepal's policies, strategies and guidance related to MHM equally committed to disability and gender, and 2) to what extent is disability included in the implementation of MHM interventions in the Kavre district. The first question is answered by conducting a policy analysis of relevant documents, and the second by carrying out a qualitative study.

Policy analysis: materials and methods

Search strategy

We followed Arskey and O'Malley's methodological framework to review the literature: after identifying the research questions, we identified relevant studies [24]. We targeted WASH policy documents, as these incorporate personal and public hygiene behaviours (including MHM). Education and health policy documents were also included because existing literature identifies that these sectors are central to improving MHM [4, 25, 26]. Eligible documents were government policies, strategies and guidelines, and Non-Government Organisations' (NGO) training materials to support policy implementation, which were expected to be relevant to MHM. No date range was applied, but all policies and supporting documents had to be drafted or in use.

Searches were conducted across four databases (PubMed, Medline, Global Health and Embase), but no relevant materials were identified. Consequently grey literature were identified through an online review, reference mining of existing documents analysing MHM policies and commitments in Nepal [27, 28], and through consultation with key actors involved in influencing national MHM policy and practice. Although the methodologies used in grey literature documents are not as rigorous as those in peer-reviewed articles, they are invariably developed by practitioners and service providers who have extensive knowledge of the local context, issues and possible solutions. WaterAid Nepal sourced materials that were not available online. The draft MHM policy [29] was only available in Nepali, so was translated through Google Translate. This was sent to a Nepali speaker who compared it to the original document. Any inaccuracies were corrected in the Google Translate version and this was included in the policy analysis. Table 2 presents the included materials.

Data extraction and analysis

The EquiFrame is a systematic policy analysis framework, which evaluates the extent to which 21 core concepts of human rights and 12 vulnerable groups are included in health policy documents [30]. Each core concept of human rights has key questions and key language to support consistent understanding and scoring against policy content. For instance, the key question for the core concept, *Individualised services* is: 'does the policy support the rights of vulnerable groups with individually tailored services to meet their needs and choices?'; its key language is: 'vulnerable groups receive appropriate, effective, and understandable services' [31]. Each reference to a core concept is awarded a quality of commitment score of 1 to 4: 1 = concept only mentioned; 2 = concept mentioned and explained; 3 = specific

Table 2 Included materials in the policy analysis

No.	Author	Date	Title	Document type
1	Government of Nepal, Ministry of Physical Planning and Works	2009	National Urban Water Supply and Sanitation Sector Policy	Policy
2	Ministry of health and population	2014	National Health Policy 2071, unofficial translation, draft ver.1 as of 08 Aug 2014	Policy
3	Government of Nepal, Ministry of Urban Development	2014	National Water Supply and Sanitation Policy 2014 DRAFT	Policy
4	Government of Nepal, Ministry of Health	2015	National adolescent health and development strategy 2015	Strategy
5	Government of Nepal, Ministry of Health and Population	2015	Nepal Health Sector Strategy 2015–2020	Strategy
6	Government of Nepal, Ministry of Education	2016	School sector development plan 2016/17–2022/23	Strategy
7	Nepal Fertility Care Center	2017	Integrating MHH in school health program	Training
8	Government of Nepal, Ministry of Water Supply and Sanitation Sector Efficiency Improvement Unit	2017	Nepal Water Supply, Sanitation and Hygiene Sector Development Plan (2017–2030)	Strategy
9	Government of Nepal, Ministry of Education, Centre for education and human resource development	2018	School WASH procedure	Guidelines
10	Government of Nepal	2020	राष्ट्रयि मयाददत मष्ट्रहनावारी नीष्ट्रत २०७४ [MHH policy draft – google translate]	Policy

policy actions identified to address the concept; 4 = intention to monitor concept was expressed.

As our study focused on disability and gender, we adapted the EquiFrame tool to only focus on the inclusion of rights with regards to these two groups. We also refined the 21 core concepts of human rights key questions and key language to reflect WASH and MHM (see Additional files 1 and 2). We applied the original EquiFrame quality of commitment score continuum of 1 to 4. We also consulted the authors of the EquiFrame application manual, and they reviewed its content and endorsed its adaptation.

Guidance was developed for the review and scoring process to ensure consistency. To establish validity and reliability of the data, JW and NS independently assessed the content of each policy document for the inclusion of information relevant to the 21 core concepts, and scored each reference. Any differences were discussed before agreeing final scores. Data was captured across disability and gender, WASH and MHM for all materials.

Each reference that scored 3 or 4, was deemed 'high quality', as the information provided specific actions points and intention to monitor. For instance, the following text from the School Sector Development Plan referenced *Capability based services, Integration* and *Efficiency* against gender, WASH and MHM. Each reference to these core concepts were awarded 3 because specific actions are identified.

> *"Nominate WASH focal teachers and menstrual hygiene management female teachers in all schools, for coordinating, planning, resource mobilisation, and monitoring of school WASH activities and facilities in coordination with school WASH coordination committees"* [32].

The percentage of the 21 core concepts referenced at least once, and the average score of each reference were presented for each document. To estimate the overall quality of commitments made to human rights, data was then aggregated across all documents to show the average score and total proportion of references made to each core concept.

Qualitative study: materials and methods

Study site

Nepal was selected as the study focus due to the widely documented sociocultural restrictions and taboos surrounding menstruation and because the Government of Nepal is committed to improving gender equality in WASH [33–36]. Kathmandu and the Kavre District were selected as the study sites for the qualitative interviews. Kathmandu was selected as it is the administrative capital of Nepal, and the Kavre district was selected because it was already chosen as the Disabling Menstrual Hygiene Barriers research study site [23]. Kavre is one of Nepal's 77 districts, with a population of 381,937, and estimated basic water coverage is 89%, whilst basic sanitation coverage is 98% [37] (water and sanitation coverage is from unpublished data). Ethical approval for the study was granted by from the Research Ethics Committee and the Health Research Council of the authors' institutes.

Study population and sample size

The study population and inclusion criteria comprised: 12 key informants, who were government officials or service providers, working at the national level in Kathmandu or at the district level, in the Kavre District, with a professional focus on WASH, MHM, health, education or disability (Table 3). Topics explored were: involvement of civil society, and people with disabilities in policy discourse, development and implementation; mechanisms to monitor the implementation of policy commitments; knowledge of WASH and MHM requirements of people with disabilities, organisational focus on MHM for people with and without a disability, and support and guidance for service providers to deliver inclusive MHM interventions.

We applied stratified purposive sampling to government officials and service providers as we believed these constituted a fairly homogeneous sample [38]. Key informants were selected through WaterAid Nepal's networks, and snowball sampling was applied to increase the sample (whereby participants identified other people to interview) [39, 40].

Data collection methods and analysis

Written informed consent was obtained and witnessed from each participant before enrolment. An information sheet and consent form (in English or Nepali) was given to, or read out to the participants by the research team. Informed written consent was received from all participants.

In-depth interviews were undertaken at the participant's place of work and lasted up to 1 hour. With consent, interviews were conducted in person by the research team, in English or Nepali and were recorded on a voice recorder. Field notes were made after the interviews. The research team met at the end of each day to discuss potential bias in data collection and analyse the findings. Once data collection was complete, voice recordings were translated into English (where necessary) and transcribed. Transcriptions were checked for precision by Nepali research team members and WaterAid Nepal staff.

Data generated through interviews was analysed thematically, firstly against the adapted socio-ecological framework for MHM, which were then coded into smaller units based on the specific topics explored and experiences of participants [9]. Codes were developed

Table 3 Study population characteristics

Study population	Characteristics	*n* = 12
Government official	Department of Water Supply and Sewerage, Kathmandu	1
	Department of Education, Kathmandu	1
	Women, Children and Social Welfare, Kavre district	1
	Federal Affairs and Local Governance, Kavre district	1
Service provider	Non-Government Organisation, Water, sanitation and hygiene, including MHH, Kathmandu	1
	Non-Government Organisation, Sexual and reproductive health, including MHH, Kathmandu	1
	Organisation for Persons with Disabilities, Disability, Kathmandu	1
	Healthcare provider, Health, Kavre district	4
	Social mobiliser, Kavre district	1

iteratively: they were compared and connections between them were identified and analysed using NVivo 11. Co-authors reviewed the themes and analyses to ensure reliability; any differences were discussed before consensus of opinion was reached. Additionally, research findings were presented for discussion and validation with participants and key stakeholders at a meeting in Kathmandu.

Research team and training

Our all-woman qualitative research team consisted of the lead author, a Nepali Research Coordinator, and two Nepali Field Researchers who have a disability. The research team undertook a week-long training, led by the lead author and a LSHTM colleague on how to conduct ethical research on MHM with key informants, people who have a disability and their caregivers [23].

Results

The government of Nepal demonstrates high level commitment to progressively realising the right to water and sanitation for all its citizens

The Government of Nepal moved to federalism in 2015, to enable the division of powers between three independent tiers of government: Federal Ministries, Provincial Ministries and Local Governments [41]. Within the WASH sector the Federal Ministries are responsible for large infrastructure and revenue distribution to three tiers from the treasury; the Provincial Ministries are responsible for medium infrastructure and grants to the Local Government; and the Local Governments (rural and urban) ensure WASH services, small infrastructure and spend local revenue [41].

The Constitution of Nepal sets out ambitions to be an inclusive state, which guarantees that all citizens have the right to equality, and the state is committed to Gender, Equality and Social Inclusion (GESI) within poverty reduction [42]. Therefore, policies take account of existing power relations (e.g. between women and men, or social groups), and how these influence access to resources and participation in decision-making mechanisms. Nepal also voted in favour of the United Nations Resolution on the human right to water and sanitation [43]. Within WASH policies, gender, caste and ethnic groups, poverty, remoteness and disability are identified as the key issues in the GESI commitment [44].

Since the Sustainable Development Goals were set in 2015 (which includes hygiene within Target 6.2 under Goal 6: clean water and sanitation), progress using a multi-sectoral response to MHM has gained momentum [45]. For instance, in 2015 a training package to integrate menstrual hygiene into school health programmes was developed [46]; in 2016, the Water Supply Sanitation and Hygiene Sector Development Plan was launched which includes policy statements related to MHM [44]; and in 2017 the Ministry of Water Supply and Sanitation formed a taskforce of government agencies and civil society organisations (with representation across disability, WASH and health) to draft a national policy on menstruation. Additionally, the WASH in Schools Procedure includes a ranking to measure MHM standards across different schools [47]. Nepal's Water Supply, Sanitation and Hygiene Sector vision is 'improved public health and living standard of people of Nepal through safe, sufficient, accessible, acceptable, and affordable water, sanitation and hygiene services–any time, everyone and everywhere' [44].

References made to core concepts of human rights across all policies and supporting documents

Ten policies, strategies, guidance and training documents were reviewed. Two of these did not include any reference to the core concepts of human rights for people with disabilities, and women and girls in relation to WASH: The National Adolescent Health and Development Strategy and the National Health Sector Strategy [48, 49].

Table 4 presents the frequency that each core concept from the adapted EquiFrame was referenced across the remaining eight documents (total references %) and the

Table 4 Frequency of references to cover concepts of human rights and average scores across all documents, and the comparison between disability and gender

Core concepts	Disability				Gender				Proportion of total references to disability and gender (*n* = 274)	
	WASH (*n* = 33 references)		MHM within WASH (*n* = 2/33 references)		WASH (*n* = 241 references)		MHM within WASH (*n* = 148/241 references)			
	Total references (%)	**Average score**	**Total references (%)**	**Average score**	**Total references (%)**	**Average score**	**Total references (%)**	**Average score**	**Disability total references (%)**	**Gender total references (%)**
Non-discrimination	15%	2.2	0%	0	11%	2.3	8%	2.3	2%	10%
Individualised services	24%	3.0	50%	3.0	19%	2.9	26%	2.8	3%	17%
Entitlement/affordability	0%	0	0%	0	3%	2.9	3%	2.8	0%	3%
Capability based services	0%	0	0%	0	6%	3.0	2%	3.3	0%	5%
Participation	0%	0	0%	0	5%	2.2	0%	0	0%	4%
Coordination of services	0%	0	0%	0	0%	0	0%	0	0%	0%
Protection from harm	12%	2.8	0%	0	10%	2.8	9%	2.6	1%	9%
Liberty	0%	0	0%	0	0%	0	0%	0	0%	0%
Autonomy	0%	0	0%	0	1%	3.0	1%	4.0	0%	1%
Privacy	0%	0	0%	0	1%	2.0	1%	2.0	0%	1%
Integration	6%	3.0	50%	4.0	3%	3.1	4%	3.3	1%	3%
Contribution	0%	0	0%	0	0%	0	0%	0	0%	0%
Family resource	0%	0	0%	0	0%	0	1%	3.0	0%	0%
Family support	0%	0	0%	0	1%	1.0	0%	0	0%	1%
Cultural responsiveness	0%	0	0%	0	0%	2.0	1%	2.0	0%	0%
Accountability	0%	0	0%	0	0%	0	0%	0	0%	0%
Prevention	0%	0	0%	0	5%	2.1	9%	2.2	0%	5%
Capacity building	6%	3.0	0%	0	7%	3.1	8%	3.2	1%	6%
Access	36%	2.9	0%	0	20%	3.0	18%	3.1	4%	17%
Quality	0%	0	0%	0	4%	3.2	7%	3.2	0%	4%
Efficiency	0%	0	0%	0	3%	3.1	3%	2.5	0%	3%
Totals	**100%**		**100%**		**100%**		**100%**		**12%**	**88%**

quality of those references (average score), separately for disability and gender, WASH and MHM.

Out of 274 references to either gender or disability across all of the materials, 88% were related to gender and 12% were related to disability (Fig. 1). Specifically, within the 148 references to MHM, 99% were gender-related and 1% (n = 2) were disability related (Fig. 2). Disability was referenced to 6 of the 21 core concepts of human rights, compared with 15 for gender. Across disability and gender, *Access* was most frequently mentioned (36 and 20% respectively). Highest quality references across all results were for *Integration* (average score 3.4) and *Individualised Services* (2.9). *Family support* received the lowest average score [2], meaning that overall, references to this core concept were not assigned specific policy actions or monitoring mechanisms.

Findings from the key informant interviews show that mechanisms are in place to ensure GESI in implementation of policies at the national and district level, including allocating budget from the national to district level to interventions targeting groups that may be marginalised. However, government officials at both the national and district level noted that policy implementation was weak. Reasons include: a lack of monitoring, inadequate staffing levels and budget allocation for inclusive WASH and MHM infrastructure; limited disability service providers, absence of training on MHM and disability and partial understanding of disability.

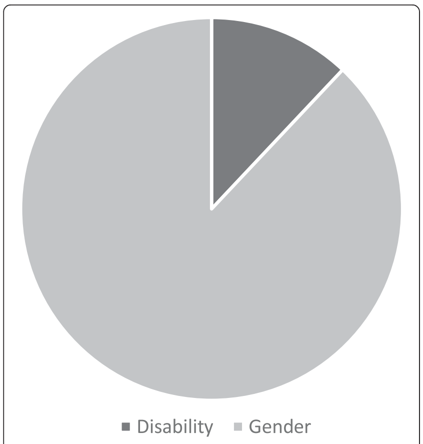

Fig. 1 Number of references to core concepts of human rights related to disability and gender

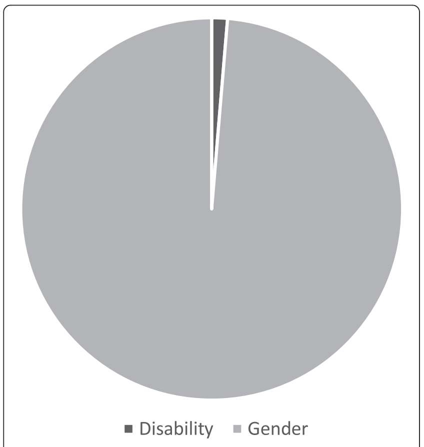

Fig. 2 Number of references to core concepts of human rights against disability and gender, within MHM

Limited involvement of people with disabilities in policy discourse and development

The core concepts, *Participation* and *Capability based services* (the latter recognizes the capabilities of people with disabilities in implementation and management of WASH activities at an organisational level) were referenced against gender (5 and 6% respectively), but they were not referenced against disability in any document.

> *"Women's participation will be emphasized in all aspects of water supply and sanitation planning, implementation, management, operation and maintenance."* [50] (page 12; scored *Capability based services, Participation* against gender).

Key informants stated that Organisations of Persons with Disabilities (OPDs) and disability service providers must actively be involved in policy discourse and development to ensure that GESI is included in national policies. Policy makers explained that it is 'compulsory' to incorporate disability in every policy.

> "The Disability and Gender terminologies cannot be excluded while developing any policy. It is a national commitment, that we must include them" (National government official).

However, the involvement of people with disabilities in policy discourse and development was not enforced, and participants expressed concerns that the involvement of people with disabilities could be tokenistic.

> " … unfortunately they are there because they were invited because someone thought it's important to see it" (Service provider, Kathmandu).

National level government officials reported that advice was sought from disability advisors (who did not have a disability) from within the relevant ministry. Reasons given for the lack of involvement of people with disabilities and OPDs in policy development included the protracted process of getting policies and guidelines signed off by the government, even without involving external groups.

Inadequate policy monitoring, limited capacities and resources to implement policies at the district level

Across all documents reviewed *Access* (supports people with disabilities with physical and information access to WASH services) was most frequently mentioned (36%) against disability, and this was followed by *Individualised services* (24%) (which support the rights of people with disabilities with individually tailored WASH services to meet their needs, choices and impairments). Together these make up more than half (61%) of all references made to disability. Similarly for gender, *Access* receives nearly one quarter of all references (20%).

> *"For all schools to have functional water and sanitation facilities that are environmentally sound and user-friendly for children, boys and girls and differently-abled students and teachers."* [32] (page 63, scored *Access* and *Individualised services* against disability and gender).

With respect to disability and MHM, *Individualised services* and *Integration* were the only core concepts referenced.

> *"Provision of adequate and CGD-friendly [accessible] WASH services including hand washing with soap and MHM facilities."* [44] (page 39; scored *Individualised services* against disability and gender for WASH and MHM).

> *"The National Institute of Education shall make provision for the inclusion of the term of Menstruation in an inclusive manner and include it in government and non-government schools and non-formal education."* [29] (scored *Integration* against disability and gender for WASH and MHM).

However, these commitments were not realised: key informants reported that school latrines were not fully accessible and did not include incinerators to dispose of menstrual hygiene materials (incinerators were explicitly mentioned by the key informant as the expected disposal option). Reasons cited included inadequate budget allocation per unit, insufficient technical training for service providers and limited technical skills.

> "The implementation is not that successful. [….] One of the problem was insufficient budget per unit. If you go to schools, you can see ramps but the ramps aren't wide enough, those are because of lack of experience and technical problems. [….]" (Service provider, Kavre district).

Accountability was not referenced at all against disability or gender in any policy or supporting document. However, national government officials reported that disability rights groups were involved in monitoring policy implementation at the district level, but district government officials explained that this did not happen. They also described inadequate staffing levels within the district government, and feeling over stretched by commitments across different sectors.

> "…. proper manpower should be allocated in the VDC's [Village Development Committees] and Municipalities for formulating and implementing and monitoring of the policies. Also, the people working in the government offices should also be allocated specific sectors, a person cannot work in all sectors and look after all sectors. So, the policies and regulations are very weak" (District level government official).

Limited disability service providers and outreach for people with disabilities at the district level

The core concept, *Coordination of services* was not referenced at all in any policy or supporting document in relation to disability or gender. Participants explained that MHM programmes in Kavre were delivered collaboratively by NGOs (including disability service providers), district government officials and healthcare workers. Government funds could be applied for by implementing organisations, but district government officials noted these were not often sought or applied for, partly because groups focussed on disability-inclusive development were not particularly active in the Kavre district, though they did exist.

> "This financial year we were not able to work on any programs related to disabled people because [

> ….] the disabled people cannot make their own program, and the team responsible for developing programs for the disabled people were not active" (District level government official).

A lack of data on MHM barriers faced by people with disabilities leads to limited professional training and support to address the issues

As part of commitments to GESI, training on MHM was delivered at the national and district levels by NGOs, which shows how MHM is becoming a more significant political priority in Nepal. At the national level, policy makers were involved in 'master trainer of trainer' programmes for MHM, in which people with disabilities were present. However, this training did not include awareness of the barriers to MHM that people with disabilities face. This disparity is reflected in the documents reviewed: with respect to MHM, *Capacity building* received 8% of references against gender, whilst it was not referenced at all in relation to disability. Furthermore, *Quality* (which highlights the need for evidence-based and professionally skilled practice) received 7% of references against gender, but was not cited against disability in any of the documents.

Among the key informants, there was a better understanding of the barriers to WASH facilities for people with mobility limitations than other impairment types.

> "There hasn't been much work done for the menstrual hygiene management of disabled children. We have a provision for separate toilets for boys and girls, and about the disabled friendly toilets, there are ramps in the toilets" (National level government official).

Service providers, who were aware that disability needs to be integrated into MHM interventions, did not have the knowledge or tools to be able to support people with disabilities and their caregivers. One expressed frustration at their inability to do so.

> "You know [people with intellectual impairments] take the pad and put it on their face. I just don't have an answer. It makes me feel very bad, but I don't have an answer. I have no idea about what to do about that. And there's so little information that's accessible to understand what to do" (Service provider, Kathmandu).

Limited professional training and support leads to inadequate understanding of the issues

The national government official who completed the MHM awareness raising training for policy makers and service providers, which was attended by people with disabilities, noted that the interactions with these participants increased their awareness of disability, but that limited understanding of disability in Nepal is pervasive.

> ".. in Nepal there is poor understanding about people with disability. There is common understanding that people having problem with legs and limbs, or paralyzed people, they are treated as people with disabilities, but in my opinion people with visual or hearing impairment, people with backbone problems are not included in the disability groups" (National level government official).

A limited understanding of disability was clear through interviews with key informants in the Kavre district. For instance, when a healthcare worker was asked if they knew of any people with disabilities living in the district, they replied that there is one girl who has a physical impairment as well as: "a 11-12-year-old girl who has problems with her earlobes" (Service provider, Kavre district). One service provider in the Kavre district explained: "I don't have much knowledge on menstrual hygiene problems of disabled people."

People with disabilities are marginalised within MHM interventions

District health care workers received MHM training from NGOs; they then trained health assistants and school teachers to teach school children to make menstrual materials, and dispose or reuse them hygienically. However, the training did not include disability and participants noted that very few children with a disability attended schools. Even though *Non-discrimination* was referenced 15% against disability across all documents, and *Integration* was one of the two core concepts referenced against disability with respect to MHM, there were no MHM outreach programmes for children with disabilities who were not in school. Reasons given by participants for this lack of representation were that children with disabilities did not attend those schools, and that people with disabilities were unable to travel to meeting locations. The core concept, *Entitlement/affordability* was not referenced against disability in any document.

> Researcher: Were there children with disabilities in the [MHM training] programmes?
> Participant: No. Because most of the participants were girls from the schools in our ward, and there were no disabled girls in those schools. We don't know much about disabled girls because they can't be present themselves in all the programs (Service provider, Kavre district).

Protection against harm was referenced 12% with respect to disability in the documents reviewed, but three service providers reported being approached regularly by family members of people with disabilities seeking to cease menstruation.

> Researcher: Have you ever been asked about sterilization?
> Participant: Yes. That is the one of the often question the parents ask me. The caretaker and parents want disabled women to get surgical sterilization so that there is no problem of taking care of menstruation and no risk of unwanted pregnancy (Service provider, Kathmandu).

Medical records on sterilisation of people with disabilities were sought, but could not be obtained. Service providers in Kavre reported that caregivers felt that menstruation was pointless for people with disabilities as they will never be married, or be able to understand how to manage menstruation. One service provider expressed agreement.

> "First, most of the disabled girls don't know about menstruation, they don't know [what] menstruation is, what hygiene is. They even take out the sanitary pads their parents put on them. So, for the mentally disabled girls, menstruation doesn't make sense for them" (Service provider, Kavre district).

The value-based language used by the participants is of particular note: "so that there is no problem of taking care of menstruation", and "menstruation doesn't make sense for them". *Autonomy* (supports the right of people with disabilities to exercise choice or control of what happens to them), *Family resource* and *Family support* (recognizes individual members of people with disabilities may have an impact on the family members requiring additional support from WASH services) are not referenced at all in relation to disability in any of the documents reviewed.

Discussion

This study aimed to review the extent to which the needs of people with disabilities are included in Nepal's policies and supporting documents related to MHM and WASH, and explores how these policy commitments are implemented, using the Kavre district as a case study. The Government of Nepal is committed to progressively realising the right to water and sanitation for all its citizens, demonstrated through its national level commitment to GESI. However, disability rights receive inadequate attention in policies and supporting documents compared to gender. Within WASH, MHM policy commitments for people with disabilities is almost non-existent. This translates into practice: people with disabilities are marginalised within MHM interventions.

Existing evidence demonstrates that a dearth of data about the barriers to MHM that people with disabilities and their caregivers face, leads to a lack of awareness, understanding, support and guidance for MHM and disability [9, 51]. Our study reflects these patterns, and this can be tracked through an absence of: 1) rights for people with disabilities with regards to MHM in national policies and supporting documents, 2) professional training and support for service providers, and 3) professional understanding of the issues.

Our policy analysis of relevant documents reveals that, when compared to gender, disability is excluded in national policies and supporting documents. Additionally, a more holistic strategy to improving gender equality (which includes promoting women's leadership and redressing gender power inequalities) is applied within Nepal's commitment to GESI. For instance, when comparing references of core concepts of human rights between disability and gender in policies and supporting documents: gender receives 88% of references across a much broader spread of commitments to core concepts than is seen for disability. Additionally, there are only two references made to disability and MHM in all documents, compared to 148 for gender and MHM. Therefore, the impact of not having their MHM needs addressed may compound the double discrimination experienced by women and girls with disabilities compared to boys and men with disabilities.

An assumption could be made that if MHM is included within a policy document, then gender equality is addressed. However, meeting the needs of women and girls who menstruate is an important step towards gender equality, but it is only a component of it. Identifying which of the core concepts within the EquiFrame are referenced provides a valuable tool for interrogating strengths and gaps in policy documentation. For instance, transformative gender approaches include ensuring women and girls receive specific, appropriate and effective MHM services, with reasonable adjustments made/supported, when necessary (*Individualised Services)*, but also that women and girls hold leadership positions with decision making responsibilities, and they are supported to perform these roles if required (*Capability Based Services*); government structures support sex and age disaggregated data (*Quality*), and hygiene facilities, goods and services are respectful of ethical principles and culturally appropriate (*Cultural responsiveness*). Therefore, gender equality requires references to a broad spread of core concepts of human rights. This is mirrored in disability inclusion. It is not enough to ensure MHM facilities are accessible for people with disabilities (*Individualised services*); agency must be enhanced to ensure people with disabilities take decisions in relation to menstrual hygiene and that these decisions are acted upon (*Participation* and *Autonomy*). Key informants noted that the participation of people with disabilities in policy discourse and development were expected, but not enforced and was tokenistic. A lack of political engagement by people with disabilities is well referenced in global literature, even though it is a core human rights principle within the Convention on the Rights of Persons with Disabilities [16, 52–56].

In terms of policy implementation, challenges that exist in the Kavre district include: inadequate staffing capacities and allocation of resources to implement and monitor national commitments, even where policy document references to core concepts are scored as 'high quality' and provide specific action points (i.e. the School Sector Development Plan). Reasons given were inadequate budget allocation for infrastructure, technical training and professional skills. This is unsurprising as limited capacities to implement national financing plans for WASH is a well-documented globally. In 2019, 75% of 107 countries reported having financing plans for WASH, but more than half of these were not implemented effectively, and less than 15% of countries had the required human resources or funds to deliver WASH plans [56]. In terms of monitoring, 79% of countries have government led monitoring processes of national WASH targets, but only 10% reported having the human resources to do this [56].

In the Kavre district, disability service providers had limited capacities and did not access all government funds allocated for disability programmes. A lack of ability to spend funds could result in even less focus on disability in national policies and plans. Our findings support existing literature on disability service provision, which highlight successes, but also challenges related to a lack of financial commitments, professional understanding and training as major challenges to implementation [57–60].

Supporting the development of evidence-based and professionally skilled practice *(Quality)* was not prioritised in policies and guidance documents. This resulted in key informant's limited understanding of disability and a focus on the requirements of people with mobility impairments. People with intellectual impairments were mentioned in relation to an inability to support their MHM requirements, and there was no mention of people with visual, hearing or communication impairments. People with these impairments are harder to reach through broad based interventions as additional inclusion measures are needed, such as sign language interpretation, working with caregivers or providing clear, simple and repetitive information [16]. Subsequently, a WASH infrastructure-based approach to improving MHM for people with mobility impairments in Nepal is prioritised, instead of a comprehensive and holistic strategy that addresses every aspect of MHM for all impairment groups, such as the provision of accurate and accessible information on the menstrual cycle and how to manage it hygienically.

Key informants cited successes related to accessible school toilets, but supporting children with disabilities in accessing school to use the facilities, and communicating MHM information in an accessible way were completely absent, even though this was committed to in the documents reviewed. None of the MHM interventions in schools included children with disabilities. Therefore, people with disabilities are marginalised within MHM interventions. As defined by de Albuquerque, marginalisation 'refers to the process that systematically denies people opportunities and resources that are available to other members of society, and which would otherwise serve to promote social integration' [61]. Furthermore, as people with disabilities could not access information and services related to reproductive health, their right to health is violated. Existing literature calls for the integration of MHM into the education system, with efforts to ensure that these are inclusive of disability [4, 62]. However, efforts must go further - outreach programmes, for people with disabilities who are not in school, must complement MHM programmes delivered through school platforms.

Global literature on MHM for people with disabilities who are unable to manage menstruation independently, highlights the central role of caregivers, as well as a lack of MHM information, guidance and support for them [11, 12, 14, 15, 63]. Our study reflects this. Within policy documents, the human rights core concepts, *Family resource* (which recognizes the value of the family members of people with disabilities in addressing MHM needs), *Family support* and *Autonomy*, were not referenced against disability. There was also inadequate support and MHM guidance for caregivers in the Kavre district, which can lead caregivers to feel overwhelmed and isolated [23]. These factors, along with menstrual taboos and disability discrimination, can result in the sterilisation of the person with a disability in order to cease menstruation and guard against unwanted pregnancies [11, 12, 51, 64–66]. We found indications that caregivers seek to sterilise people with disabilities who are unable to manage their menstruation independently. We also found that 'The National Adolescent Health' and 'Development Strategy' and the 'Nepal Health Sector Strategy' did not consider MHM, which indicates that MHM is not consistently considered part of health, or specifically sexual and reproductive health [48, 49]. A cross sectoral approach to addressing the sexual and reproductive health and rights of people with disabilities, and women generally, needs to be considerably strengthened.

Study strengths and limitations

A key strength of this study is that we used a structured tool for policy analysis to assess the inclusion of disability, compared to the inclusion of gender, in relevant policies and supporting documents in Nepal. We complemented this by looking at one district to consider the implementation of policies around disability, WASH and MHM.

Some limitations should be considered when interpreting the study findings. These include potential selection bias during the identification of policies and supporting documents, and that the MHM policy draft [29] was translated from Nepali into English via Google Translate. The latter was managed by a Nepali speaker who checked the translation and corrected inaccuracies. Expired policies and supporting documents were not included so an analysis of shifting policy priorities over time was not conducted.

Conclusion

Though the Constitution of Nepal enshrines disability inclusion, we highlight consistent gaps in attention to disability and MHM in policies and practice. The Government of Nepal should invest in generating rigorous evidence about the barriers to MHM that people with disabilities and their caregivers face. Drawing on this data, training on these issues should be developed and delivered to improve professional understanding. With a more nuanced knowledge, policy makers could then integrate more core concepts of human rights against disability in policies and supporting documents and increase the focus on MHM. A more comprehensive, holistic and cross-sectoral strategy must be developed to addresses every aspect of MHM for people with disabilities, and will require provision of support and guidance for service providers. Addressing these recommendations would allow the Government of Nepal to progressively realise the rights of persons with disabilities to water and sanitation.

Abbreviations

GESI: Gender, Equality and Social Inclusion; LMIC: Low- and middle-income country; *[LSHTM]*: *[London School of Hygiene & Tropical Mecidine]*; MHM: Menstrual Health and Hygiene; MHM: Menstrual Hygiene Management; NGO: Non-Government Organisation; OPD: Organisations of Persons with Disabilities; VDC: Village Development Committees; WASH: Water, sanitation and hygiene

Supplementary Information

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Additional file 1. Adapted EquiFrame for WASH, MHM and Disability.
Additional file 2. Adapted EquiFrame for WASH, MHM and Gender.

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Authors' contributions

Conceptualisation, JW; methodology, JW, HK, BT and NS; training of research team, JW; formal analysis, JW; investigation, JW, NS; data curation, JW; supervision, JW, HK, TM, SH and BT; project management, coordination and administration, JW; funding acquisition, TM, JW; writing—original draft preparation, JW; writing, review and editing, JW; visualisation, JW, IM; manuscript review, HK, BT, SH, NS, IM, GS. All authors have read and approved the manuscript.

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Availability of data and materials

The data underlying this article will be shared on reasonable request to the corresponding author.

Declarations

Ethics approval and consent to participate

Ethical approval for the study was granted by from the Research Ethics Committee at the London School of Hygiene and Tropical Medicine (LSHTM) (reference: 12091) and the Nepal Health Research Council 171 (reference: 102/2017). Informed consent was obtained and witnessed from each participant before enrolment. An information sheet/consent form (in Nepali or English) was given to, or read out to the participants by the research team. Informed written consent was received from all key informants. It was made clear that participation was voluntary.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Author details

[1]London School of Hygiene & Tropical Medicine, Keppel Street, London WC1E 7HT, UK. [2]WaterAid Nepal, JM Road 10, Pabitra Tole Nakkhipot 44700, Nepal. [3]WaterAid, 27-29 Durham Street, London SE11 5JD, UK.

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Publisher's Note

Supporting information [see Appendix 3]

Additional file 1. Adapted EquiFrame for WASH, MHM and Disability

Additional file 2. Adapted EquiFrame for WASH, MHM and gender

Chapter 5 Paper Three: Investigating the barriers to menstrual hygiene management that young people with disabilities and their carers face in the Kavre district, Nepal

(Build step)

From top to bottom: Barriers to MHM faced by people with disabilities and their carers in the Kavre district

Image drawn by Raju Shakya during the dissemination of formative research findings, Kathmandu.

Preamble

The systematic review in Chapter 3 (Paper One) revealed a gap in evidence on the MHM needs of people with disabilities and their carers, and interventions targeted at these groups. It also identified several barriers to MHM faced and the dire consequences that these had. More evidence on MHM for people with different impairments and their carers in low- and middle-income settings is required. For instance, within South Asia, only one study has been published that investigates MHM for people with disabilities and their carers in India, and this focuses on people with intellectual impairments only (31).

Consequently, with the *Build* step, Paper Three aims to investigate the barriers to MHM that young people with disabilities and their carers face in the Kavre district. The study population comprised 20 people with a range of impairments who menstruate, aged 15-24 (as this age range is particularly vulnerable to exclusion (158). These individuals were identified by KIRCAC, CIUD and government social mobilisers working in the Kavre district, who arranged a meeting between these individuals and the research team. The research team then visited those individuals and screened them for disability using the Washington Group Short Set of questions on functioning (231). These are six questions on functioning for application in national surveys and censuses, developed and tested by the Washington Group on Disability Statistics. These questions align with the ICF framework (presented in Chapter 1) and focus on activity limitations. People were identified as having disabilities if they answered that they had 'a lot of difficulty' or more across any of the functional domains (seeing, hearing, cognition, communication, and self-care). Not all individuals met the inclusion criteria, so KIRDAC, CIUD, or the government social mobilisers identified more individuals and the process was repeated. Paper Three explains the identification and selection of participants with disabilities in more detail.

I also selected 13 carers who provided menstrual support to participants with disabilities. Carers were professionals and family members. I recruited two women with disabilities and an experienced Nepali qualitative researcher on the research team to achieve co-produced research. All members advised on the data collection tools developed, gathered data and collaboratively analysed the findings.

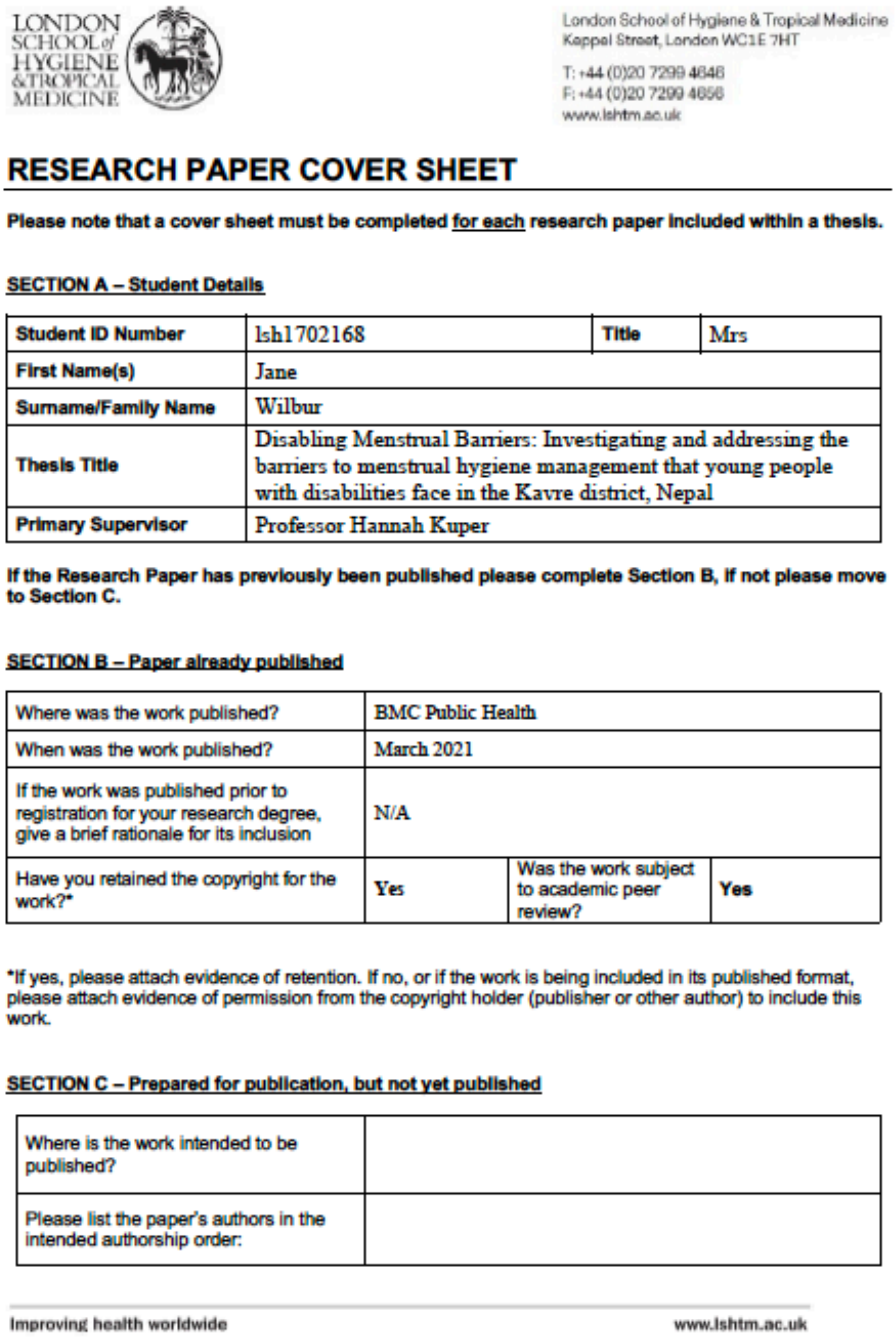
The Socio-ecological framework for MHM, adapted for disability (published in Paper One), formed the basis of the data collection methods, and data analyses applied. Topic guides explored the Sub-factors, such as the person with disabilities' ability to manage menstruation independently and support required; the carer's ability to manage another person's menstruation independently and support required and the intensity of menstrual pain experienced and influences on behaviour. Data were analysed thematically, but initial codes were structured according to the Factors that support MHM and Sub-factors detailed in the framework. I also applied a selection of qualitative methods to enable participants to describe their MHM related experiences, beliefs and feelings verbally and visually. We also observed the behaviour setting by carrying out accessibility and safety audits of the MHM facilities.

To ensure a holistic view of MHM was gained, all seven factors that support MHM and the correlating sub-factor (or outcome) set out in the adapted Socio-ecological framework (1) were explored. Findings are presented across the following areas: barriers to MHM faced by different impairment groups (all factors), menstrual material preference and disposal mechanisms (environmental and resource availability factors), premenstrual symptoms and behaviours (biological factors), menstrual restrictions (societal and government policy factors), and MHM information and guidance for people with disabilities and their carers (personal factors).

I applied a range of participatory methods to generate evidence, which helped me fully understand the participants' views. For instance, photos of participants' MHM experiences taken during PhotoVoice were ranked by participants according to which they thought were the most significant, instead of my perceptions of what those might be. These priorities were then compared to the analysis of data generated through in-depth interviews. Across carers, the importance of adhering to menstrual restrictions and the discomfort felt when people with disabilities did not follow them was ranked as the most critical issue by the carer who completed PhotoVoice; they were also widely discussed by carers during in-depth interviews. Consequently, findings related to menstrual restrictions and their impacts are reported fully in Paper Three.

All participants who completed PhotoVoice requested that they are credited using their real names when their photos are used. Participants also consented to having their identifiable features visible in photos.

Paper Three was published under a creative commons license with the license type (e.g. CC BY) in the BMC Public Health in March 2021.



London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

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SECTION A – Student Details

Student ID Number	lsh1702168	**Title**	Mrs
First Name(s)	Jane		
Surname/Family Name	Wilbur		
Thesis Title	Disabling Menstrual Barriers: Investigating and addressing the barriers to menstrual hygiene management that young people with disabilities face in the Kavre district, Nepal		
Primary Supervisor	Professor Hannah Kuper		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	BMC Public Health		
When was the work published?	March 2021		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	N/A		
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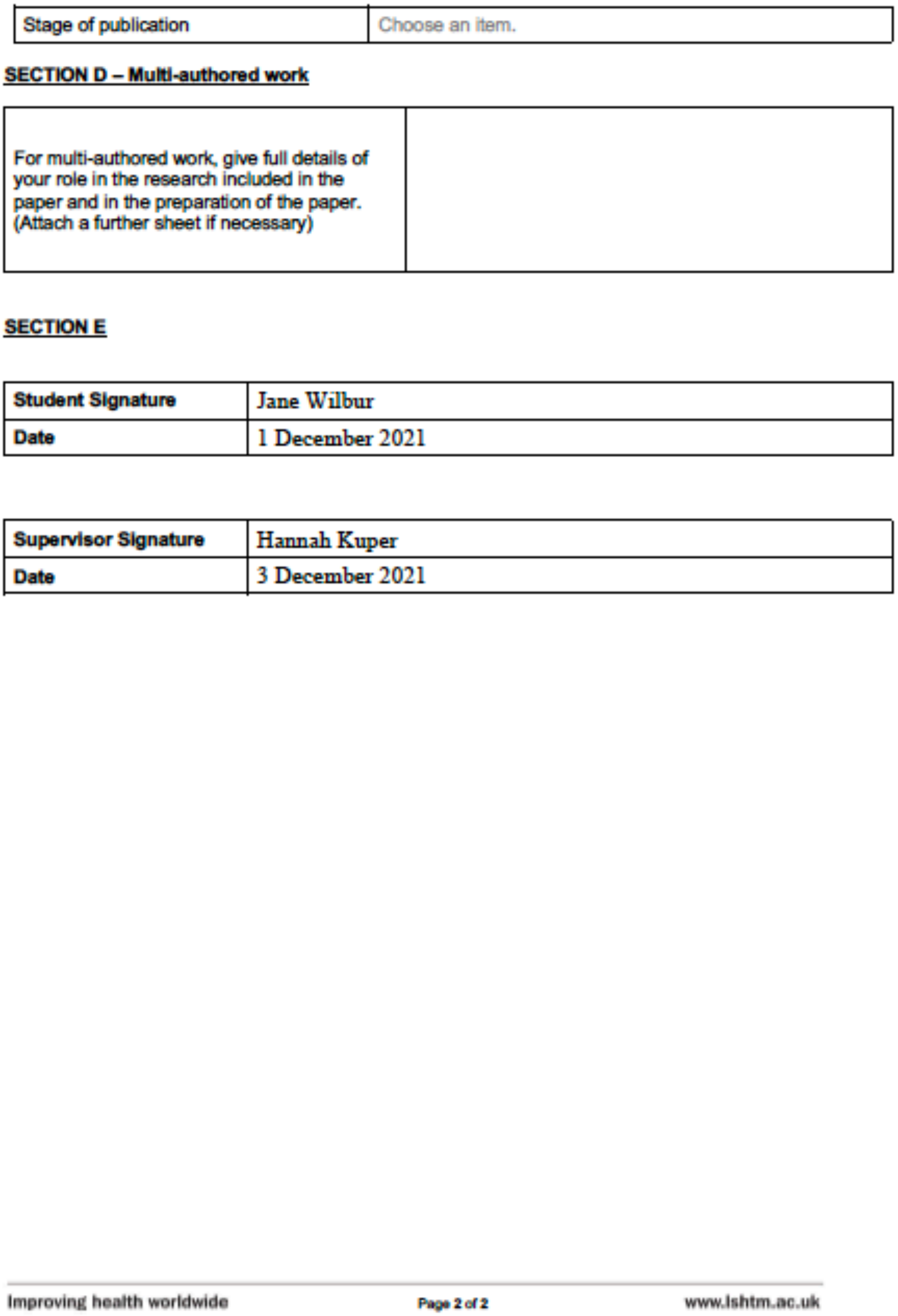

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SECTION E

Student Signature	Jane Wilbur
Date	1 December 2021

Supervisor Signature	Hannah Kuper
Date	3 December 2021

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RESEARCH ARTICLE **Open Access**

Qualitative study exploring the barriers to menstrual hygiene management faced by adolescents and young people with a disability, and their carers in the Kavrepalanchok district, Nepal

Jane Wilbur[1*], Shubha Kayastha[2], Thérèse Mahon[3], Belen Torondel[1], Shaffa Hameed[1], Anita Sigdel[2],
Amrita Gyawali[2] and Hannah Kuper[1]

Abstract

Background: Menstrual hygiene management (MHM) is a recognised public health, social and educational issue, which must be achieved to allow the realisation of human rights. People with disabilities are likely to experience layers of discrimination when they are menstruating, but little evidence exists.

Methods: The study aims to investigate barriers to MHM that people with disabilities and their carers face in the Kavrepalanchok, Nepal, using qualitative methods. Twenty people with disabilities, aged 15–24, who menstruate and experience 'a lot of difficulty' or more across one or more of the Washington Group functional domains were included, as well as 13 carers who provide menstrual support to these individuals. Purposeful sampling was applied to select participants. Different approaches were used to investigating barriers to MHM and triangulate data: in-depth interviews, observation, PhotoVoice and ranking. We analysed data thematically, using Nvivo 11.

Results: Barriers to MHM experienced by people with disabilities differ according to the impairment. Inaccessible WASH facilities were a major challenge for people with mobility, self-care and visual impairments. People with intellectual impairments had difficulty accessing MHM information and their carers despaired when they showed their menstrual blood to others, which could result in abuse. No support mechanisms existed for carers for MHM, and they felt overwhelmed and isolated. Menstrual discomfort was a major challenge; these were managed with home remedies, or not at all. Most participants followed menstrual restrictions, which were widespread and expected; many feared they would be cursed if they did not. As disability is often viewed as a curse, this demonstrates the layers of discrimination faced.

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* Correspondence: jane.wilbur@lshtm.ac.uk
[1]London School of Hygiene & Tropical Medicine, Keppel Street, London WC1E 7HT, UK
Full list of author information is available at the end of the article

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Conclusion: Issues related to MHM for people with disabilities is more complex than for others in the population due to the additional disability discrimination and impairment experienced. Research exploring these issues must be conducted in different settings, and MHM interventions, tailored for impairment type and carers requirements, should be developed. Attention to, and resourcing for disability inclusive MHM must be prioritised to ensure 'no one is left behind'.

Keywords: Disability, Carers, Menstrual hygiene management, Water, Sanitation and hygiene, Rights

Background

Menstrual hygiene management (MHM) is a recognised public health, social and educational issue [1]. Research shows that the realisation of human rights is inhibited by lack of provision for MHM, including the right to education, health and work [2–7]. This can happen when there is: inadequate physical water, sanitation and hygiene (WASH) infrastructure to support menstruation at home and in public spaces, a lack of affordable, comfortable and appropriate menstrual products, a lack of accurate information on the menstrual cycle and how to manage it with dignity, as well as harmful social beliefs and taboos related to menstruation.

Underlying these issues is menstrual stigma, which is rooted in power and gender inequalities, and means that menstruation is not often openly discussed. This discourages sharing accurate information on the menstrual cycle, and how to manage it hygienically and with dignity [8]. It also leads people to be unsure how they can seek support at home, at school or through healthcare services [8]. This is the case in Nepal, where menstruation is not spoken about openly, and many prepubescent girls do not receive information about menstruation, so their first menstrual cycle can be a frightening experience [9, 10]. Accurate information on the menstrual cycle and how to manage it hygienically is likewise inadequate [11]. Management of menstrual discomfort is limited and menstrual hygiene information is predominantly shared between family members, and focuses on the use of menstrual products and maintaining the current social beliefs and taboos surrounding menstruation. In this context, unhygienic practices are common [9].

Cultural, religious and behavioural expectations related to menstruation varies globally and within countries, as does the extent to which these impact on people's ability to fully participate in society when they are menstruating. A recent study in Nepal, found that 89% of women and girls experienced restrictions whilst menstruating [12], which involves the seclusion from the community and within the home [10, 13, 14]. Within Nepal, the extent to which menstrual restrictions are followed relates to caste and religion; 81.3% of the population are Hindu and adhere to the caste system, which is based on ritual impurity and purity [11, 15]. There are four broad castes: Brahmin, Kshatriya, Vaishya, Sudra, and these can determine individual's behaviours, including how strictly menstrual restrictions are followed. For instance, Brahmins are the upper-caste, and tend to follow menstrual restrictions closely so that they are not contaminated by menstrual blood [12, 16, 17].

Evidence about how a lack of MHM negatively impacts gender equality is growing [1, 18, 19]. However, there is a consistent blind spot on disability, even though 15% of the world's population have a disability, and 80% of people with disabilities live in low- and middle-income countries (LMICs) [20]. Where studies do exist, they focus on a specific impairment group such as intellectual, visual or mobility instead of gaining a holistic view of the barriers faced by people with different impairments [21–23]. Within South Asia, only one study explores the MHM experiences of people with intellectual impairments and their carers [22]. With a dearth of evidence on the MHM requirements of people with disabilities and their carers, very few interventions exist [5, 24].

This lack of attention is compounded by disability discrimination, demonstrated by misconceptions. These include that people with disabilities do not have the same reproductive systems as non-disabled people, so may not menstruate and cannot have children, or people with disabilities are considered contagious, dirty and impure [20, 25–27]. Without social assistance, carers struggle to support another person's menstrual cycle [22, 28–30]. Management strategies applied include putting the person with a disability on long-term contraception, limiting their physical mobility during menstruation and sterilisation [22, 29–32]. Therefore, people with disabilities living in LMICs may face layers of discrimination when they are menstruating. These may negatively impact on the extent to which they can fulfil their human rights, including education, water and sanitation, and sexual and reproductive rights, but more evidence is required [5, 33, 34]. The study aims to begin filling this gap by investigating the barriers to MHM that adolescents and young people with a disability and their carers face in the Kavrepalanchok (Kavre) district, Nepal, using qualitative methods.

Methods

Research design

Phenomenological research methodology underpins this study, and influenced the data collection tools applied [35]. We recognise menstruation as a physiological and social phenomenon: a participant's life experiences of menstruation are situated within socio-cultural factors, and menstrual related behaviours and opinions are shaped by individual and external influences. Our data collection methods guided participants to describe their lived experiences, beliefs and feelings about menstruation visually and verbally, and we observed the behaviour setting by carrying out accessibility and safety audits of the MHM facilities used. Interactions were reciprocal, and researchers answered participants' questions about menstruation, providing accurate information on the menstrual cycle and how to manage it hygienically.

Research team and training

Qualitative data was generated by the lead author (JW), a Nepali Research Coordinator (SK) and two Nepali Field Researchers (AS and AG). As we are committed to disability-inclusive research, we recruited AS (with a visual impairment) and AG (who has a mobility impairment) as field researchers and JW and SK mentored them throughout the data collection so that they could develop their research skills. All the research team members were women.

The research team participated in a week-long training, led by the lead author and a second experienced qualitative researcher on how to conduct research ethically with people who have a disability and their carers [36]. Participants included eight people with a range of disabilities, sign language interpreters, SK, and representatives from WaterAid, CBM and Plan Nepal. Attendees were involved in this study, and the 'Strengthening voices of adolescents with disabilities in Nepal' research, which aimed to understand what was important for the wellbeing of adolescents with disabilities [37]. The latter was conducted by the London School of Hygiene and Tropical Medicine (LSHTM), CBM and Plan International and started soon after the research training workshop. Participatory methods, including the Age Line [38], Feeling Dice [39], the Johari Window [40] and Collage [41], were applied to facilitate discussions on seeking informed consent, MHM, and confidently but sensitively discussing 'private' topics [42]. Guidance was given on how to generate data with people who have different impairments using qualitative methods, including ensuring breaks are regularly offered to participants throughout the process, always addressing the person with a disability directly and not an interpreter or carer, being encouraging, patient and respectful at all times. Specifically, when interviewing people with a hearing impairment, ensuring sign-language interpretation is available if required, speaking slowly, clearly and at a steady rhythm and never shouting. When interviewing people with visual impairments, identifying yourself clearly and introducing everyone in the room; not leaving when the person is talking, and asking the participant if they prefer to sit in bright light or shade as this may affect their vision. Researchers should sit at the same level as a person with a mobility impairment, and not push a wheelchair without asking the person first. For people with intellectual impairments, carers should be present; researchers should always acknowledge the participant's contribution, speak in short, simple sentences and explain more than once if the person does not understand. Researchers should also be guided by the person's body language and end the interview if the participant becomes disengaged. Data collection tools used in this study were tested and refined during this training.

Study site

The Kavre district was selected as the study site as the research partner, WaterAid implements MHM programmes there with local NGOs, Karnali Integrated Rural Development and Research Centre (KIRDAC) and Centre for Centre for Integrated Urban Development (CIUD). The Kavre district is one of Nepal's 77 districts, with a population of 381,937, it is classified as 'mid-hilly' [43]. The district's basic water coverage is 89% and basic sanitation coverage is 98% (unpublished data). The Kavre district was the epicentre of the 2015 earthquakes and much of its infrastructure was destroyed, including household latrines. Efforts to rebuild infrastructure are ongoing.

Study population and sample size

The study population and inclusion criteria comprised:

1) 20 individuals, aged between 15 and 24 years, who menstruate and experience'a lot of difficulty', or more across one or more of the visual, hearing, mobility, cognition, self-care and communication-functional domains [44].
2) 13 carers, who were selected if they provided menstrual care for a participant with a disability. Carers were interviewed about their experiences of supporting another person's menstrual cycle, as well as their interpretation of the person with disability's MHM experiences and related feelings.

Table 1. details the study population characteristics, including ages, locations and functional domains.

We applied purposeful sampling to select participants who experience the phenomenon researched [45, 46].

Table 1 Study population characteristics

Study population	Variables	n=
Person with a disability	*Age group*	
	15–19	9
	20–24	11
	Location	
	Urban	16
	Rural	4
	Functional domain	
	Visual	3
	Hearing	2
	Mobility	8
	Cognition	1
	Self-care	1
	Multiple*	5
Carer	*Location*	
	Urban	6
	Rural	7
	Functional domain of the person with a disability	
	Visual	1
	Mobility	3
	Cognition	7
	Multiple*	2
	Person providing care	
	Relative	11
	Professional	2

*Multiple included: mobility, cognition, self-care and communication

Firstly, the lead author explained the Washington Group short set of questions [25] to WaterAid's partner organisations: KIRDAC, CIUD and government social mobilisers, who had knowledge of people with disabilities living in the study area. The Washington Group Short Set, is a tool recommended for data disaggregation, and includes questions about a person's abilities across six functional domains: visual, hearing, mobility, cognition, self-care, and communication [44]. Disability is identified as anyone having at least 'a lot of difficulty' in one or more of these domains. Functional domains are referred to as 'impairments' in this article, and cognition as an 'intellectual impairment'.

These representatives identified 20 females with a disability, aged between 15 and 24. Secondly, the research team visited the potential participants and asked them the Washington Group short set of questions [25], their age and if they menstruate to confirm that they met the inclusion criteria. Participants that did not qualify were excluded. We intentionally selected people with a range of impairment types, so we applied snowball sampling to ensure representation across the six functional domains. Snowball sampling is a method of increasing the sample by asking participants to identify other people to interview [47, 48]. Carers were selected if they provided menstrual care for a participant with a disability.

Data collection methods and activities

Data collection was carried out in September 2017. The study applied four different qualitative methods to allow for methods triangulation: In-depth interviews, observation and PhotoVoiceand ranking (described in Table 2) [50]. Additional Files 1-3 contain the in-depth interview guide for carers and people with disabilities, and PhotoVoice guidance, which were developed for, and used in this study. PhotoVoice participants were selected after their in-depth interview; they represented different impairments (mobility, self-care) and roles (person who menstruates, or supports another's menstrual cycle), settings (household and residential institution) and spoke about their menstrual experiences openly. PhotoVoice can be a very effective method for a person to represent their experiences visually, but it can be time intensive and takes approximately one day to complete. We aimed to complete PhotoVoice with four participants with a disability and two carers, but two individuals declined.

At the end of each day, the research team met to discuss findings and themes; when all topics were explored and no new data emerged, we concluded that data saturation was met and stopped data collection.

Data analyses

Data analyses was iterative: the research team met at the end of each day to review field notes, discuss their influence within the data collection process, and emerging themes (such as similarities of barriers to accessing MHM facilities for people with mobility impairments, or a lack of support for carers of persons with disabilities), as well as to review and revise the interview technique and topic guides. When data collection was complete, voice recordings of interviews were translated and transcribed verbatim into English. Transcriptions were checked for accuracy by Nepali researchers in the team and WaterAid Nepal staff. Transcripts were not returned to participants for comment or correction, but overall research findings were shared with participants at a later date (see Wilbur and Bright, 2019 [24]).

The lead author then applied a thematic analytical approach to analyse transcriptions, which involved: 1) familiarisation with the data, 2) generation of initial codes that were structured according to outcomes in the adapted socio-ecological framework for menstrual hygiene management [5]. Outcomes included: access to water and sanitation facilities, including menstrual materials disposal mechanisms, appropriate menstrual

Table 2 Summary of methods

Method	Purpose	Description	Sample characteristics	Sample size
In-depth interview	To understand barriers to MHM, and how these effect participants' lives.	Undertaken at the participant's home, school, care home or hospital; interviews lasted between 1 and 1.5 h. With consent, interviews were conducted in Nepali, recorded on a voice recorder, and translated into English if JW (who does not speak Nepali) was present. Field notes were made after the interviews.	Individuals with disabilities, aged 15–24 and menstruates, and carers who support them	20 individuals with disabilities 13 carers
	To understand the menstrual products available, user preference and rationale.	Market survey, product attribute assessment and user preference with ranking: a range of menstrual products available on the local market were displayed to participants during interviews. Researchers asked participants if they had used any, their preference with reasons for why, and to rank the products according to preference. A photo was taken of the products in ranked order.	Individuals with disabilities	16 individuals with disabilities
Observation	To observe if any participants face accessibility or safety barriers when using water, sanitation and menstrual hygiene management facilities (revised version of *WEDC, WaterAid (2013) Accessibility and safety audit* [49]).	Observed participants demonstrating where they stored their menstrual product, how they changed, washed and/or disposed of it; where they collected water from, what soap was used, and where they washed their bodies. Issues explored included accessibility, privacy and safety of facilities, such as distance to water source, ability to use facilities independently, if the participant can be seen in the facility; if it is well lit, if it has a door with a lock that can be used independently. Photographs of facilities were taken and field notes recorded. Observation took place after in-depth interviews.	Individuals with disabilitiesand carers	20 individuals with disabilities 13 carers
PhotoVoice	To allow participants to express themselves visually; allow participants time to reflect on the issues, and rank their experiences against perceived levels of importance.	Cameras were lent to participants, who were asked to take five photos of their own menstrual experience or of caring for another person's menstrual cycle. Photos were printed and discussed with the participants, who provided captions and ranked the photos according to which was the greatest to least important issue. The whole process took 0.5 to 1 day per participant. All participants requested that their real names are credited whenever their photos and captions are used. Participant's names are used in this article.	Individuals with disabilities, able to understand the task, use a camera or direct a third party to take photos. Carer who provides care throughout the menstrual cycle.	3 individuals with disabilities 1 carer

materials, relationship with carers / the person with a disability, ability to manage menstruation independently, ability to manage another person's menstrual cycle and tasks carried out. 3) Searching for, and identifying sub-themes within the outcomes included in the adapted socio-ecological framework for MHM, 4) reviewing sub-themes, 5) defining and naming sub-themes and 6) producing the report [51]. Codes were compared and relationships between codes were identified and analysed using analytic memos in NVivo 11.

Results

In summary, results showed that:the barriers to MHM differ depending on the person's impairment, disposable menstrual pads were preferable, but disposal practices and services were inadequate, pre and menstrual symptoms were not well understood or managed; menstrual restrictions added additional layers of challenges for people with disabilities and carers, and that there was inadequate menstrual hygiene information, training and support.

The barriers to MHM differ depending on the person's impairment

People's experience of managing menstruation was influenced by their impairment. For instance, people with mobility impairments identified challenges related to their use of the menstrual product. Some reported that the type and positioning of the product made it uncomfortable to sit in a wheelchair all day. Many other participants with mobility impairments were concerned that the product was not absorbent enough and worried about leakages.

> *"When I sit in the wheelchair the pads may fold or something like that might happen which makes me feel uneasy […]. It becomes very uncomfortable to sit. Unlike my sisters who keep moving around, I have to sit in a place continuously. I get angry then and it gets difficult"*(person with multipleimpairments).

Inaccessible WASH facilities affected people with mobility impairments most severely. They were unable to easily or safely reach the place they change their menstrual product, comfortably change, wash or dry their menstrual product, or wash their bodies in private.

> *"[I] need to wash the menstrual cloth in the toilet. There is no water in the toilet…. I have to carry water in a bucket while also managing the crutches […] I can't wash [the menstrual] cloths either. [……] I keep it under my bed when I can't wash it, and wash it when I get water. I have a problem during menstruation when there is no water"* (person with a mobility impairment).

> *"For those with spinal cord injury, it is easier and necessary for them to use this kind of [raised, Western] toilet. During their period they can't stand to change their pads so these kinds of toilet become more essential"* (person with a mobility impairment).

All of the people with disabilities who participated in PhotoVoice took images to show how inaccessible WASH facilities presented a major challenge. Of the nine photos taken by Sharmila and Babita (who have mobility and/or self-care impairments), five images related to inaccessible WASH facilities (Figs. 1, 2, 3, 4 and 5, Additional file 4: PhotoVoice images). Tulasa, who has a self-care impairment, took four photos and one related to a lack of safe and private WASH facilities (Fig. 6, Additional file 4: PhotoVoice images).

Carers reported that some participants with intellectual impairments, had difficulties retaining MHM information. Carers repeatedly told them how to change and wash the menstrual cloth every month and every time it needed changing, but found this frustrating.

Fig. 1 "It is difficult to go to the toilet." PhotoVoice image taken by Sharmila Tamang. Ranked 1 out of 4

People with visual impairments highlighted difficulties seeing blood on clothes and bed sheets, and disposing of the product discretely. This was stressful and worrying because of the prevailing menstrual taboos:

> *"While washing the pants we know which parts to wash properly, but with the bed sheets, I cannot see the stains so it is difficult for me to clean the stains properly[….]. For throwing the pads in the dustbin, sometimes the dustbin may be outside the toilet, so I might have to throw it outside of the toilet. At those times I feel worried that a male person from my*

Fig. 2 "Water issue is also there, I would have to carry water which is difficult." PhotoVoice image taken by SharmilaTamang. Ranked 2 out of 4.

Fig. 3 "It is not only easier to use this type of toilet for those with spinal cord injury but it is a necessity. So even in villages, these types of toilets should be built for people as not everyone can live in the cities. During period also it is difficult to stand to change pads so these kind is easier to use." PhotoVoice image taken by Babita Thapa. Ranked 1 out of 5

Fig. 5 "For us to be able to wash our own clothes, bathroom should be made in such a way that we can wash our clothes ourselves while sitting on wheelchair. It will be much easier. I can't wash clothes while standing or sitting. At home, I sit in a small stool but there is none here. If the washing space could be reached while sitting on a wheelchair, it would be good." PhotoVoice image taken by Babita Thapa. Ranked 5 out of 5

Fig. 4 "During period one should be careful using bathroom. Our legs might already feel weak so we might fall down and meet an accident. Here the toilets are made for everyone to use but if it was to built at home for crutches user, it is to be made in a way that it is not slippery. Marble should not be used as it is slippery." PhotoVoice image taken by BabitaThapa. Ranked 3 out of 5

Fig. 6 "When I have to use the toilet, I need someone else to help with the latch otherwise I can't do it myself." PhotoVoice image taken by Tulasa Karki. Ranked 3 out of 4

> *family would see them* (person with a visual impairment).

Participants with self-care impairments, who relied on carers, felt humiliated when asking another person to change their menstrual product, and guilt seeing their carer handle their menstrual blood. Consequently, they changed their menstrual product less frequently than they wanted to.

> *"She says that the blood smells during my periods. [….]. She finds it disgusting. […]. I feel bad. If I had my own hands, I wouldn't suffer so much. I wouldn't have to depend on someone else. I could do it on my own; it's not something you show it to others. I feel like crying. I feel bad"* (person with self-care impairments).

> *"Even to change a pad I have to wait until my sister comes in the evening and helps me change, if not, I will have to wear the same pad till tomorrow"* (person with self-care impairments).

In contrast, people with hearing impairments interviewed said they did not face any specific challenges explicitly related to their disability.

Disposable menstrual pads are preferable, but disposal practices and services are inadequate

All participants had access to menstrual materials, including commercial pads, menstrual cloth or tailor made pads, and results from the menstrual product market survey show that preference is highly individualised. Results of the market survey, product attribute assessment and user preference, show that disposable commercial pads with wings were preferred, and cloth was the least preferred. Table 3 captures the results across 16 people with a disability.

Though the disposable commercial pads with wings were preferred by participants, hygienic and environmentally friendly disposal behaviours were often inadequate. Many participants threw used disposable commercial pads in rivers or down hillsides, so other people were less like to see the used product. Some wrapped the pads in plastic, so they were less visible. These behaviours did not correlate to impairment type; instead, reasons include a lack of waste disposal options and little knowledge about the environmental consequences.

There were no clear preferences for product type by impairment due to the small number of participants in each category (see Tables 1 and 2 in Additional file 5: Menstrual product preference across impairment type). Through PhotoVoice, Sharmila (who has a mobility impairment) explained that she prefers using disposable commercial pads as they do not require washing, which she finds particularly challenging as she is unable to carry water and use her crutches (Fig. 2 and Fig. 7, Additional file 4: PhotoVoice images).

Pre and menstrual symptoms are not well understood or managed

Many participants said that menstrual cramps were one of the biggest challenges they face when menstruating. Pain management strategies included home remedies, such as drinking warm water, sleeping and tying a cloth tightly around the abdomen. There is a belief that commercial pain relief tablets can damage your health, so few people took them and few carers provided them.

> *"If I take medicine I will have more pain during the next period. That's why I don't take any medicine"* (person with a mobility impairment).

Carers reported that changes in behaviour before and during menstruation for participants with intellectual impairments included withdrawal, increased hyperactivity, self-injury, showing their used menstrual product to others, excessive sleeping, being frightened, withdrawn and refusing to eat. Without social support mechanisms to help people understand and respond to the changes in behaviour, carers of people with intellectual

Table 3 Markey survey: most and least preferred menstrual product

Menstrual product	Preference	
	Most preferred	Least preferred
Disposable commercial pad with wings	8	0
Disposable commercial pad without wings	2	3
Cloth	3	5
Reusable tailor-made pad with wings	3	4
Reusable tailor-made pad without wings	0	0
Diaper	0	1
Total	16	13

Fig. 7 "Pad is easy to use compared to cloth." PhotoVoice image taken by Sharmila Tamang. Ranked 3 out of 4

Fig. 8 "During menstruation we are not allowed to enter the house." The image is of the hut Tulasa sleeps in when menstruating. PhotoVoice image taken by Tulasa Karki. Ranked 2 out of 4

impairments felt frustrated and overwhelmed, as demonstrated by these quotes.

> *"When she gets her period, if I ask her if she wants to put [a menstrual] cloth [on], she would just go to her room"* (carer of a person with an intellectual impairment).

> *"She doesn't understand, she won't listen. [….] For someone like my daughter who does understand but wouldn't remember, we can't do much"* (carer of a person with an intellectual impairment).

> *"I feel annoyed. She doesn't listen to me"* (carer of a person with an intellectual impairment).

> R: "Have you ever spoken to any medical people about her menstruation?"

> C: "What could we do! We can't stop it."

Menstrual restrictions add additional layers of challenges for people with disabilities and carers

Most participants followed menstrual restrictions, which dictate that menstruating people must sleep separately, are not allowed to worship, enter the kitchen, cook or touch plants, because it is believed that menstrual blood is dirty and contaminating.

> *"Dirty blood leaves the body during period, so we should not worship during that time"* (person with a hearing impairment).

Tulasa took two photos representing the menstrual restrictions: the hut, outside her home where she sleeps when menstruating, and plants that must not be touched during menstruation (Figs. 8 and 9, Additional file 4: PhotoVoice images). During an in-depth interview, one participant also explained she lived in a cow shed during menstruation when at home.

> *"I had to be banished in the cowshed for seven to 12 days"* (person with ahearing impairment).

If a person does not adhere to the restrictions, it is believed that the gods will curse the family. Disability was also viewed as a curse. Therefore, people feared that they will be doubly cursed if they did not follow restrictions.

> *"….I am already suffering like this and people say that my disability is a curse, so if I don't obey I will be further cursed"* (person with a mobility impairment).

People with visual impairments reported that menstrual restrictions were a major source of concern, fearing that they might inadvertently touch a 'restricted object', and thus lead the gods to curse the family.

> *"I also cannot go against my family. It has been followed by our family, it is a tradition. […] I feel odd to move around because I am worried that I might touch [things that I should not]"* (person with a visual impairment).

Two of four PhotoVoice images taken by Bishnu (a carer of a person with an intellectualimpairment), focused on menstrual restrictions (Figs. 10 and 11, Additional file 4: PhotoVoice images). She ranked these as the biggest challenges she faces when her daughter menstruates. Similarly, during in-depth interviews, carers of people

Fig. 9 "There is a belief that if you touch plants during period, it will rot." PhotoVoice image taken by Tulasa Karki. Ranked 4 out of 4

Fig. 10 "Cannot touch during period as per our tradition." The image is of worshiping area inside Bishnu's home. PhotoVoice image taken by Bishnu Maya Sapkota. Ranked 1 out of 4

with an intellectual impairment reported being worried that their family would be cursed if restrictions were not followed. Additionally, carers of people with an intellectual impairment explained some people did not wear a menstrual cloth, preferring to soak up the menstrual blood with underwear or trousers. Some participants isolated themselves when they are menstruating and otherswent out with blood stained clothes. One carer explained*:*

> *"She just walks like that with blood on her clothes"* (Carer of a person with multiple impairments).

> *"She would take it out and show it to others and would tell them to look at it. It was embarrassing"* (Carer of a person withan intellectualimpairment).

Inadequate menstrual hygiene information, training and support

Some carers were surprised when their charges reached menarche, and one carer did not believe it when the person with a disability said they were bleeding until they saw the menstrual blood. Furthermore, information on menstrual hygiene was commonly withheld from people with intellectual impairments, though one carer did persist and explained that her charge *"took one year to understand the process and experience"* (carer of a person with multiple impairments). One carer reported that a teacher sent her daughter home from school at the onset of menarche, and the carer never sent her back.

> *"That day, [her] teacher showed up at the house and suggested not to send [her] to the school because [she] had her mensuration in the classroom and the blood leaked on the bench she was sitting on. They said that it is difficult for [her] to take care of herself during the menstruation so it would be better that she stays at home and we take care of her. Then I stopped sending her to the school"* (carer of a person with multiple impairments).

Providing menstrual care was viewed as a very private issue by carers: very few discussed this subject with other people, including medical professionals. No support or support networks existed for carers, and many carers felt isolated and overwhelmed.

> *"We don't know anything else. I don't go anywhere. I hear that people come to our village to teach about those things, but I haven't been taught about menstruation management"* (carer of a person with multiple impairments).

Two carers of people with a self-care impairment requested MHM training for the young person in order to increase the young person's independence. A motivation for carers was fear for the future, as they worried about who would look after their daughter when they are no longer able to.

Fig. 11 "We have to follow our tradition, so should not touch kitchen during period. If one touches kitchen, worshipping area is also touched. If touched, I feel discomfort and fear that something might happen. However, in case of my daughter if she touches, god will forgive her." PhotoVoice image taken by Bishnu Maya Sapkota. Ranked 2 of 4

> *"For now, I am here, but in future we don't know what will be the situation. [...]. I won't live long but she has lots of time, I am very worried"* (carer of a person with multiple impairments).

Discussion

This qualitative study among people with disabilities and their carers living in Nepal responds to the calls for information on the MHM barriers faced by people with disabilities, and contributes new evidence to the global discourse on MHM for the largest minority group [5, 52–55]. To the authors' knowledge, this is the only study to date which investigates the barriers experienced across all impairments. We found that the barriers to MHM are complex and differ according to the person's impairment. Furthermore, these barriers inhibit the person with a disability's ability to live a dignified life and fulfil their human rights, including going to school.

The barriers to MHM differ depending on the person's impairment

To meet the MHM requirements of people living with a disability, water, sanitation and hygiene facilities must be located close to where the person lives. For instance, people with mobility, self-care and visual impairments may require an accessible water point inside latrines, accessible locks on toilet doors, raised toilet seats, non-slippery toilet floor, accessible washing and drying area for the body, clothes and menstrual products, as well disposal mechanisms that can be easily used by everyone.

Research exploring the barriers to MHM experienced by people with different impairments and their carers in different LMIC settings must be conducted to allow for comparison. Findings should be incorporated into the global MHM agenda alongside researching MHM for school going girls and non-disabled women [56–58]. Furthermore, MHM interventions appropriate for impairment type, and carers must be developed to overcome barriers.

Participants with hearing impairments in our study explained that they did not face challenges related to their disability. However, these participants all attended a school for children with hearing impairments and said they read about menstruation in books, and were supported by friends and teachers to practically manage menstruation. This finding may not reflect the experiences of people with hearing limitations who do not attend this type of school.

The study demonstrates that people with disabilities can be separated into those who manage their menstrual cycle independently, and possibly with great difficulty, and those who are reliant on carers for MHM. MHM interventions for people without disabilities are delivered directly to the person who menstruates. Yet, for people with disabilities, there may be a third party (carer) involved, who also requires MHM information and support so that they can help another person manage their menstruation comfortably, hygienically and with dignity. Such interventions must cover all aspects of MHM, including addressing harmful social beliefs, so that people who are reliant on carers to manage their menstrual cycle do not feel humiliated when asking for support, or guilty when carers change their menstrual material. These emotions are driven by shame and disgust caused by menstrual taboos. Carers must be supported to understand that supporting another person to manage their menstrual cycle as independently as possible would benefit both parties. Additionally, low cost lifting devices to support carers bathe and change a menstrual product should also be widely promoted to support carers and protect the person with disability's dignity (see section 4.4 in Rosato-Scott et al. (2019) [59]. If carers move the person without such devices, they may experience back pain and associated issues [60].

Disposable menstrual pads are preferable, but disposal practices and services are inadequate

More research is needed to identify comfortable, appropriate and affordable menstrual products for all people with disabilities, including people who are unable to sit out of bed unaided and / or who experience incontinence. Clear information on each product option, their implications for use and disposal need to be disseminated so that people can make informed choices. Policy makers and implementers should be encouraged to strengthen waste management service chains and incorporate menstrual waste management within it.

Pre and menstrual symptoms are not well understood or managed

Menstrual discomfort was a key challenge expressed by participants and carers did not always manage this. A lack of pain management may have more negatively impacted people who have intellectual and / or communication impairments as they may not have understood the cause of the discomfort, or been able to communicate if they were in pain. This raises concerns that unmanaged pain may negatively impact on behaviours, which in turn can make carers feel overwhelmed, and a negative cycle forms. This is documented in three studies, which linked an inability of people on the autistic spectrum to understand the reason for menstrual discomfort or communicate when in pain. Menstrual related behaviours documented across this population in these studies included increased hyperactivity, self-injury, fatigue and anger [22, 28, 61].

Menstrual restrictions add additional layers of challenges for people with disabilities and carers

Menstrual taboos, including restrictions to movements, are widely followed by people with and without disabilities in Nepal [12–14, 62]. However, due to vulnerability to violence, people with disabilities may be more susceptible to abuse when sleeping in menstrual huts [63–65]. For instance, a person with a hearing impairment may not hear an intruder approaching; people with a mobility impairment may be less able to escape, and people with communication and/or intellectual impairments may be less able to disclose experiences of abuse. Our study also highlights the fear expressed by people with disabilities that they would be 'doubly cursed' if they did not adhere to the menstrual restrictions. These findings reveal layers of stigma and discrimination faced by people with disabilities in Nepal when they menstruate.

Our findings show that carers were particularly concerned that the young person with an intellectual impairment would not follow cultural and social norms (including menstrual restrictions); that they would refuse to wear a menstrual product and would go out with menstrual blood on their clothes. In a study conducted in India, where the socio-cultural norms are similar to those of Nepal, carers reported the biggest challenge faced was that their daughters with an intellectual impairment would not wear a menstrual pad, and leave home with blood stained clothes. As a result, the carers would keep their daughters at home whilst they were menstruating, put them on long-term contraception or sterilise them [22]. When people with a disability in our study went out in public with blood stained clothes, community and family members verbally and physically abused them. Therefore, ensuring MHM for this population is also a safeguarding issue.

Inadequate menstrual hygiene information, training and support

The misconception that people with disabilities do not have the same reproductive systems as non-disabled people [20, 26], means they are even less likely to receive MHM information than non-disabled people. Additionally, such information was commonly withheld from people with intellectual impairments, because of the perception that they would not understand it. However, consequences of providing repetitive and simple MHM information for one participant was a greater ability to manage her own menstruation. Thus, people with intellectual impairments may be able to understand information about the menstrual cycle, if it is tailored to their level of understanding and repeated regularly. Ability to recall information would be dependent on the extent of the intellectual impairment.

MHM information is mainly delivered at schools, but many participants with intellectual impairments did not attend school so were excluded from receiving this information. One participant was sent home from school at the onset of menarche, and this marked the end of her formal education, which could negatively impact on her life chances [66]. Carers who were unable to leave the home because of caring duties were also at a disadvantage as they were unable to access MHM information shared in the community.

Our study showed that there is a lack of social support and information about how to care for another person's menstrual cycle, that menstrual care is viewed as a private issue, and that this results in carers feeling overwhelmed and isolated. These findings are reflected in studies from Taiwan, India, and the UK [22, 28, 29]. They showed that menstruation is viewed by carers (family members) as a confidential topic, so people did not speak to others or seek support from anyone, including medical professionals. This lack of support can negatively affect carer's wellbeing [5, 22, 28, 67–69].

Strengths and limitations

The strengths of this study include the use of a range of qualitative methods to explore a very private topic with people who may never have spoken about menstruation to another person. Data triangulation was applied to compare information generated through different modes, and data saturation was perceived to have been reached. Another strength was the inclusion of people with disabilities on the research team; we believe they were able to challenge misconceptions of carers that people with disabilities are unable to work and therefore always reliant on family members.

In terms of limitations, several possible sources of bias arose due to different types of missing data. Though participants were recruited from each impairment group (communication is included in 'multiple'), we were unable directly interview one person with an intellectual impairment. As participants in this functional domain were unable to fully understand the consent process, their carers were interviewed instead, which may not reflect their own perspectives.

The lead author's employment history includes working as a WASH practitioner focused on mainstreaming disability inclusion in development, which influenced the data collection tools applied and topics explored. For instance, experience and studies conducted dictate that people with disabilities faced more physical barriers to accessing WASH facilities than people without disabilities, so participants were observed using them and asked about barriers faced during interviews [27, 70, 71]. To minimise potential bias, a systematic review of relevant literature was conducted before the study to understand existing evidence and question personal assumptions about the barriers faced and data collection tools to apply [5].

AS and AG have a disability and we were cognisant that their experiences may introduce bias. To manage this, the week-long training for the research team included encouraging the team to mainly talk about their own experiences with participants after the interview. We also met regularly to discuss potential bias in data collection and analysis of results.

Conclusion

This study highlights the additional barriers to MHM that people with disabilities, and their carers experience, as well as the negative impacts that these have on their physical, emotional, mental and social wellbeing. Issues related to MHM for people with disabilities is even more complex than for others in the population, due to the additional disability discrimination and constraints experienced, so require innovative and adapted solutions to existing MHM approaches that often fail to reach them. Even though MHM is not explicitly included in the Sustainable Development Goals (SDGs), it is essential for achieving the goals on gender, health and education [72]. Disability is the largest minority group, so attention to, and resourcing for disability inclusive MHM must be prioritised for progress to be made within the last nine years of the SDGs, which aims to 'Leave No One Behind'.

Abbreviations

CIUD: Centre for Integrated Urban Development; CRPD: Convention on the Rights of Persons with Disabilities; KIRDAC: Karnali Integrated Rural Development and Research Centre; LMICs: Low- and middle-income countries; LSHTM: London School of Hygiene and Tropical Medicine; MHM: Menstrual hygiene management; WASH: Water, sanitation and hygiene; WEDC: Water and Engineering Development Centre

Supplementary Information

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Additional file 1. In depth interview question guide, product attribute assessment (market survey) and accessibility and safety audit for carers.

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Additional file 5. Menstrual product preference across impairment type, containing Table 1: Most preferred product according to the person's impairment, and Table 2. Least preferred product according to the person's impairment.

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Availability of data and material

The authors confirm that the data supporting the findings of this study are available within the article [and/or] its supplementary materials.

Authors' contributions

Conceptualisation, JW; methodology, JW, HK, BT, and SH; training of research team, JW; formal analysis, JW; investigation, JW, SK, AS and AG; data curation, JW; supervision, JW, HK, TM, SH and BT; project management, coordination and administration, JW; funding acquisition, TM; writing—original draft preparation, JW; writing, review and editing, JW; visualisation, JW; manuscript review, HK, BT, SH, SK. All authors have read and approved the manuscript.

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Declarations

Ethics approval and consent to participate

Ethical approval for the study was granted by from the Research Ethics Committee at the LSHTM (reference: 12091) and the Nepal Health Research Council (reference: 102/2017).

Informed consent was obtained and witnessed from each participant before enrolment. An information sheet/consent form (in Nepali) was given to, or read out to the participants by the research team. Informed written (or a thumb print if illiterate) consent was received from carers and implementers. Assent was sought from participants under 18 years, and consent sought from their carer or parent. Participants were given the option to have their carer present during the interview. Assent also was sought from people who could not fully understand the consent process, and then consent sought from carers, who were interviewed instead of the person with a disability. It was made clear that participation was voluntary. Methods were adapted to be fully inclusive. For example, for individuals who speak in sign language, sign language interpreters would be available. Simplified information sheets were available for participants with intellectual and communication impairments.

The ethics and consent process of PhotoVoice was very thorough to ensure that the participants understood the purpose of the activity and what they are agreeing to. Written consent was sought at the start of the process. The researcher explained how participants could take photos without showing their face and how to represent menstrual issues in a dignified way. Secondary written consent was sought after the photos were taken, the participant viewed the photos, the interview conducted and the photo ranking so the participant could make a better judgement about how they wish them to be used. This consent related to how the photos could be used and if the photographer wanted to be credited by their real name or a pseudonym. All participants requested that their real names be credited whenever their photos and captions are used.

Consent for publication

Participants gave explicit written consent for their identifying images to be published in this study. Participants own their images taken during PhotoVoice and requested that their real names are credited when their photos are used. No individual or identifiable personal details gained through in-depth interviews are included in this manuscript.

Competing interests

The authors declare that they have no competing interests.

Author details

[1]London School of Hygiene & Tropical Medicine, Keppel Street, London WC1E 7HT, UK. [2]Independent consultant, Kathmandu, Nepal. [3]WaterAid, 27-29 Durham Street, London SE11 5JD, UK.

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Publisher's Note

Supporting information [see Appendix 4]

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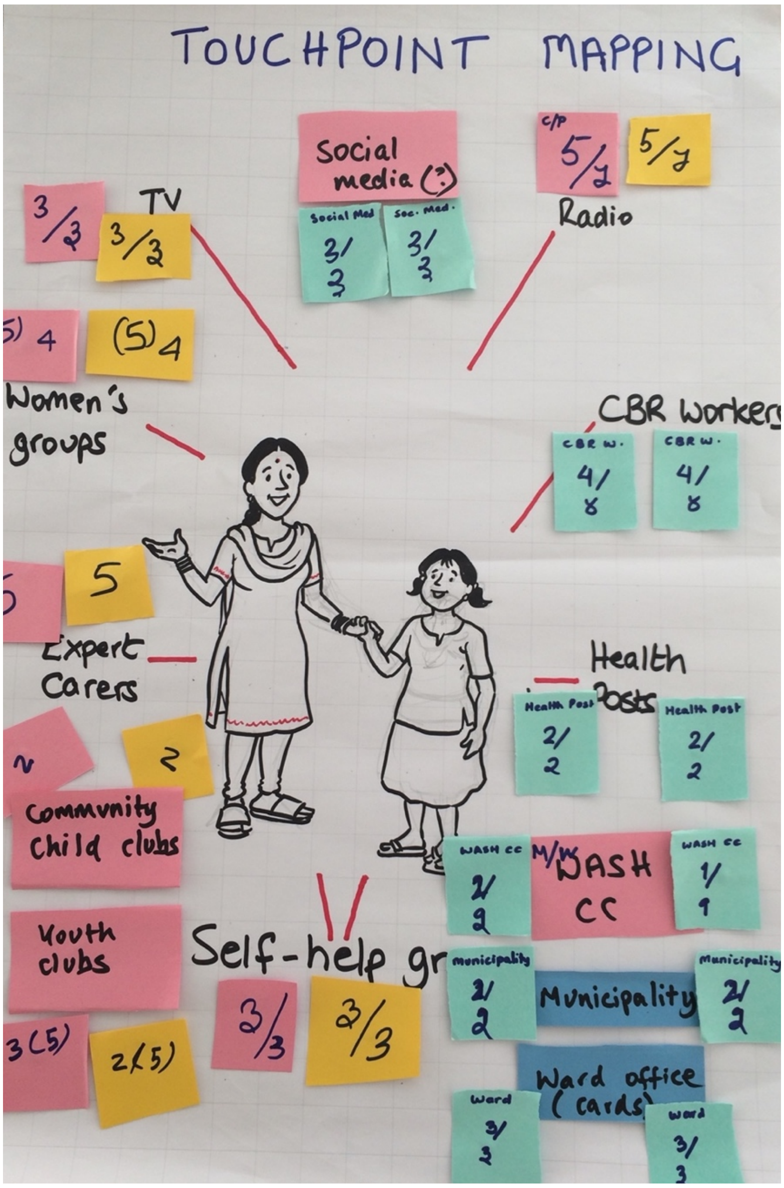
Additional file 5. Menstrual product preference across impairment type, containing Table 1: Most preferred product according to the person's impairment, and Table 2. The least preferred product according to the person's impairment.

Chapter 6 Paper Four: Developing a menstrual hygiene management behaviour change intervention for people with intellectual impairments and their carers (Create step)



Touchpoint mapping exercise completed by the Create team to determine where the target group could come into contact with the Bishesta campaign.

Photo taken by the author

Preamble

Findings generated during the *Assess* and *Build* steps (Chapters 3, 4, and 5) about the policy context, the specific MHM behaviours of people with disabilities and their carers, as well as their drivers directly informed the development of an MHM behaviour change intervention for people with disabilities and their carers in the Kavre district. For instance, results presented in Chapter 3 (Paper One) and Chapter 5 (Paper Three) demonstrate that MHM for people with disabilities can be split into two groups: those who manage their MHM independently, albeit potentially with difficulties, and those who are reliant on carers for MHM. Many of the latter are people with intellectual impairments. Outcomes of a lack of MHM for this group include shame, physical isolation, and interpersonal and gender-based violence (232). These experiences intersect three important public health issues: disability (233), MHM (64) and violence (234). Carers are integral to enabling MHM for people with intellectual impairments who are unable to manage independently. Findings from Chapters 3, 4 and 5 (Papers One, Two and Three) underscore the impacts on carers if they are not supported to carry out this role. These include anxiety, shame and isolation, which are risk factors for depression (235). These are partly rooted in menstrual taboos and the subsequent desire to follow restrictive socio-cultural practices. If individuals with intellectual impairments do not adhere to these, carers and the public can react negatively and violently, thus deepening the sense of shame and isolation. Without intervention, the cycle of oppression and violence perpetuates.

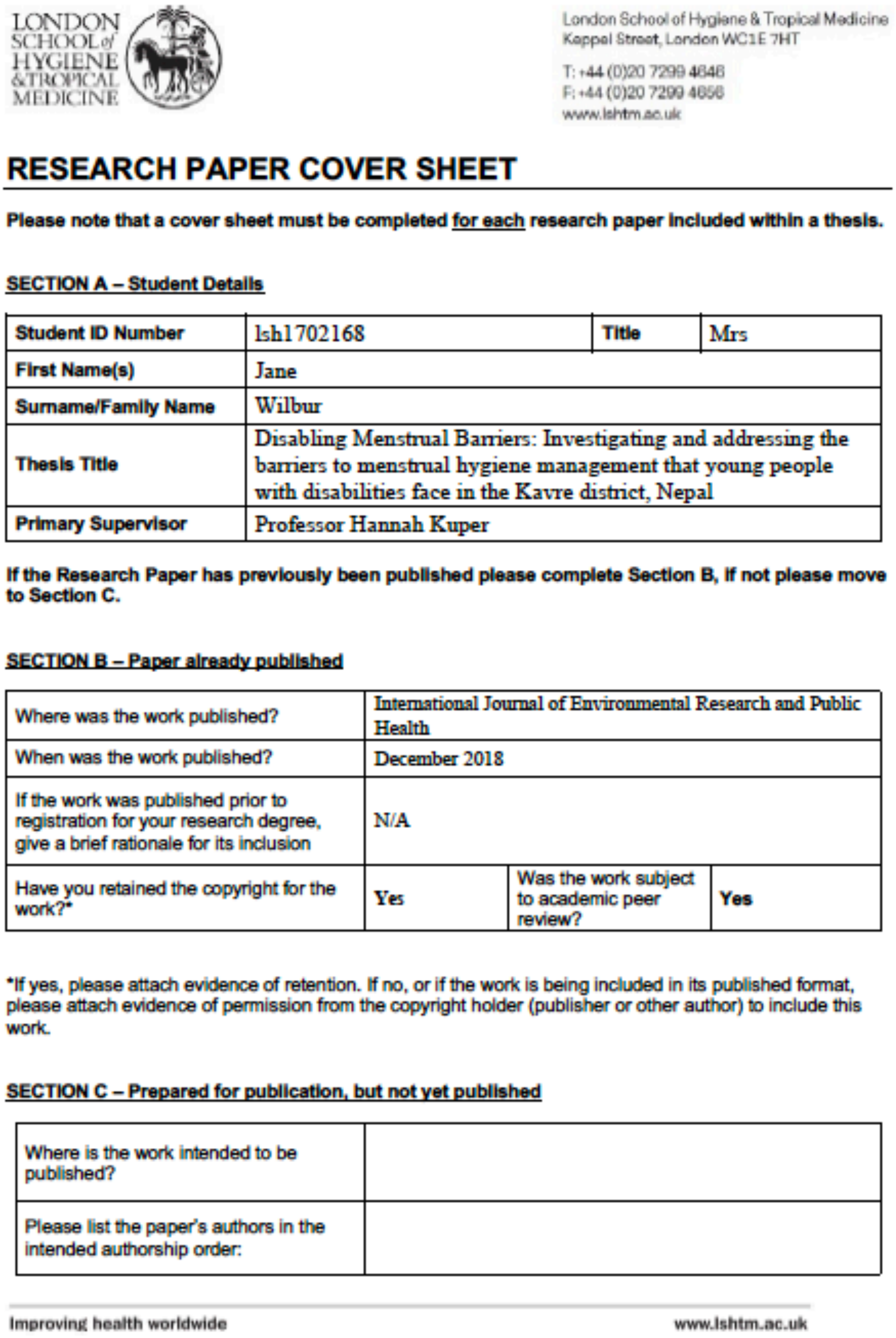
Study findings, documented in Chapters 3 and 5, also revealed that people with mobility impairments faced difficulties due to a lack of appropriate menstrual materials and inaccessible WASH facilities. However, developing a new menstrual material would have been prohibitively expensive within the scope of the current project and guidance about how to design inclusive WASH facilities already exists (59, 218, 236, 237). Furthermore, several interventions support the MHM of people with visual and hearing impairments (238, 239). However, few interventions for people with intellectual impairments and their carers exist globally. Considering the evidence, an MHM behaviour change for people with intellectual impairments and their carers was developed within this PhD.

Paper Four presents the process of developing two public health interventions for people with disabilities in LMICs. The first is a programme to improve the uptake of referrals for ear and hearing services for children with disabilities in Malawi, designed using the Medical Research Council's Guidance for developing and evaluating complex interventions (180). The second is the MHM behaviour change for people with intellectual impairments and their carers in Nepal, using the BCD (170) presented in this PhD study. The paper was jointly written with Tess Bright, who designed the intervention for people with disabilities in Malawi.

The *Create* step within this PhD study involved conducting a scoping review to explore existing strategies to improve MHM of people with intellectual impairments in middle- and high-income countries. These included 1) a study in Turkey, where a doll was used to teach the target group about how to change and dispose of a used menstrual product (240), 2) 'Susan's Growing Up' (241): a visual story of a girl who begins menstruating designed and produced by Beyond Words (an organisation that produces visual stories to help guide people with intellectual or communication impairments through complex situations), and 3) a step-by-step visual guide on how to change and dispose of a menstrual material (242). Additionally, I had discussions with Beyond Words staff about the process they took to develop and deliver the visual stories to understand their approach fully.

A Theory of Change was then developed. It draws on findings generated in the *Assess* and *Build* steps and presents the MHM intervention designed to disrupt the behaviour setting in a way that causes the target groups to adopt the target behaviours. A creative team was formed to develop campaign components designed to grab the participant's attention, be memorable and make the target behaviours easier to practice. These drew on materials generated through the scoping review. For instance, the Bishesta doll (described in Paper Four) incorporated learning from Altundağ and Calbayram's evaluation of using a doll to teach MHM to people with intellectual impairments (240); the visual stories drew on the format and process applied by Beyond Words (241). Campaign component visuals were developed by the artist, reviewed by the creative team, revised, finalised, and produced for the pre-testing phase of the pilot study.

Paper Four concludes that the BCD is a systematic approach to designing public health interventions for people with disabilities in LMICs and that people with disabilities should meaningfully participate throughout the process. This paper was published under a creative commons license with the license type (e.g. CC BY) in the International Journal of Environmental Research and Public Health in December 2018.



London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

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SECTION A – Student Details

Student ID Number	lsh1702168	**Title**	Mrs
First Name(s)	Jane		
Surname/Family Name	Wilbur		
Thesis Title	Disabling Menstrual Barriers: Investigating and addressing the barriers to menstrual hygiene management that young people with disabilities face in the Kavre district, Nepal		
Primary Supervisor	Professor Hannah Kuper		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	International Journal of Environmental Research and Public Health		
When was the work published?	December 2018		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	N/A		
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

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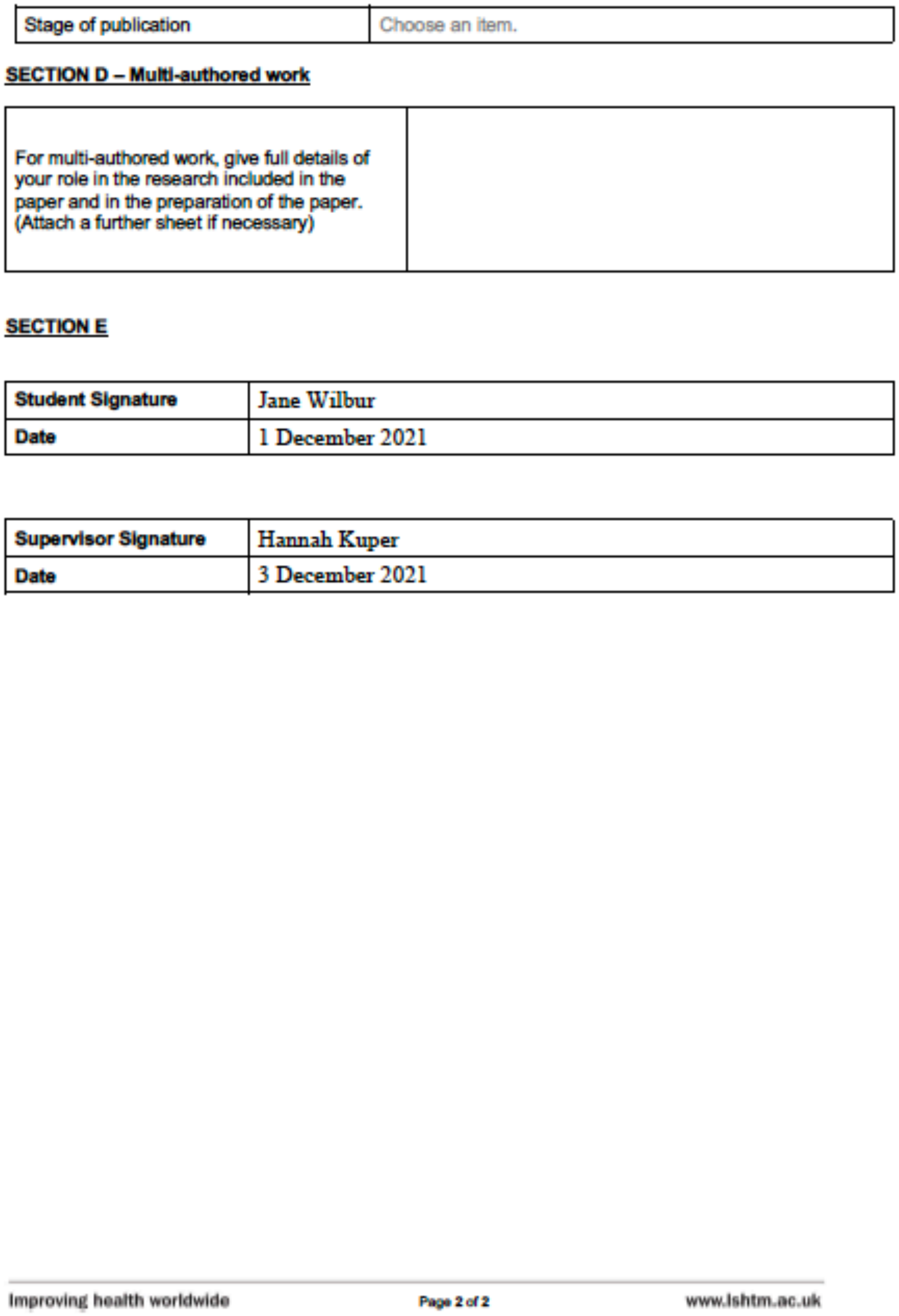

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Student Signature	Jane Wilbur
Date	1 December 2021

Supervisor Signature	Hannah Kuper
Date	3 December 2021

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Article

Developing Behaviour Change Interventions for Improving Access to Health and Hygiene for People with Disabilities: Two Case Studies from Nepal and Malawi

Jane Wilbur [1,*,†], Tess Bright [1,†], Thérèse Mahon [2], Shaffa Hameed [1], Belen Torondel [3], Wakisa Mulwafu [4], Hannah Kuper [1] and Sarah Polack [1]

[1] International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, London WC1E 7HT, UK; tess.bright@lshtm.ac.uk (T.B.); Shaffa.Hameed@lshtm.ac.uk (S.H.); Hannah.Kuper@lshtm.ac.uk (H.K.); Sarah.Polack@lshtm.ac.uk (S.P.)
[2] WaterAid, London SE11 5JD, UK; ThereseMahon@wateraid.org
[3] Environmental Health Group, Department of Clinical Research, London School of Hygiene & Tropical Medicine, London, WC1E 7HT, UK; Belen.Torondel@lshtm.ac.uk
[4] Department of Surgery, College of Medicine, University of Malawi, Blantyre, Malawi; wakisamulwafu@gmail.com
* Correspondence: jane.wilbur@lshtm.ac.uk
† Contributed equally to this work.

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Abstract: Limited evidence exists about how to design interventions to improve access to health care for people with disabilities in low and middle-income countries (LMICs). This paper documents the development of two behaviour change interventions. Case study one outlines the design of an intervention to improve uptake of referral for ear and hearing services for children in Malawi. Case study two describes the design of an intervention to improve menstrual hygiene management for people with intellectual impairments in Nepal. Both followed existing approaches—Medical Research Council Guidance for developing and evaluating complex interventions and Behaviour Centred Design. The purpose is to demonstrate how these frameworks can be applied, to document the interventions developed, and encourage further initiatives to advance health services targeting people with disabilities. Important components of the intervention design process were: (1) systematic reviews and formative research ensure that interventions designed are relevant to current discourse, practice and context; (2) people with disabilities and their family/carers must be at the heart of the process; (3) applying the theory of change approach and testing it helps understand links between inputs and required behaviour change, as well as ensuring that the interventions are relevant to local contexts; (4) involving creative experts may lead to the development of more engaging and appealing interventions. Further evidence is needed on the effectiveness of these types of interventions for people with disabilities to ensure that no one is left behind.

Keywords: people with disabilities; access to health care; developing countries; menstrual hygiene management; hearing loss; hearing impairment; intellectual impairment; carers

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1. Introduction

One billion people are estimated to have a disability worldwide, and more than 80% live in low and middle income countries (LMICs) [1]. People with disabilities are considered to be those who have "long-term physical, mental, intellectual or sensory impairments which in interaction with various

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barriers may hinder their full and effective participation in society on an equal basis with others" [2]. Evidence suggests that disability is linked to poverty in a cycle, whereby poverty increases the risk of disability, and disability increases the risk of poverty [3,4]. Through the underlying impairment, poverty and other mechanisms, people with disabilities are likely to experience poorer health than people without disabilities [1]. People with disabilities have the same healthcare needs as those without disabilities (e.g., access to vaccinations, routine health checks, HIV services, water, sanitation and hygiene, sexual and reproductive health). In addition, people with disabilities may require access to specific specialist services such as rehabilitation and assistive devices [5]. Overall, therefore, the need for healthcare services may be higher among people with disabilities, but some evidence suggests that their access to these services is poorer than for people without disabilities [1]. This may be due to the barriers faced in accessing health services, such as stigma, lack of accessible transportation, or lack of trained health professionals. Therefore, overcoming these challenges, and improving access to health and health-related services is of vital importance.

Improved access to health services has the potential to maximise functioning, improve participation in a range of activities, and improve quality of life for people with disabilities [6]. Equitable access to health services for people with disabilities is essential to achieving Universal Health Coverage and for fulfilling the United Nations Convention for the Rights of People with Disabilities (articles 25 and 26) [5]. Further, the Sustainable Development Goals adopted in 2015, clearly state that no-one shall be left behind in the global push to attain these goals [7]. Despite this, there are very few examples in existing literature on the steps taken to design interventions to improve access to health and health-related services for people with disabilities in LMICs. Previous reviews on interventions to improve access to health services for children in LMICs have found no studies focusing on children with disabilities [8,9]. There is evidence from a wide range of LMICs suggesting that people with disabilities face substantial barriers to accessing care, which are often complex and interacting, arising across all dimensions of access – from the individual-level to health system and policy levels [10–14]. Addressing these multi-dimensional barriers, needs a multifaceted or 'complex' intervention approach [15]. A complex intervention can be one which: targets multiple groups or organisational levels; has a number of interacting components; or addresses a number of behaviours [15]. This paper describes the development of two behaviour change interventions designed to improve access to health or health-related services in Malawi and Nepal drawing on the Medical Research Council's framework for designing complex interventions and the Behaviour Centred Design model to develop interventions. The purpose is to demonstrate how these frameworks can be applied, to document the interventions developed and to encourage further initiatives to advance health services targeting people with disabilities.

2. Approaches to Designing New Interventions

Several approaches exist for designing complex interventions to address public health issues. The case studies described in this paper draw on two key approaches in their development: The Medical Research Council (MRC) framework for designing complex interventions and Behaviour Centred Design (BCD) [16,17]. These two approaches are complementary. This section provides a brief summary of each. For a more comprehensive overview, see the MRC and BCD guidance [16,17].

The MRC framework suggests that first a systematic review should be carried out to understand what does or does not work (identifying the evidence base). Then an appropriate theory for the intervention should be developed drawing on the existing evidence, and also supplementing this with additional research, for instance qualitative research with the target population to understand need (e.g., people with disabilities) [17]. Next, participatory workshops with key stakeholders are recommended to develop a Theory of Change (ToC) and potential solutions, which are then developed, pilot tested for feasibility and acceptability, and studied in a wider trial to understand impact. The ToC is a pragmatic framework which describes how an intervention is expected to influence change. It is usually developed in collaboration with key stakeholders and includes a series of hypothesised causes and effects which lead to the intended impact. Indicators of success are developed for each stage to measure progress.

BCD follows a similar stepwise process, including analysing available literature on the topic, conducting formative research and developing a ToC, but it includes a greater focus on understanding the underlying drivers of behaviour [16]. Formative research methods proposed by the BCD focus on observation rather than asking participants to describe their behaviour through in-depth interviews or focus group discussions [18]. This is because many people are not consciously aware of what drives their behaviours [16,18].

These approaches have been used for designing and evaluating interventions targeting a range of health related behaviours, including hand washing with soap, food hygiene and nutrition, however there is little evidence of how this works for people with disabilities [19–22]. People with disabilities may face unique barriers to accessing health services, which presents additional challenges to designing interventions to suit their needs. For instance, people with disability may face discrimination from providers, or communication barriers. They may also incur greater financial barriers to accessing health care as a result of additional health care needs (e.g., rehabilitation or specialist health care) [23].

2.1. The Medical Research Council's Framework

The MRC definition of a complex intervention includes interventions that have many interacting components, or those that target a number of behaviours that are difficult to change, and those that result in a number of possible outcomes. The MRC's guidance for developing complex interventions include the following steps [15,17]:

1. Identifying the desired outcome
2. Identifying how to bring about change based on theory and evidence
3. Testing the feasibility of the intervention to ensure that it is acceptable and can be delivered as intended
4. Evaluation of the intervention through both impact and process evaluations

2.2. Behaviour Centred Design

BCD was developed by the London School of Hygiene and Tropical Medicine (LSHTM) and is grounded in behaviour science and design theories [16]. BCD recognises that interventions cannot directly affect behaviour. Instead they work through a series of causal links from their implementation in the environment through the bodies and into the brains of the target individuals to influence their behaviour and meet the desired impact, such as improved health. It focuses on human motives (e.g., affiliation: desire to be part of a group or status: desire to improve one's social standing), which are used to increase the reward associated with the target behaviour. The series of causes and effects as a result of the intervention is captured in a ToC (Figure 1) [16].

The process of developing a behaviour change intervention is shown through the arrows around the outside: Assess, Build, Create, Deliver and Evaluate. The purpose of Assess is to understand what is already known about the target behaviour. Build includes formative research to enhance context specific knowledge about the target behaviour in relation to the target population. Create involves a team of stakeholders developing the behaviour change intervention, including those involved in the formative research, as well as practitioners and creative/marketing experts to ensure products developed are relevant, appealing and user-friendly. The intervention is then delivered and evaluated. The process through the center of Fig 1. shows the ToC, starting with the intervention and ending at the "state of the world"—the desired impact.

Table 1 provides a comparison of the steps used in intervention development in the BCD and MRC frameworks. Although both frameworks were drawn upon in each of the case studies, the findings are presented using the BCD steps for simplicity. This paper focuses on the intervention development (ABC) part of the process; deliver (D) and evaluation (E) components will be addressed separately.

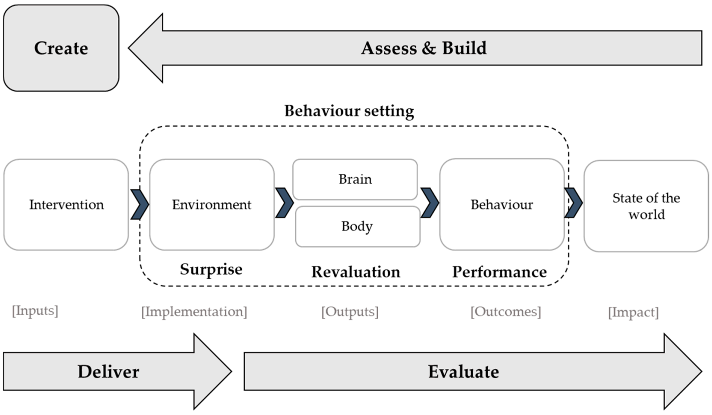


Figure 1. Behaviour Centred Design (BCD) approach (adapted from Aunger et al. 2016) [16].

The approaches used in each case study differed somewhat in the approach taken to create the interventions. In Nepal, the BCD was followed more closely because it was designed by environmental health researchers for developing complex water, sanitation and hygiene behaviour change interventions, and it has been applied in hygiene promotion programmes in Nepal and other south Asian countries with some success [21,22]. In Malawi, the intervention development was informed by the well-recognised MRC guidance. For the intervention design process the MRC is less prescriptive, so in addition to the formative stages of research, other frameworks were drawn from in the creative stage, including the BCD manual and the Behaviour Change Wheel [24].

Table 1. Comparison between steps in Medical Research Council (MRC) and Behaviour Centred Design (BCD) frameworks.

	BCD	MRC
Step 1	Assess and build	Identifying the desired outcome
Step 2	Create	Identifying how to bring about change based on theory and evidence
Step 3	Deliver	Testing the feasibility of the intervention to ensure that it is acceptable and can be delivered as intended;
Step 4	Evaluate	Evaluation of the intervention through both impact and process evaluations.

3. Case Studies

3.1. Case Study 1: Designing an Intervention to Improve Uptake of Referral for Ear and Hearing Services for Children in Malawi

Ethical approval for this research was obtained from LSHTM (code 14433), and the College of Medicine Research Ethics Committee (COMREC) in Malawi (code P.09/17/2278). Informed consent in the local language was obtained for all components of the study involving research participants.

3.1.1. Study Aim and Setting

This study aimed to develop an intervention to improve uptake of referral for children with ear and hearing conditions in Thyolo district, Malawi. Previous evidence from other LMICs had shown poor uptake of referral for children with disabilities [10,11]. Low uptake of ear and hearing services had also been observed anecdotally by practitioners within Malawi. The target population were children needing a referral, either on account of: disabling hearing loss (average of moderate or worse hearing in the better hearing ear according to the World Health Organisation [25]), or ear diseases which have the potential to lead to permanent disabling hearing loss if untreated (i.e., conditions that cannot be treated at health centres such as chronic suppurative otitis media, and dry perforations). Thyolo district is a poor rural district of Southern Malawi with a population of approximately 500,000.

3.1.2. Assess: Systematic Review

A systematic review was conducted on improving access to health services for children in LMICs, in order to understand what works elsewhere. The results of this review have been published previously [8,9]. In brief, this review considered evidence for effectiveness of the following interventions to improve healthcare uptake: delivery of services close to home, service level improvements, educational programmes, text message reminders, and provision of incentives. This review concluded that text message reminders and delivery of services close to home showed the most promising results. The findings for educational interventions were mixed, with some, but not all finding positive results. The review concluded further evidence was needed, however it provided vital background to what has been attempted previously in other LMICs.

3.1.3. Build: Formative Research

An initial study using the Key Informant Method in Thyolo district was carried out in 2015, whereby community health workers (known in Malawi as Health Surveillance Assistants) identified children with hearing impairment and/or ear disease [26,27]. Screening camps were then carried out in the district during which children were examined by ear and hearing professionals. For children who needed surgery, hearing aids or further assessments, referrals were made to Queen Elizabeth Central Hospital (QECH) in Blantyre. QECH is the closest health service to Thyolo that provides specialist ear and hearing services. Evidence from a follow up survey found that uptake of referrals for those in need was extremely low (<5%). We conducted a mixed methods study to explore reasons for low uptake of referrals. This involved structured questionnaires administered to 170 children who were referred to QECH, followed by in-depth interviews with a sub sample of 23 caregivers of children who did not attend QECH following referral, and 15 stakeholders involved in ear and hearing care in Malawi. This research was conducted between June–August 2016 and the results have been published previously [12]. The key barriers reported included:

1. Fear and uncertainty about the referral hospital
2. Procedural problems within the camps leading to lack of understanding about the referral
3. Distance to the hospital
4. Low awareness and understanding of hearing loss
5. Lack of and cost of transport

3.1.4. Create: Designing the Intervention

(1) Focus Group Discussion and Theory of Change Development

A focus group discussion was held with five caregivers from the original Key Informant Method study. The focus group was facilitated by a local researcher who was guided by an experienced qualitative researcher. The purposes of the focus group were to feed back the findings from the formative research and discuss strategies (interventions) to address the key barriers. This focus group formed an important part of the create step, as we wanted to ensure the caregivers could share their views in a comfortable environment, amongst peers facing similar care-seeking challenges. In order to understand more detail about decision making about care seeking and inform the intervention design, discussion also covered this topic. The caregivers validated findings from the formative research, and raised other key issues. Caregivers suggested that hearing impairment is not a priority for many families as there are no immediate complications like there are with acute conditions such as malaria. Regarding decision-making, the caregivers asserted that decisions about seeking care are made at home in a family meeting. Caregivers discussed a range of interventions that could address the barriers which were incorporated in to the next step (participatory workshop).

Following the focus group, a participatory workshop was held to present research findings from the formative research, focus group discussion, and systematic review and to develop ideas on how to overcome the barriers identified and improve uptake. To do this, a ToC workshop was conducted at QECH in Blantyre. In total, 19 stakeholders working in, or with an interest in ear and hearing care in Malawi attended the workshop. This included ear and hearing health professionals and administrative staff/project coordinators from QECH, Health Surveillance Assistants from Thyolo, a Ministry of Health official, a representative from Malawi Counsel for the Handicapped, a representative from Malawi National Association for the Deaf, other Disabled Persons Organisations (DPOs), and caregivers whose children were referred in the 2015 Key Informant Method study. For the workshop, participants were divided in to three groups, ensuring a balance between different sectors, whilst also ensuring that group members could all communicate with each other (some participants did not speak English/Chichewa). Three experienced facilitators ran the workshop (TB, RT, WM), two of whom were Malawian. First the research on uptake and barriers to referral services was presented, and additional findings from the focus group discussion with carers incorporated. Following this, we used a traditional ToC development approach [28], which included the following steps:

- Developing a long-term goal for the project
- Backwards mapping from the long-term goal to outcomes and intermediate outcomes required to reach the long-term goal
- Discussing possible activities (interventions) to achieve the prioritised outcomes
- Prioritisation of suggested activities (interventions) in terms of cost, feasibility, acceptability and sustainability

The long-term goal for this project—and the target behaviour to change - was improved uptake of ear and hearing referrals for children. As attending QECH is often not a one-off event, with most people needing additional appointments beyond the initial referral, our ultimate goal was that attendance at follow-up appointments was also sustained, resulting in improved ear and hearing health. To develop outcomes, each of the barriers identified in the formative research were reversed e.g., “lack of transport” became “transport is available”. Thus, five key outcomes related to the barriers identified in the research were developed.

(2) Proposed Interventions

Table 2 shows the five outcomes (addressing each barrier) and the interventions that were proposed to achieve these. Members of the focus group and ToC workshop particularly emphasised that learning from peers who had been through the experience of attending QECH would be encouraging for caregivers.

Table 2. Outcomes of theory of change workshop.

	Barrier	Outcome	Proposed Interventions
1	Fear and uncertainty about the referral hospital	Reduced fear about hospital	Peer support/counseling Information about hospital procedures communicated effectively during outreach
2	Procedural problems within the camps leading to lack of understanding about the referral	Sufficient information about referral	Information provided through: - Peer support/counseling - Village health committees - Videos about the referral process - Text message reminders
3	Low awareness and understanding of hearing loss/hearing loss is not prioritised	Improved awareness and understanding about ear and hearing health; hearing loss is prioritised	Ear/hearing day advocacy event Education of "gatekeepers" in the community (e.g., community leaders)
4	Distance to the hospital	Service available closer to the community	Expand outreach camps in the community
5	Lack and cost of transport	Transport is available	Group transport provided with community escort

A prioritisation task was held whereby each member of the group voted on their top three interventions—with consideration to costs, feasibility, acceptability, and sustainability. Through this task, a consensus was reached to focus on interventions 1–3 in Table 2 (i.e., those that address fear about the hospital, awareness and understanding about ear and hearing health, and information about the referral). Provision of transportation was not considered to be a sustainable option by all members of the ToC workshop, including caregivers, due to the high perceived long-term costs, despite transportation being a key barrier.

Building on the recommendations from the workshop, consultation with experts in educational interventions, and the evidence obtained from the systematic review, the following multi-component intervention was agreed:

1. A photograph/pictorial information booklet providing information about the process of going to the hospital for ear and hearing services
2. Counsellors trained to deliver information booklet in camp settings, including one "expert" mother (i.e., mother of a child with ear and/or hearing issue who has attended QECH for referral previously) who would provide peer support and a community health worker
3. Text message reminders for caregivers who had been referred to QECH

Each component of the intervention aimed to address the barriers raised in the formative stages of the research, and drew on the results of the systematic review, and existing behaviour change techniques [24]. The final ToC can be found in supplementary material (Figure S1). The rationale behind each component of the intervention can be found in Supplementary Material (Table S1).

(3) Engagement with Creative Team

A London-based creative agency, RE-UP (https://thisisreup.com/), was contracted to create the information booklet. The agency was briefed on the background of the project, the Malawi context, and the intervention proposed. The key sections of the booklet that the agency were tasked with developing included: a story of a child going to QECH with their caregiver, directions to the hospital and department, and a plan of action for counselors to discuss with each caregiver.

The development of the booklet involved an iterative process. Firstly, to tell the story of a family attending QECH, interviews were conducted with two caregivers of children from Thyolo who had previously attended QECH—one for their child's ear surgery and one for hearing aid fitting. These caregivers were selected from QECH registries. Details were gathered about their child, the referral process, the journey and their experiences at the hospital. In addition, photographs were taken by a local photographer of the caregivers, a typical village in Thyolo, the hospital, ear and hearing health professionals, and landmarks that would be important for caregivers to recognise on their journey. These stories and photographs were used to draft the first version of the booklet. The creative agency suggested that a storyline would work well with illustrations of the child and caregiver attending QECH, rather than photographs, so that the intervention was more engaging and surprising. An element of surprise is recommended in the BCD approach to ensure people will pay attention to it and assist engagement in the behaviour change process [16].

An iterative process of consultation and adaptation of the booklet was undertaken, with recommended changes incorporated by RE-UP between each of the following consultation stages:

- Draft 1 and 2 reviewed by LSHTM researchers
- Draft 3 reviewed by eight stakeholders from Malawi (six from original ToC workshop)
- Draft 4 reviewed by target population (caregivers of children with ear and hearing issues from Thyolo district) through a focus group discussion). Caregivers were asked to reflect on suitability of the images, comprehensibility of the text, and usefulness of the components of the booklet.

(4) Intervention

The final components of the intervention include:

- A booklet with three main parts (Figure 2): (1) An illustrated storyline of "The Banda Family" going through the process of being referred and attending the referral at QECH; (2) Information on how to get to the hospital including photographs of key landmarks that caregivers would see on the way to the ENT department; (3) Action planning stage that was tailored to each caregiver—including how they plan to go, how much money they need, and what they need to take with them. This booklet would be delivered by a trained "expert mother" (i.e., mother of a child with ear and/or hearing issue who has attended QECH for referral previously) at the point at which the referral was made (in camps).
- A text-message reminder to be sent two weeks after the referral (Figure 3).

THE BANDA FAMILY

ONE DAY, THE PARENTS NOTICED THAT THEIR SON, CHIMWEMWE, HAD A PROBLEM WITH HIS EARS.

A COMMUNITY HEALTH WORKER CAME TO THEIR HOME AND TOLD THEM TO GO TO THE HEALTH CENTRE.

THEY TOOK THEIR SON TO THE HEALTH CENTRE, WHERE THEY WERE GIVEN A REFERRAL FOR QUEENS HOSPITAL.

THAT EVENING, THE PARENTS TALKED TO EACH OTHER ABOUT THE TRIP TO BLANTYRE.

THE NEXT DAY, THEY GOT ON A BUS TO LIMBE AND THEN WENT TO QUEENS HOSPITAL.

THEY MET A FRIENDLY NURSE WHO SAID EVERYTHING WOULD BE OK. SHE TOOK THEM TO THE EAR DOCTOR WHO HELPED CHIMWEMWE'S EARS.

AFTER THAT, CHIMWEMWE COULD HEAR BETTER. THE FAMILY WERE HAPPY AND CHIMWEMWE DID WELL AT SCHOOL.

HOW TO GET THERE

1 **Bus stop for Queens** - get off when you see the blue flyover. Then walk and ask for Queens.

2 **QECH main gate** – walk straight along main road. Image above is the **Main reception**, where you can ask for directions.

3 **Junction 1** – when you walk up to the first junction, take the left road.

4 **Junction 2** – then when you come to the second junction, take a right.

5 **Eye clinic** - the Qech eye clinic is approx 50 metres away from the ENT clinic. When at the eye clinic, you will be guided to the ENT.

6 **John Hopkins Centre** - this is what you will pass by, when you're on your way to the ENT clinic.

7 **Entrance to ENT/Mercy James** - turn left here when you see Mercy James Centre – it's a large building.

8 **ENT Clinic** - here is where you will meet the doctor who will treat your child. The **Audiology Clinic** is also next door.

PEOPLE YOU WILL MEET

THE NURSE
You can ask a nurse at the hospital to help you find the ENT department.

THE ENT CLINICIAN
They will be the person who will deal with your child's hearing problem.

THE HEARING SPECIALIST
They will check your child's ears and take you to the ENT doctor.

THINGS TO KNOW

TODAY YOUR CHILD WAS FOUND TO HAVE:

○ A problem with their ears that might be helped with surgery.
○ A problem with their hearing that might be helped with hearing aids.

YOU NEED TO GO TO QUEENS FOR FURTHER TREATMENT OR TESTS. YOU CAN GO BETWEEN MONDAY AND FRIDAY.

You will not be asked to give money at hospital but you will need to pay for transport. The counsellor will discuss with you how much money you need.

You may be asked to pay what you want for hearing aids (as much as you can afford).

WE WANT TO HELP YOU TO PLAN YOUR JOURNEY TO QUEENS SO THAT YOUR CHILD CAN ALSO GET THE HELP THEY NEED.

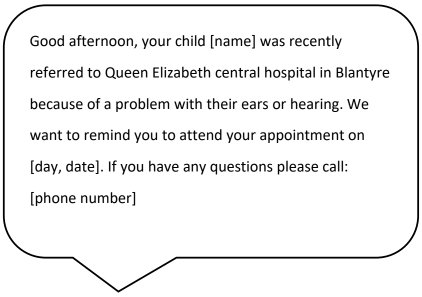
How are you going to get there? ____________________
How much money will I need? ____________________
Who will stay at home with the other kids when you go to Queens? ____________________
Who will go with you? ____________________
How are you going to get home? ____________________
How long to wait? ____________________
What you need to take? ____________________
When are you going to go? ____________________

DO YOU HAVE ANY QUESTIONS?

If you still have any questions here are some useful contacts:

QECH Audiology clinic: 0995471446 or 0881379664.
QECH ENT clinic: 0998683716.
Mwanaisha Phiri: 0993667553.

Figure 2. Final English version of the information booklet for Malawi intervention, before translation into Chichewa. The set of illustrated images at the top show the storyline, and the bottom shows further information about how to get to the hospital, the people that will be met, and a section on action planning (things to know) which was tailored to the individual family. The booklet was folded down to A6 format with page 1 of the booklet showing the first panel of the story (The Banda Family).



Good afternoon, your child [name] was recently referred to Queen Elizabeth central hospital in Blantyre because of a problem with their ears or hearing. We want to remind you to attend your appointment on [day, date]. If you have any questions please call: [phone number]

Figure 3. Text message reminder (English version).

3.1.5. Deliver: Feasibility Studies

In the next stage of the development process, the feasibility of the intervention will be assessed in a study with 30 members of the target population. Mixed methods approaches will be used. Research will seek to understand from stakeholders whether the intervention is appropriate, and what adjustments can be made. Following this, the intervention will be adapted, and a trial setting to understand impact.

3.2. Case Study 2: Designing an Intervention to Improve Menstrual Hygiene Management of People with Intellectual Impairments in Nepal

Ethical approval was granted from the Nepal Health Research Council (code 102-2017 and 39-2018 and the LSHTM Ethics Board (code 12091 and 15703).

3.2.1. Study Aim and Setting

This study aimed to improve menstrual hygiene management (MHM) by adolescents and young people with disabilities and their carers in Kavrepalanchok district, Nepal. MHM is defined as 'women and adolescent girls using a clean menstrual management material to absorb or collect blood that can be changed in privacy as often as necessary for the duration of the menstruation period, using soap and water for washing the body as required, and having access to facilities to dispose of used menstrual management materials. They understand the basic facts linked to the menstrual cycle and how to manage it with dignity and without discomfort or fear' [29]. MHM also involves addressing harmful social beliefs and taboos surrounding the issue. There are concerns that people with disabilities face particular difficulties in MHM, yet few interventions are available to address this issue. This was a collaborative study between the LSHTM and WaterAid, with funding from the Bill and Melinda Gates Foundation.

3.2.2. Assess: Systematic Review

Initially a systematic review of peer-reviewed literature was conducted to understand the MHM requirements of people with disabilities in different settings. The results of this review will be reported separately. In brief, few eligible studies were identified, but in general the review showed that people with intellectual impairments faced particular difficulties in MHM, yet few interventions are available to support MHM in this group.

3.2.3. Build: Formative Research

Formative qualitative research was conducted in the Kavrepalanchok district, to understand the specific MHM requirements of (1) adolescents and young people with a disability and the barriers they face in managing their menstruation hygienically and with dignity; and (2) carers who support these people during menstruation.

Twenty women and girls with disabilities aged 15–24 who menstruated, were identified using the Washington Group Short Set of questions [30]. Twelve carers who support these people during their menstrual cycle and 13 policy makers and practitioners focusing on water, sanitation, hygiene, disability and/or sexual and reproductive health at the district or national levels also formed the sample.

Observing all menstrual hygiene management related behaviours is difficult to do as they are private, so a range of participatory methods were applied: in-depth interviews, PhotoVoice, market survey and product attribute assessments of the menstrual products, and accessibility and safety audits of the menstrual hygiene management facilities. In-depth interviews were conducted instead of focus-group discussions, so that individual's nuanced experiences could be explored in detail and with a level of sensitivity that group interviews are less suited to.

Findings from the formative research will be reported elsewhere, however they supported the results from the systematic review that people with intellectual impairments faced the greatest difficulties in MHM. Whilst people with physical impairments faced barriers to MHM many of these were similar to the barriers experienced by this group when accessing water and sanitation facilities, on which considerable research has been published [31–33]. Additionally, the few initiatives to develop MHM interventions for people with disabilities in LMICs focused on people with visual and hearing impairments [34,35]. These findings formed the rationale for the focus on people with intellectual impairments for the intervention. The key barriers to MHM among people with intellectual impairments that emerged from the formative research were:

- Limited MHM training, information and support. MHM information is often withheld from people with an intellectual impairment because of perceived levels of understanding. Carers have no support, information or guidance on how to manage another person's menstrual cycle, leading many to feel overwhelmed.
- Limited ability to communicate verbally, understand menstruation and related social norms. Some people with intellectual impairments are unable to communicate verbally that they have pre-menstrual symptoms and may not understand the reason for these. Carers do not always provide pain relief for menstrual cramps. During menstruation some participants are frightened, withdrawn, or refused to eat. Some showed their menstrual blood or hygiene products to others and are abused for doing so.
- Poor access to existing MHM interventions. In Nepal, MHM interventions are predominantly delivered through school and community mechanisms. Many research participants with an intellectual impairment do not attend school so cannot access these. Some carers are unable to leave their home because of caring duties, so are unable to access the MHM information delivered through the community.

3.2.4. Create: Designing the Intervention

(1) Focus Group Discussion and Theory of Change Development

Drawing on the systematic review and formative research findings, a ToC was developed by the lead researcher (JW) using the BCD approach, instead of developing it collaboratively at a stakeholder meeting due to resource constraints. The theory considers the target groups and behaviours, human motives, and intervention activities. The final theory is found in the supplementary material (Figure S2). Strategies to improve MHM of people with intellectual impairments were explored through the systematic review, and a scoping review of MHM resources developed for people with disabilities for high-income country settings.

JW shared the formative research findings with carers of people with intellectual impairments from the original sample at individual meetings. A problem tree was used to show the root causes of the issues and their effects. For instance, a lack of MHM information and support to people with intellectual impairments can lead to feelings of fear and confusion when they menstruate. Carers were asked semi-structured questions to understand if they agree with these findings, which they all did. The research findings were then disseminated to key stakeholders at a meeting in Kathmandu.

(2) Engagement with Creative Team

A creative team was set up to develop the MHM behaviour change intervention for people with intellectual impairments in Nepal. The team included a local artist and a marketing professional, as well as people experienced in developing interventions in Nepal (WaterAid, Mitra Samaj), working with people with disabilities (the Down Syndrome Society Nepal), and implementing MHM programmes in the Kavrepalanchok district (KIRDAC, CIUD and government social mobilisers). The creative team attended the dissemination of the formative research findings meeting, and then developed the intervention over 3.5 days during a participatory workshop.

JW and TM led the workshop, which followed the intervention development stages set out in the BCD manual [22]. In summary, the formative qualitative research findings were clustered into six overarching themes: (1) Independence: MHM information at the right time and place, (2) Comfort and confidence: providing pain relief, pads, understanding and communicating pain, (3) Reproductive rights: most girls menstruate, including girls with intellectual impairments, and everyone has a right to understand their bodies and make choices about them, (4) Harmony in the household: providing emotional support, (5) Be recognised as a good citizen: a good citizen adheres to positive social norms/behaviours about MHM, (6) Love your body, love yourself, love your period: address harmful social norms and menstrual restrictions. The themes were then mapped against the human motives identified in the ToC.

The creative team then came up with a statement that connected each theme with the relevant target behaviour. Positive visions (known as "insights") of what adoption of target behavious could lead to were then developed (e.g. a person with an intellectual disability can feel more comfortable and confident to manage bleeding, pain and stress if they use effective menstrual products). An example of how the insight for the 'comfort and confidence' theme was developed is included in the supplementary materials (Table S2). The strongest insight was chosen, using criteria pre-defined in the BCD manual. This insight was developed into the intervention concept.

(3) Intervention Concept

The intervention concept is a narrative which brings the intervention components together under a single package. The aim was to create a concept that captured the audience interest, evoke an emotional response and encourage the adoption of the target behaviours. The intervention concept developed was:

Bishesta (meaning 'extraordinary' in Nepali) is a young woman with an intellectual impairment with hidden, and extraordinary talents. She gets her menstrual product and pain relief from her carers; she uses them properly. She feels comfortable and confident at home and in public. She lives a dignified life. She is loved by all her family members and everyone in the village. She is an inspiration to others as she is learning to be as independent as possible. Whenever she needs support to understand the changes she faces when growing up, Perana (meaning 'motivation' in Nepali) motivates and helps her.

Perana provides information and emotional support to Bishesta. She also offers enough menstrual products and provides pain relief when Bishesta needs it. When Perana does this, Bishesta shows her love. Perana feels confident that Bishesta is more able to take care of herself. The family is happy and they are respected in the community.

Figure 4 shows the faces of the intervention: Bishesta and Perana.

Figure 4. Bishesta and Perana.

The Down Syndrome Society Nepal (DSSN) advised on how to depict Bishesta, who has Down syndrome. Involvement of this DPO in the create stage was integral to developing a credible intervention, especially as the representative from the DSSN was a carer of a person with Down syndrome. The intervention is also branded for greater legitimacy; for instance, the brand colours are blue and yellow and its logo is on all the components.

(4) Touchpoints

'Touchpoints' are the ways in which the target audiences should come into contact with the intervention. [18] All possible touchpoints were identified by the creative team. These were then discussed and ranked according to which were the most appropriate for the context and available resources. The chosen touchpoints for the Bishesta intervention were household visits and group training sessions delivered by staff members from the DSSN and Centre for Integrated Urban Development (CIUD).

(5) Intervention

The intervention includes a menstrual hygiene pack for the person with an intellectual impairment containing: a menstrual storage bag (for inside home), menstrual shoulder bag (for outside home), a menstrual bin, a pain bangle and visual stories. Carers receive a menstrual calendar. Each participant also receives a branded key ring, badge and mirror. Table 3 shows the target group for each intervention component, the target human motive, and the required training for each component. Each component and training activity encourages the adoption of the target behaviours. Further details about each of the intervention components are described in the following section.

Table 3. Intervention components and training activities.

Relevant Intervention Component	Target Group	Target Behaviour	Human Motive	Relevant Intervention Training Activity
Menstrual storage and shoulder bag, menstrual bin	Person with an intellectual impairment	Use a menstrual product	Comfort, dignity	Bishesta doll, role play
Pain symbol bangle		Use pain relief for menstrual cramps	Comfort, reward	
Menstrual shoulder bag, visual stories		Does not show menstrual blood in public	Affiliate, dignity	Bishesta doll, role play 'Reading' visual stories with carers
Menstrual storage and shoulder bag, menstrual bin	Carer	Provide enough menstrual products	Nurture, affiliate, reward	Emo-demos (surprising and motivating demonstrations and activities), peer-to-peer support, competition to become 'Bishesta households', guiding the person they care for through Bishesta doll role play and 'reading' visual stories, household monitoring visits/ad-hoc support
Menstrual calendar, visual stories		Provide pain relief for menstrual cramps	Nurture, reward	
Menstrual calendar, visual stories		Provide emotional support	Nurture, reward	

a. Intervention component details

The menstrual storage bag contains reusable menstrual pads. It is for use inside the home and ensures the participant can always access a menstrual product. The menstrual shoulder bag is designed for use outside the home. It includes reusable menstrual pads and a small waterproof zip bag for a soiled menstrual product.

The menstrual bin is plastic with a swing lid, so can be wiped clean. It should be placed near the participant's bed for disposing of used menstrual products.

The pain symbol bangle has a red, orange and yellow coloured strip. These represent severe, moderate and mild pain respectively. These allow people who are unable to communicate verbally to request pain relief from carers by pointing to the relevant colour.

Two visual stories: (1) 'I change my pad' is about Bishesta menstruating for the first time and how Perana supports her through this, (2) 'I manage' shows Perana helping Bishesta to understand she must not show her menstrual blood in public. The stories include all the target behaviours, human motives and bring the intervention concept to life (These visual stories are based on a method developed by Beyond Words (www.booksbeyondwords.co.uk)).

Carers will be given a menstrual calendar to help track the menstrual cycle, including any changes in related behaviour of the person they support. Prompts for carers' target behaviours are included at the bottom of the calendar.

b. Training

The implementation of the intervention is planned as follows: implementers will deliver three MHM training modules over three months to groups of ten people with intellectual impairments and their carers. During the group sessions, peer-to-peer support for carers will be facilitated and menstrual hygiene packs will be distributed.

JW developed monitoring indicators to track participant's progress against adopting the target behaviours and using the menstrual hygiene packs. Implementers will visit participant's homes to monitor progress against these indicators and offer ad-hoc support. Households that adopt the target behaviours will be recognised as 'Bishesta households' at the next group training session.

The indicators are designed to be achievable to ensure that all participants can achieve this status. Implementers will also monitor attendance and the fidelity of the intervention delivery.

A large Bishesta doll, which has a number of features to facilitate communication and develop skills in MHM, will be used in the training sessions (Figure 5). The doll has all the components included in the menstrual hygiene packs, so all participants can understand their purpose and practice using them with the doll before taking their packs home. In addition, the doll includes a range of other components, such as removable pain symbols that can be placed on the doll to show where discomfort may be felt, and a ‘clean’ and ‘soiled’ menstrual pad that participants can practice changing.

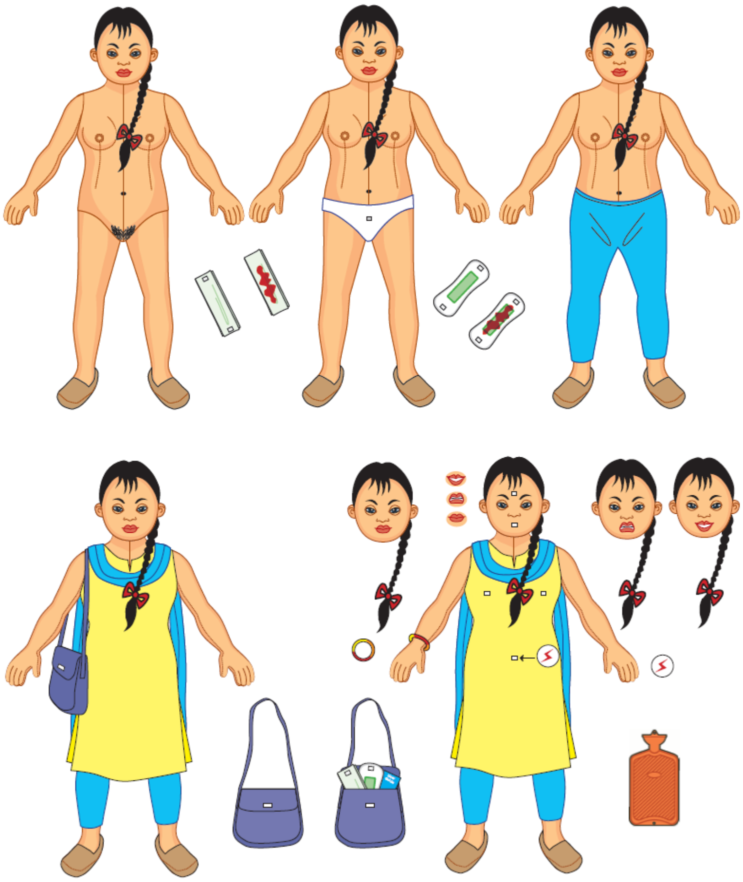


Figure 5. Large Bishesta doll.

3.2.5. Deliver: Feasibility Study

In the next steps, a pilot study will be undertaken to test the intervention components and training manual with implementers, four people with intellectual impairments and their carers. Materials will be revised based on participant’s feedback before implementation. A process evaluation and feasibility study will be conducted to assess the fidelity of the intervention, and feasibility and acceptability of the intervention. The intervention will then be adapted and/or delivered at a wider scale with an impact evaluation conducted at the end.

3.2.6. Comparison of Intervention Design Processes

The two case studies presented above used different approaches within the 'build' and 'create' stages. The projects were distinct, each with their own set of resource constraints, epistemological positions, researchers and collaborating partners who influenced the research design. In Nepal, one priority was to develop a multi-component intervention that systematically disrupted the environment, body and brain of the target group. Another was that a local creative team actively participated in the whole 'create' stage, which led to a strong level of ownership. In Malawi, the priority was to create a low-cost multi-component intervention within a short time frame which could be easily incorporated in to existing programmes. Unlike Nepal, the Malawi project used London-based creative agency was employed due to substantial time constraints, leading to inability to identify appropriate local designers within the specific time-frame.

The nature of the behaviours explored were vastly different in each setting. This determined the data collection methods applied in the 'build' and 'create' stage of the research. For instance, in Nepal menstrual hygiene management behaviours are extremely private, so a number of participatory methods were applied to ensure participants could express themselves in different ways (e.g., PhotoVoice). In Malawi, semi-structured interviews and focus group discussions were used because the researchers felt that the topic could be spoken about openly. Table 4 provides a comparison of the processes followed in the two case studies.

Table 4. Comparison of the processes followed in Malawi and Nepal.

Stage	Malawi	Nepal
Assess	Systematic review of relevant literature	Systematic review of relevant literature
Build	Formative research: • Key informant method • Structured questionnaires • In-depth interviews with caregivers and stakeholders	Formative research: • Research team of women with and without a disability • In-depth interviews • PhotoVoice • Market survey and product attribute assessment of menstrual products • Observation (accessibility and safety audits of the menstrual management facilities)
Create	• Focus group discussions with carers from the key informant method study • Participatory workshop to develop a Theory of Change and design the intervention • Engagement with a creative agency • Intervention: guidance booklet, counseling, text message reminder	• Theory of change development • Formation of a creative team • Problem tree analysis and in-depth interviews with carers from the formative research sample • Stakeholder workshop to disseminate the formative research findings • Creative team workshop to design the intervention and its delivery mechanisms • Intervention: menstrual hygiene packs and training for carers and people with intellectual impairment
Deliver	Feasibility study	Feasibility study

4. Discussion

This paper describes the process of designing multi-component behaviour change interventions for people with disabilities in LMICs using two unique case studies. Although the settings and purposes in the two case studies are vastly different, the steps used in each were broadly similar, drawing on the BCD and MRC approaches, including systematic review, formative research, participatory development of intervention and (in the future) assessment for feasibility and impact.

4.1. Key Lessons, Implications for Research and Practice

The BCD and MRC frameworks offer systematic approaches to developing interventions. In both case studies, the steps to develop an intervention outlined in the BCD manual for practitioners were found to offer clear and concise guidance [18]. Using this process to design interventions for people with disabilities highlighted some important aspects that could be applied in other settings and sectors, beyond public health.

Firstly, conducting a systematic review of relevant literature meant the studies were relevant to current discourse. It also ensured learning from existing interventions so that work was not duplicated and successes could be built upon. For example, studies evaluating text message reminders generally found a positive effect on access to health services in LMICs for the Malawi case study. The formative research was valuable as it provided more in-depth contextual information to inform the intervention design.

Secondly, both case studies sought to ensure people with disabilities, their carers and DPOs are at the heart of the process in each stage of the development. This is in line with the principle of 'nothing about us without us': no disability related policy or intervention should be designed without the full and direct participation of people with disabilities. The process also maximises the likelihood that the intervention developed is relevant and acceptable to the target audiences. There are also challenges with meaningfully engaging people with disabilities, which are discussed below.

Thirdly, applying the theory of change approach and testing it, helps understand links between inputs and required behaviour change as well as ensuring that the interventions are relevant to local contexts. This supports findings from a paper by de Silva et al., which found that stakeholder engagement in intervention development is helpful for context specific solutions using the theory-driven ToC process [36]. This process also ensured stakeholders had a common understanding of the final goal from the outset. In the future, the ToC process will allow authors to identify if the critical activities were delivered as intended. If they have been, the logical linkages between inputs and subsequent behaviour change can be tested. If behaviour change is achieved, this will suggest a positive causal link between inputs and outcomes [36].

Further, creative experts were involved in the product design and marketing process in order to create demand and ensure appealing and user-friendly interventions to encourage the adoption of target behaviours. In the Nepal case study, the intervention was branded for greater legitimacy and recognition. In Malawi, the creative agency was UK-based due to time and resource constraints limiting opportunities to engage local designers. Thus, pilot testing the materials with the target population was essential to ensure cultural relevance. In both case studies, the involvement of DPOs throughout the process was key in ensuring that the materials are appropriate for the target group, and therefore may improve stakeholder buy-in.

There is limited evidence on intervention design with or for people with disabilities in the existing literature. However, in the field of mental health the MRC approach has been followed to develop a range of interventions. For instance, in Ethiopia, Asher and colleagues describe the development of a community-based rehabilitation intervention for people with schizophrenia using the MRC approach. They assert that the ToC allowed articulation of assumptions and development of culturally appropriate ways to improve functioning for people with schizophrenia through community-based rehabilitation [37]. The BCD has been applied in water, sanitation and hygiene interventions [22,38]. For example, the 'SuperAmma' campaign in India, which focused on improving handwashing with soap at critical times (i.e., after using the latrine, and before preparing food and eating), followed the ABCDE principles to design and implement the intervention. Results from the clustered randomised control trial reported an increase in handwashing with soap in the intervention group from 1% at baseline to 29%, 12 months post intervention [22].

In this paper we focus on the processes followed and which aspects are important for designing interventions for people with disabilities. We are unable to say whether the interventions developed in this research are effective as it is outside the scope of these case studies. Given this constraint, further studies are needed that evaluate the effectiveness of these types of interventions for people with disabilities. This evidence is vital to ensure that no one is left behind in the Sustainable Development Goal era.

4.2. Challenges

A number of common challenges were faced in the case studies. Although in both studies, every effort was made to engage people with disabilities, this is not a straightforward process. For example, there was some concern that inviting the target groups from the formative research sample (persons with disabilities and their carers) to the create workshop may be tokenistic. In both settings, the key stakeholders in the create workshop were educated professionals from DPOs, government and non-governmental organisations. The caregivers involved in the formative research were from poor rural areas in both settings and were less educated. These differences would have made equal input into theoretical discussions challenging. In an attempt to mitigate this and ensure in-depth understanding of carers views inclusion of voices in the create process, focus group discussions and in-depth interviews were conducted prior to the workshops in both case studies. In Malawi, the focus group discussions were held in addition to a wider workshop in order to ensure that caregiver's perspectives on how to address barriers that were particular to their lived experience were meaningfully incorporated in to the intervention development. In the workshops in Malawi, we ensured that the makeup of the discussion groups included people that the caregivers would be comfortable with, for example community health workers. In Nepal, the creative team included a carer of a person with Down syndrome from the DSSN, so her unique perspective helped shape the intervention design. The intervention will be also be tested with carers (from similar socio-economic groups as those in the formative research sample) prior to implementation to ensure their continued input into the creative process.

Further efforts are needed to ensure that people with disabilities actively and meaningfully participate in the whole process of intervention development. In both settings, resource constraints limited the levels of participation that was possible. Alternative participatory approaches, such as Body Mapping and using Feeling Dice, should be investigated to ensure that children with disabilities and people with intellectual impairments can receive and communicate information non-verbally and therefore participate more meaningfully in the intervention design [39–41]. These methods will be applied during the feasibility study in Nepal. Wickenden et al. are working on developing these methods for children with disabilities, with a focus on removing barriers that prevent children from sharing their views [42]. They argue that advocating for participatory research with children with disabilities without making adaptations for their needs could lead to unethical or tokenistic practices.

5. Conclusions

The two case studies demonstrate how a systematic approach to designing context specific behaviour centred interventions for people with disabilities in LMICs can be applied. This approach could potentially be used elsewhere. Meaningfully involving people with disabilities in the whole intervention design process is vital. Future studies are needed that evaluate the effectiveness of these types of interventions for people with disabilities to ensure that no one is left behind.

Supplementary Materials: The following are available online at http://www.mdpi.com/1660-4601/15/12/2746/s1, Table S1: Rationale for each component of the intervention in Malawi, Table S2: Example: Insight development for the 'comfort and confidence' theme, Figure S1: Theory of change for improving uptake of referral for ear and hearing services in Malawi, Figure S2: Theory of Change for the menstrual hygiene behaviour change intervention in Nepal.

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Supporting information [see Appendix 5]

Figure S1. Theory of Change for improving uptake of referral for ear and hearing services

Figure S2. Theory of Change for the menstrual hygiene behaviour change campaign

Table S1. Rationale for each component of the intervention in Malawi

Table S2. Example: Insight development for the ‘comfort and confidence’ theme

Chapter 7 Paper Five: The Bishesta Campaign (Deliver step)

The Bishesta campaign facilitation team (left to right): Dhana Kumari Sunar, Pramila Dewan, Shila Thapa, Pramila Humigain, Rumani Pyakurel and Sandhya Chaulagain.

Photograph taken by the author.

Preamble

During the *Create* step, the Bishesta campaign was developed based upon the findings from the *Assess* and *Build* steps, and its delivery mechanisms were identified. This chapter presents the Bishesta campaign: an MHM intervention for people with intellectual impairments and their carers in Nepal within the Deliver step.

The campaign aims to improve MHM among people with intellectual impairments in Nepal, documented in Chapters 3 to 5 in the *Assess, Build,* and *Create* steps. It supports people with intellectual impairments (henceforth referred to as ‘young person’) to use a menstrual material effectively, to know when and how to change it, where to get a new one, where to dispose of it, or wash and dry a reusable material. It assists carers understand what menstruation is and the importance of supporting young people to manage menstruation hygienically and with dignity. It guides carers within a supportive network; to understand pre-menstrual symptoms and related behaviours and how to respond. Importantly, it challenges harmful menstrual beliefs and taboos and encourages open communication on menstruation between the carers and young people. It visually and through roleplay provides accessible and repetitive information to aid the understanding of people with intellectual impairments and anyone with limited literacy.

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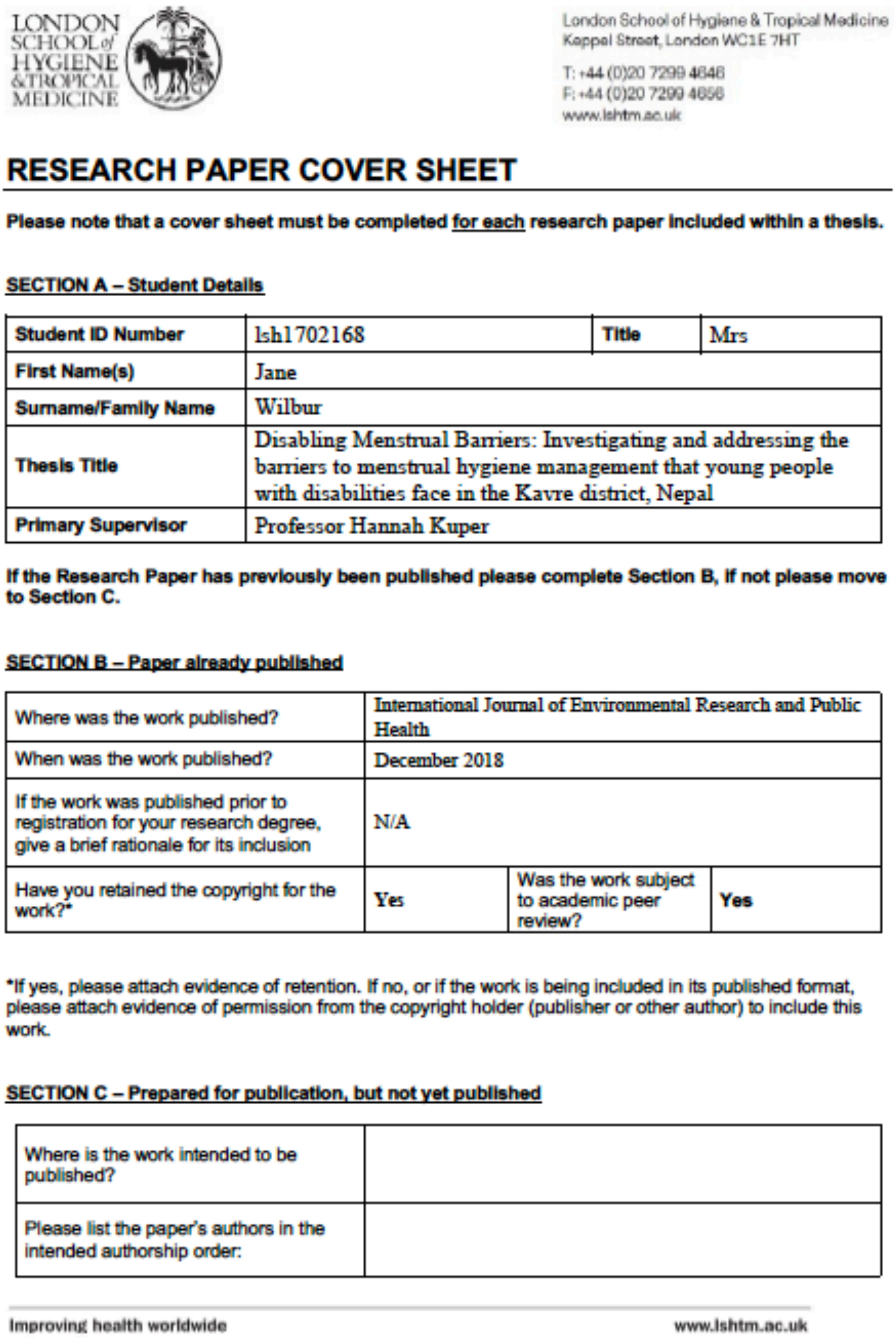

LONDON SCHOOL of HYGIENE & TROPICAL MEDICINE

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

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Surname/Family Name	Wilbur		
Thesis Title	Disabling Menstrual Barriers: Investigating and addressing the barriers to menstrual hygiene management that young people with disabilities face in the Kavre district, Nepal		
Primary Supervisor	Professor Hannah Kuper		

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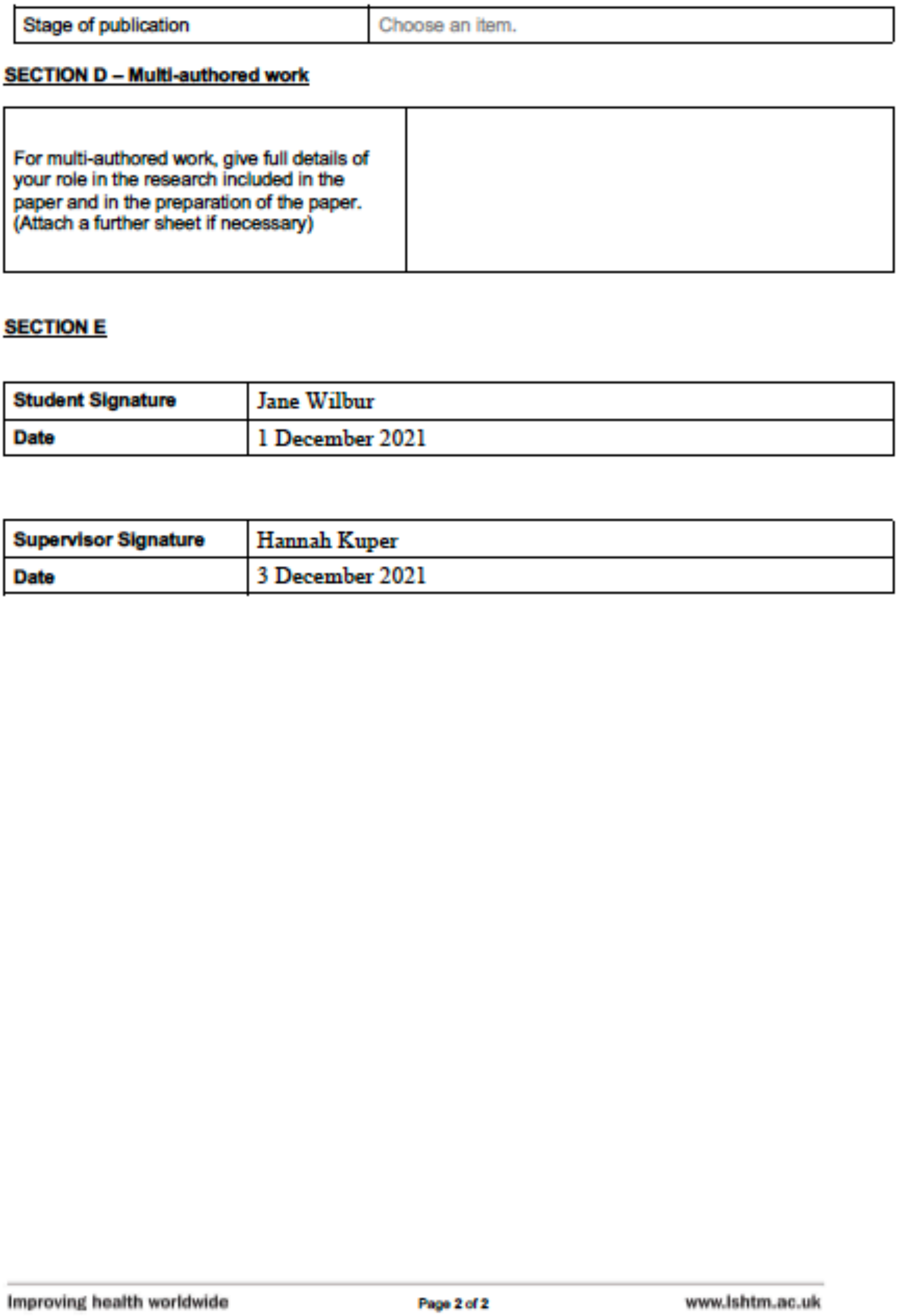

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Supervisor Signature	Hannah Kuper
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The Bishesta campaign: a menstrual hygiene management intervention for people with intellectual impairments and their carers

Jane Wilbur, Islay Mactaggart, Thérèse Mahon,
Belen Torondel, Shaffa Hameed, and Hannah Kuper

Abstract: *This paper describes the components of the Bishesta campaign: a behaviour change intervention for menstrual hygiene management (MHM), targeting young people with intellectual impairments, and their carers in Nepal. The campaign uses two fictitious characters: Bishesta (a young person with an intellectual impairment) and Perana (her carer), and consists of three group training modules. 'Period packs', designed to make MHM behaviours attractive and easy to adopt, are given to the young people. Packs include storage bags, a bin, and stories about Bishesta menstruating and learning to manage as independently as possible, with Perana's support. Carers receive a calendar to track the young person's menstrual cycle. A Bishesta doll, with removable clothes, underwear, and a miniature 'period pack' is used in training to demonstrate MHM. Evaluation findings show the intervention is feasible at small scale, so further research on how to scale up the intervention in an evidence-based way is required.*

Keywords: menstrual hygiene management, behaviour change, disability, carer, Nepal

GLOBALLY, AN ESTIMATED 800 MILLION PEOPLE menstruate every day (Sebastian et al., 2013). Many of these people face challenges managing their menstruation hygienically, especially those living in low- and middle-income countries where there is inadequate menstrual hygiene management (MHM) information, guidance, and facilities (Sommer et al., 2016; Hennegan et al., 2017, 2019). A growing body of evidence highlights that people with disabilities face additional barriers to MHM and very few interventions exist to address these (Wingfield et al., 1994; Kaskowitz et al., 2016; Márquez-González et al., 2018; Harvey et al., 2019; Dündar and Özsoy, 2020). The consequences of a lack of MHM for people with disabilities are severe and include shame, abuse, social isolation, and sterilization

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Jane Wilbur (jane.wilbur@lshtm.ac.uk), Research Fellow, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine; Islay Mactaggart (Islay.Mactaggart@lshtm.ac.uk), Assistant Professor, London School of Hygiene & Tropical Medicine; Thérèse Mahon (Thérèsemahon@wateraid.org), Regional Programme Manager, South Asia, WaterAid, London; Belen Torondel (belen.torondel@lshtm.ac.uk), Assistant Professor, London School of Hygiene & Tropical Medicine; Shaffa Hameed (Shaffa.hameed@lshtm.ac.uk), Research Fellow, London School of Hygiene & Tropical Medicine; Hannah Kuper (Hannah.Kuper@lshtm.ac.uk), Professor, London School of Hygiene & Tropical Medicine

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(Harvey et al., 2019; Wilbur et al., 2019b, 2021; Dündar and Özsoy, 2020; Steele and Goldblatt, 2020). We therefore used evidence-based methods to design and evaluate an MHM intervention for people with disabilities. This article describes the intervention developed, its implementation, and feasibility and acceptability in the Kavre district, Nepal.

Box 1 MHM definition

'Women and adolescent girls are using a clean menstrual management material to absorb or collect menstrual blood, that can be changed in privacy as often as necessary for the duration of a menstrual period, using soap and water for washing the body as required, and having access to safe and convenient facilities to dispose of used menstrual management materials. They understand the basic facts linked to the menstrual cycle and how to manage it with dignity and without discomfort or fear' (UNICEF, 2019).

The Bishesta campaign: overview

The Bishesta campaign is an evidence-based intervention to improve understanding and behaviours around menstrual hygiene management (MHM) for people with intellectual impairments and their carers. It was designed using the Behaviour Centred Design model (Aunger and Curtis, 2016), and included: 1) systematically reviewing existing literature on disability and MHM (Wilbur et al., 2019b); 2) formative research to understand the behaviours and barriers to MHM faced by young people with a disability, and their carers in the Kavrepalanchok (Kavre) district, Nepal (Wilbur et al., 2021); 3) co-creating the Bishesta campaign (Wilbur et al., 2018); 4) pilot-testing; and 5) evaluating the intervention (Wilbur et al., 2019a).

Informing the Bishesta campaign

Formative research was conducted to understand behaviours and barriers to MHM for 20 people with a disability, aged 15–24 who menstruate, and 13 carers who provide menstrual support (Wilbur et al., 2021). A variety of qualitative data collection methods were applied to triangulate findings: in-depth interview, observation, PhotoVoice, and ranking. Results showed that barriers to MHM differed according to impairment group: for people with mobility, self-care and visual impairments, inaccessible WASH facilities were a significant issue. People with intellectual impairments were unable to access MHM information, or it was withheld. Many showed their menstrual blood to others and were abused by their carers and the general public as a result. Carers had no information on how to support another person's menstruation and felt isolated. Very few participants used pain relief and the majority followed menstrual restrictions. A systematic review of relevant literature revealed that there are MHM interventions for people with mobility, visual, and hearing impairments, but nothing for people with intellectual impairments and their carers in low- and middle-income countries (Wilbur et al., 2019b). Therefore, the Bishesta campaign was developed to begin to address this.

Bishesta campaign target groups, behaviours, and human motives

The review of existing literature and formative research findings both showed that the largest gap in MHM was for people with intellectual disabilities and their carers, and so these were chosen as the campaign's target groups (see Table 1). The target behaviours of the campaign were to use a menstrual material and pain relief, not to show

Table 1 Campaign target groups, behaviours, components, and rationale

Target group	*Target behaviours*	*Campaign components: 'Period packs'*	
		Item	*Rationale and action*
Young person	Use a menstrual material	A branded storage bag to keep menstrual materials at home, containing a tailor-made cloth menstrual pad and a strip of folded, soft cloth A small, flip-top menstrual bin for disposal at home, always kept next to the young person's bed	Young person always knows where to get new menstrual material and does not need to rely on carers. She knows where and how to dispose of used menstrual material.
	Use pain relief	A pain bangle with three colours (red, orange, and yellow) representing the severity of menstrual discomfort	If the young person is unable to communicate verbally, she can use the pain bangle to request pain relief.
	Don't show menstrual blood in public	A shoulder bag to carry materials outside the home, with a plastic bag to put used menstrual materials	The young person always has enough clean menstrual materials for use inside and outside the home.
		Two visual stories about Bishesta menstruating and learning to manage it as independently as possible with Perana's support	Participants see Bishesta and Perana following the target behaviours and are inspired to adopt them.
Carer	Provide enough menstrual materials	Storage bag Shoulder bag Menstrual bin Menstrual calendar	The bags are always full of new menstrual materials and placed next to the young person's bed. The menstrual bin is placed next to the young person's bed and emptied regularly. Track the young person's menstrual cycle and prepare by filling the menstrual bags.
	Provide pain relief	Pain bangle	If the young person shows that she is in pain, the carer provides pain relief.
	Show love and emotional support	Menstrual calendar	Track changes in the young person's emotions before and during menstruation to understand any changes in behaviour and respond compassionately.
		Two visual stories	Participants see Bishesta and Perana using target behaviours and are inspired to adopt them.

menstrual blood in public, and to provide enough menstrual materials, pain relief, and emotional support. Campaign components were designed to build upon human motives and trigger behaviour change by making the target behaviours easy to adopt (e.g. through provision of a menstrual storage bag and a menstrual calendar).

The campaign is based on two characters: Bishesta (meaning 'extraordinary' in Nepali), a young person who has an intellectual impairment, and her carer, Perana ('motivation'), both of whom practise the target behaviours (Figure 1). The characters and their lifestyle were designed to make the target behaviours attractive and inspire participants to behave like Bishesta and Perana.

Figure 1 Bishesta and Perana

A competitive thread runs through the campaign, whereby participants strive to become 'Bishesta households' meaning they have adopted the campaign's target behaviours. Those that achieve this are awarded a certificate at the next group training. The competition is introduced in *The Game of Life*, during the first group training and referred to throughout.

Intervention delivery

The campaign was implemented in the Kavre district by members of the Down Syndrome Society Nepal and the Centre for Integrated Urban Development, under the supervision and guidance of JW and WaterAid Nepal. Two groups were established, each including five young people with an intellectual impairment (herewith referred to as 'young people') and their carers, who were family members and professionals. The groups met for three training sessions, lasting 2–3 hours each, to learn about MHM through participatory methods. The facilitation team followed a campaign manual which guided intervention delivery, and used flash cards during the sessions. The lead facilitator had a 'buddy' who observed and supported her to ensure all aspects of the session were covered.

We wanted participants to feel a sense of excitement upon arrival, so training venues were decorated with a branded campaign banner with the target behaviours on it (Photo 1), and yellow and blue flags (Photo 2).

It was important that young people felt comfortable, so the venue had a quiet space that they could withdraw to at any time. During training sessions, carers were encouraged to interact with each other to develop a support network, and help young people to feel confident and valued. To encourage the latter, a campaign ritual was carried out at the start of each group training: all participants stood in a circle, with carers facing the young person. Carers were asked to show the young person love (e.g. smiling, embracing); each introduced the other person to the group (if able and willing) and told the group something they love or appreciate about them.

Participants were asked to use positive and accurate language when talking about menstruation, instead of euphemisms that encourage taboos (Wilson et al., 2018; Hennegan et al., 2019). To ensure all information was accessible, any instructions given during the training were explained verbally, visually, and through role play. For instance, whenever key behaviours and hand washing were mentioned, visuals of these were referred to (see Supplementary material 1). Information was also repeated regularly throughout the intervention delivery to reinforce the young person's learning.

Photo 1 Campaign banner

Photo 2 Yellow and blue flags

Campaign components

'Period packs' were distributed to the young people, and a menstrual calendar was given to carers (see Table 1, Figure 2, and Photos 3–5). A branded mirror was handed out to be put near the young person's bed to remind them of the target behaviours (Photo 6).

A large Bishesta doll, with removable clothes, underwear, and miniature contents of the 'period packs' were used in the group sessions to facilitate communication about, and knowledge of MHM. A smaller version of the doll was offered to the young person to take home, so that they could practise changing and disposing of Bishesta's menstrual material when they were not menstruating (Photos 7 and 8).

Group training modules

The first group training introduced the Bishesta campaign, the journey to behaviour change and the large Bishesta doll. The campaign materials were distributed, including the menstrual storage bag, menstrual bin, campaign mirror, and small Bishesta doll. The second training reinforced the target behaviours, introduced the menstrual calendar and shoulder bag, and practised their use, and announced any 'Bishesta households'. The final session introduced the visual stories, explained how they should be used, and handed out campaign certificates to all participants. Table 2 presents the content, purpose, key messages, target behaviours, and human motives of each group training.

Figure 2 Menstrual calendar

Photo 3 Period pack: menstrual material storage bag

Photo 4 Period pack: menstrual bin

Photo 5 Period pack: menstrual shoulder bag

Photo 6 Branded mirror

Photo 7 Large Bishesta doll

Photo 8 Small Bishesta doll

Table 2 Outline of group training modules

Group training 1		
Session and method	*Purpose*	*Key messages*
1. Introduction (plenary discussion)	• Everyone introduces themselves • Agenda shared • Agree how group works together • Conduct campaign ritual	• We can all learn from each other • The workshop is a supportive space where people can talk about menstruation • A good carer shows the young person love. A good carer supports her to manage her menstruation
2. The Game of Life (activity, plenary discussion)	• Help carers understand the importance of helping the young person manage her menstruation as independently as possible • Introduce the Bishesta campaign, behaviours, and the Bishesta household competition	• You can be a Bishesta household • Supporting a young person to manage her menstruation more independently, providing pain relief and emotional support can make her more comfortable and confident
3. The Bishesta Doll (group work)	• Introduce the Bishesta doll, menstrual storage bag, shoulder bag, and menstrual bin Helps young person: • know when to change a pad • practise changing a pad and re-dressing Bishesta • understand where a person feels menstrual discomfort • understand that menstrual symptoms can make you feel sad, angry, tired • understand that pain relief may help Helps carers understand: • when to give pain relief • when to provide emotional support	• Young person can manage their own menstruation more independently if supported • Young person can feel more comfortable and confident at home and in public when menstruating, if carers and young people follow key behaviours
4. Close the session (plenary discussion)	• Remind participants of topics covered • Encourage a sense of competition • Explain household monitoring visits • Share next training session date; encourage people to attend • Thank attendees for participating	• We can all be Bishesta households • Attending the next training session is important
Group training 2		
Session and method	*Purpose*	*Key messages*
1. Introduction (plenary discussion)	• Facilitators and participants greet each other • Agenda shared	• See 'Introduction' in Group training 1

(Continued)

Table 2 Continued

Group training 1		
Session and method	*Purpose*	*Key messages*
	• Remind the group how to work together • Carry out campaign ritual	
2. Menstrual shoulder bag (group work)	• Introduce the menstrual shoulder bag and how to use it • Young person – practise changing Bishesta's menstrual pad • Carers – understand the importance of keeping the shoulder bag full and in the same place	• Change your pad • Get clean menstrual pads out of the menstrual storage bag or shoulder bag • Always take the shoulder bag out with you when you're menstruating • Carers ensure bags are always full and in the same place
3. Menstrual calendar (group work)	• Introduce the menstrual calendar and how to use it • Handout menstrual calendars	• Tracking the young person's menstrual cycle helps carers prepare for her menstruation • Carers can help the young person feel more comfortable and confident when menstruating. Young person will show you love when you do this
4. Close the session (plenary discussion)	• Remind participants of training content and target behaviours • Encourage a sense of competition • Hand out shoulder bags • Remind about the household monitoring visits • Share next training session date; encourage attendance • Thank people for their active participation	• We can all be Bishesta households
Group training 3		
Session and method	*Purpose*	*Key messages*
1. Introduction (plenary discussion)	• See 'Introduction' in Group training 2	• See 'Introduction' in Group training 1
2. I Change My Pad visual story (group work) 3. I Manage visual story (group work)	• Introduce visual stories and how to use them • Young person tells the story to the carer • Discuss menstruation openly • Handout I Change My Pad and I Manage visual stories	• All young people can lead a dignified life when they are menstruating • Menstrual blood is not shameful. Sometimes menstrual blood leaks on your clothes. People should not be scolded for this

(Continued)

Table 2 Continued

Group training 1		
Session and method	*Purpose*	*Key messages*
		• Menstrual materials absorb blood and can prevent clothes staining. Materials need to be clean, soft, absorbent and stay in place without rubbing. They need to be clean and comfortable, they must be washed and dried thoroughly after use
4. Certificate and close (plenary discussion)	• Remind participants of training content, target behaviours, 'period packs' and what they are for • Thank participants for their active participation • Congratulate people for completing the Bishesta campaign • Hand out certificates	• We are all Bishesta households!

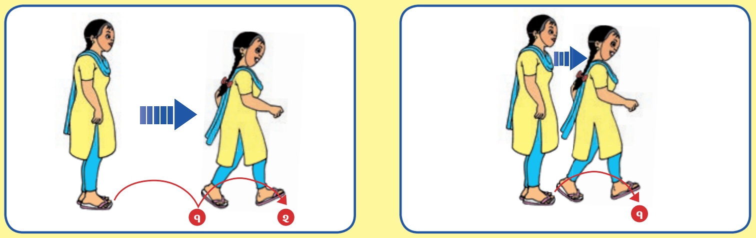
Group training 1

The Game of Life (a participatory way to convey a message; Coe and Wapling, 2015) was conducted to introduce Bishesta and Perana, the key behaviours and benefits of adopting them, as well as the 'Bishesta household' competition.

Four volunteers were asked to stand in a line representing two households: one with Bishesta and Perana, and the other with a Nepali carer and a Nepali young person who has an intellectual impairment. Each volunteer wore a mask with the character's face on it. The facilitator explained that three scenarios would be read out, and the volunteers must take two steps forward if they considered it to be a very positive experience, one step forward for a somewhat positive experience, one step back if they considered it a less positive experience and two steps back for a very negative experience. These verbal instructions were also explained visually (Figure 3).

The facilitator ran through the following three scenarios: 1) when the young person menstruates for the first time; 2) when the young person has menstrual cramps, is upset, refusing to eat, and is withdrawn; and 3) when the carer needs to leave the young person at home alone when she is menstruating. After each scenario was read out, the volunteers took their steps and then the group discussed why.

In the Bishesta household, Perana explains about menstruation and how to manage it, she comforts Bishesta when she is upset and gives her pain relief (e.g. a hot water bottle for her stomach), which Bishesta uses. Perana reminds Bishesta how to change her menstrual material and shows her where to get a new one. When she leaves the home, Bishesta feels comfortable and confident. In the second household, the carer does not provide this support, she follows menstrual restrictions (such as sleeping separately from others, not worshipping, entering the kitchen, not touching food or plants because menstrual blood is believed to be dirty



1. Two steps forward in response to a very positive experiences

2. One step forward for a positive experience

3. One step back for a less positive experience

4. Two steps back for a negative experience

Figure 3 Visual instructions for The Game of Life

and contaminating); does not understand why her daughter is upset and gets angry with her. She puts an uncomfortable, thick, folded menstrual material in the young person's underwear, does not show her where she can get a new one, and leaves home for the day to work. The young person takes the menstrual material off and goes out in the community with menstrual blood on her clothes. People she meets are surprised and shun her; her family is embarrassed and scold her. At the end of the session, the participants are asked which household they want to personify, and they enter a competition to become 'Bishesta households'.

During the *Bishesta Doll* session, facilitators worked with up to two young people and their carers, and introduced the large doll. The young person was asked, or supported, to take a used menstrual material out of the doll's underwear, dispose of the used material in the menstrual bin, and wash her hands. Next, to get an unused menstrual material from the menstrual storage bag, place it in the doll's underwear and dress her. Whenever key behaviours were enacted, the facilitator responded positively and held up the relevant card to positively reinforce the target behaviour (see Supplementary material 1).

The facilitator demonstrated that the doll was experiencing menstrual discomfort, by putting a sad expression on her face and doubling her over while the doll held her stomach. The young person was then asked what she thought was wrong with Bishesta. The facilitator put a pain symbol on areas of the body (breasts, back, head, stomach) where pain may be experienced and asked the young person if, and where she has felt menstrual discomfort. Carers were asked what they could do to help

Bishesta, such as giving her a hot water bottle, reassuring her, encouraging her to rest. Once pain relief or comfort was provided, the facilitator took the pain symbol off and put a happy expression on the doll.

Group training 2

During the second group training session, young people were reminded of the content of the first session using the Bishesta doll. The facilitator showed the menstrual shoulder bag and contents to the participants, then enacted the doll leaving home without it. In this role play, Perana called Bishesta back and gave her the bag with a new menstrual material and plastic bag in it. While out, Bishesta needed to change her menstrual material and the young person was encouraged to do that; putting the used material in the plastic bag inside the shoulder bag, taking it home, and disposing of it in the menstrual bin before washing her hands. Menstrual calendars were given out to carers and their purpose explained, before the group revisited key behaviours.

Group training 3

The visual stories were presented which show Bishesta menstruating for the first time and Perana supporting her to manage as independently as possible. They are intended to improve communication on MHM and reinforce the target behaviours (see Supplementary material 2).

Looking at the visual stories should be an enjoyable and empowering experience for the young person. To encourage this, role play was used to explain how carers can facilitate this. Carers worked in pairs: one was the young person, the other was the carer. Firstly, the carer held the books and did not let the young person touch it; the carer turned the pages and told the young person what was happening in each scene. In plenary, pairs reflected on how that made them feel (e.g. frustrated, disempowered, disinterested). In the second role play, the young person held the book; the carer asked what she thought was happening on each page, and encouraged the young person when she responded, correcting information if required. The young person turned the page when she was ready and continued to interpret the story herself. In plenary the group discussed how the carer helped the young person feel confident, respected, and empowered through the process. Carers then introduced the visual stories to the young person they support and facilitators walked around reminding carers of the process, if required.

In the final session, the facilitator congratulated all participants for becoming Bishesta households and handed out campaign certificates.

Acceptability and feasibility of the intervention

The Bishesta campaign was evaluated in 2019. Data was collected through interviewing carers, facilitators, and WaterAid staff, observing the young people, and gathering process monitoring data. Results showed that the intervention was acceptable and feasible for the target groups and facilitators; most of the ‘period pack’ content was used, improvements were recorded across all target behaviours and there were indications that young people's levels of comfort, self-confidence, and independence had increased during menstruation (Wilbur et al., 2019a). Recommended amendments to the campaign included: 1) making minor changes to the intervention, such as simplifying the menstrual calendar as it was difficult for participants to understand and use; and 2) integrating the campaign into disability service providers' existing self-care programmes aimed at supporting people with intellectual impairments to live as independently as possible.

The Bishesta campaign is free to download (see WaterAid, 2020). However, to date it has been piloted at a small scale in Nepal, and potentially needs modifying for different settings (WaterAid, 2020). This adaptation would include conducting formative research to understand if the target behaviours are relevant, and revising the visuals, names of the characters, and potentially delivery mechanisms to ensure relevance to the new context.

The London School of Hygiene & Tropical Medicine and World Vision received funding from Elrha's Humanitarian Innovation Fund to adapt and pilot the campaign in humanitarian settings in Vanuatu and a refugee camp in a second country (to be confirmed) (Elrha, 2020). This includes developing the capacity of local researchers (including people with disabilities) to conduct formative research to assess the need for and feasibility of the campaign. Visuals, characters' names, and implementation mechanisms will be adapted so that the campaign is culturally relevant and potentially suitable for the humanitarian setting. It will be delivered and evaluated to understand its feasibility and acceptability.

Further evidence is required to support scale up of the campaign, ensuring that it continues to be acceptable and feasible in other settings beyond Kavre. Recommendations for this are to evaluate the intervention's impact on behaviour change in Nepal. This would involve conducting a mixed methods baseline across 100 people with an intellectual impairment, implementing the Bishesta campaign with that group and their carers, gathering process monitoring data and conducting a process and impact evaluation to assess if behaviour change is sustained. If findings are positive, the intervention could be scaled up in the Central Development Region of Nepal, which includes the Kavre district.

Conclusion

The Bishesta campaign is the first MHM behaviour change intervention for people with intellectual impairments and their carers in Nepal. It has been shown to be acceptable and feasible at small scale, so further research is required to evaluate the impact of the intervention on changing behaviours among participants before it can be scaled up within Nepal.

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The authors would like to thank the young people and carers who participated in the Bishesta campaign in the Kavre district. We also thank our wonderful facilitation team: Shila Thapa (lead facilitator), Pramila Dewan, Pramila Humigain, Dhana Kumari Sunar, and Rumani Pyakurel; Sandhya Chaulagain for coordinating the delivery and Tripti Rai for her ongoing support of the campaign.

Ethics approval

Ethical approval was received at each stage of this study. Approval for the formative research was granted by from the Research Ethics Committee at the LSHTM (reference: 12091) and the Nepal Health Research Council (reference: 102/2017). Ethical approval for the delivery of the intervention and the feasibility study was given by the Nepal Health Research Council (code 39-2018) and the LSHTM Ethics Board (code 15703).

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Supporting information [see Appendix 6]

Supplementary material 1: Visuals of key behaviours and handwashing

Supplementary material 2: I Change My Pad Visual story

Chapter 8 Paper Six: Feasibility study of a menstrual hygiene management intervention for people with intellectual impairments and their carers in Nepal (Evaluate step)

Campaign components placed near young people’s beds.

Photographs were taken by the author.

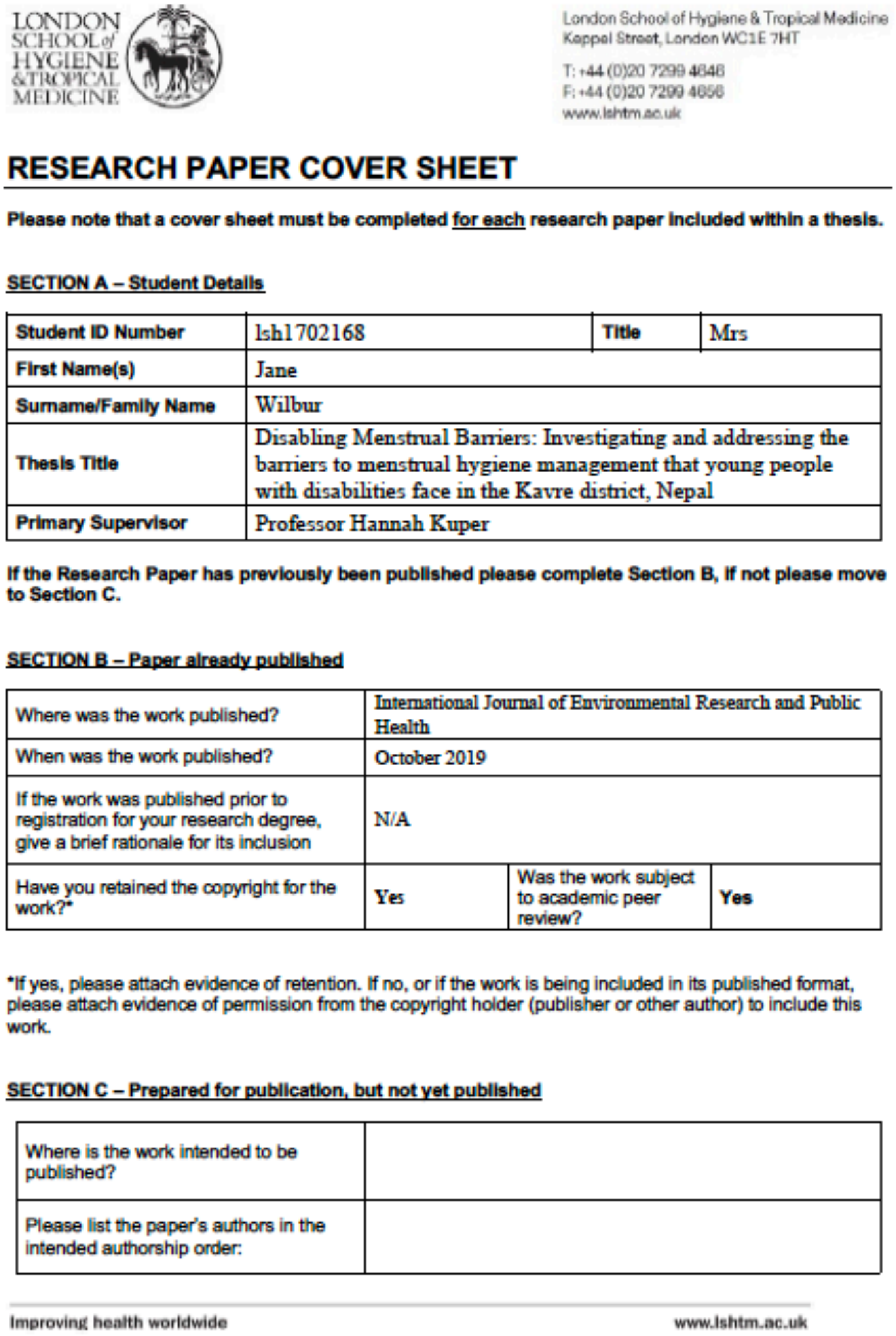
Preamble

Public health policy and decision-makers, donors and practitioners should prioritise evidence-based interventions. These are defined as interventions informed by data generated from a range of research and evaluation methods (243). Feasibility studies are a vital first step in the systematic process of evaluating that evidence to understand if an intervention merits efficacy testing (171, 244, 245). Feasibility studies have been carried out on many public health interventions and have proved to be an effective method to inform decisions about further intervention testing (186, 246-250).

In the *Evaluate* step, Bowen et al.'s Feasibility study framework (introduced in Chapter 2) was applied as it provides a structured approach to assessing the appropriateness of an intervention. The feasibility study of the Bishesta campaign is presented in this Chapter. Topics explored were how participants and implementers responded to the intervention, the use of the campaign components, perceived demand if the campaign was delivered as intended, and the positive and negative effects on the target population. Data was gathered before, during and after implementation across the participants, implementers and WaterAid staff involved in the campaign. The *Deliver* step informed the *Evaluate* step in the following ways: 1) the facilitation team that delivered the Bishesta campaign, participants who participated in the campaign, and WaterAid staff involved in the intervention development and delivery formed the Feasibility study population, 2) process monitoring data was gathered during the *Deliver* step to assess if the Bishesta campaign was delivered with fidelity, 3) contents from the 'period packs' and the large Bishesta doll were used during the observation of young people to explore participant's recognition, understanding, and perception of the campaign concepts.

Findings show that the Bishesta campaign was delivered as intended, that participants used most campaign components, the target behaviours were adopted by several participants, and the campaign was acceptable for those who received and delivered it. Consequently, the intended outcomes and process followed the likely Theory of Change.

Paper Six was published under a creative commons license with the license type (e.g. CC BY) in the International Journal of Environmental Research and Public Health in October 2019.



LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

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Primary Supervisor	Professor Hannah Kuper		

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Supervisor Signature	Hannah Kuper
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Article

Feasibility Study of a Menstrual Hygiene Management Intervention for People with Intellectual Impairments and Their Carers in Nepal

Jane Wilbur [1,*], Thérèse Mahon [2], Belen Torondel [3], Shaffa Hameed [1] and Hannah Kuper [1]

[1] International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, London WC1E 7HT, UK; shaffa.hameed@lshtm.ac.uk (S.H.); Hannah.Kuper@lshtm.ac.uk (H.K.)
[2] WaterAid, 47-49 Durham Street, London SE11 5JD, UK; Theresemahon@wateraid.org
[3] Environmental Health Group, Department of Clinical Research, London School of Hygiene & Tropical Medicine, London, WC1E 7HT, UK; Belen.Torondel@lshtm.ac.uk
* Correspondence: jane.wilbur@lshtm.ac.uk

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Abstract: *Background:* The Bishesta campaign is a menstrual hygiene management (MHM) intervention developed to meet the specific needs of people with intellectual impairments and their carers. It was designed and delivered in the Kavre district, Nepal. This paper explores the campaign's feasibility and acceptability. *Methods:* The Bishesta campaign was delivered to ten people with an intellectual impairment and their eight carers. Data on the feasibility and acceptability of the intervention was collected through: Structured questionnaire to participants before and after the intervention, process monitoring data, post-intervention in-depth interviews with all carers, observation of people with intellectual impairments, key informant interviews with all facilitators and staff involved in the campaign, as well as ranking of the perceived appropriateness and acceptability of campaign components by carers and facilitators. *Results:* The Bishesta campaign was acceptable for the target groups, facilitators, and implementers. It was largely delivered with fidelity. Participants used most of the campaign components; these made the target behaviours attractive and enabled participants to carry them out with ease. There were improvements across all target behaviours. The focus of this study was feasibility, not limited-efficancy; however, indicative positive outcomes from this small sample were observed, such as an increase in young people's levels of confidence, comfort, and autonomy during menstruation. *Conclusion:* Within the sample, the Bishesta campaign appears to be a feasible intervention to ensure that one of the groups most vulnerable to exclusion from MHM interventions is not left behind.

Keywords: menstrual hygiene management; intellectual impairment; carers; adolescent; young people; disability; behaviour change; feasibility study; behaviour-centred design

1. Introduction

1.1. Background

An estimated one billion people live with a disability worldwide [1]. In low- and middle-income countries, many people with disabilities have inadequate access to water, sanitation, and hygiene (WASH) services [2–5]. WASH services are vital for effective menstrual hygiene management (MHM). MHM is defined as women and adolescent girls using a clean menstrual management material to absorb or collect blood that can be changed in privacy as often as necessary for the duration of the menstruation period, using soap and water for washing the body as required, and having access to facilities to dispose of used menstrual management materials. They understand the basic facts linked

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to the menstrual cycle and how to manage it with dignity and without discomfort or fear” [6]. MHM also involves addressing associated harmful social beliefs and taboos.

Menstruation is a sign of good health, but it is shrouded in taboo and secrecy [7–10]. In many countries, menstrual blood is considered polluting [10] and people with disabilities are also considered ‘dirty’ and ‘contagious’ [11,12], and so may face double taboos when menstruating. At the onset of menarche, girls are taught ‘menstrual etiquette’, which encourages secrecy and discomfort, as well as limited formal puberty guidance [9], and perpetuates difficulties in MHM.

1.2. Disabling Menstrual Hygiene Barriers Research

People with disabilities may not be included in training on menstrual etiquette, whether through preconceptions that they will not menstruate, exclusion from school, or difficulties understanding. They may also face additional difficulties in managing their menstruation independently, as a result of physical, sensory, or intellectual impairments. Consequently, people with disabilities may have additional needs for MHM, but there has been a lack of research investigating this issue in low- and middle-income countries (LMICs).

The disabling menstrual hygiene barriers research aims to investigate and address the barriers to MHM that people with disabilities face in Nepal. Drawing on the behaviour change design model in its design [13], research activities conducted include: (1) Completing a systematic review of relevant peer reviewed literature on the MHM requirements of people with disabilities in different settings, and the barriers that they face [14]; (2) formative research to understand the specific MHM requirements of (a) adolescents and young people with a disability, and the barriers they face in managing their menstruation hygienically and with dignity in the Kavre district, Nepal, and (b) carers who support these people during menstruation [15]; (3) identifying strategies to improve MHM of people with intellectual impairments in Nepal; (4) developing the Bishesta campaign—an MHM behaviour change intervention that aims to enable people with intellectual impairments to manage their menstruation more independently, and carers to support another person’s menstrual cycle [16]; (5) delivering the MHM behaviour change intervention in Nepal and collecting process monitoring data over a three-month timeframe; and (6) conducting a process evaluation and a feasibility study to assess the feasibility and acceptability of the intervention.

Key findings from the systematic review and the formative research revealed: People with intellectual impairments face particular barriers to MHM; limited MHM interventions for this group exist; carers have limited understanding of severity of pre-menstrual symptoms experienced by people with intellectual impairments, and that they receive no information or guidance about how to support the management of someone else’s menstrual cycle. Consequently, an MHM behaviour change intervention targeting people with intellectual impairments and their carers was developed by professionals experienced in developing and delivering WASH, MHM, and/or disability interventions and marketing in Nepal. This included the Down Syndrome Society Nepal (DSSN) and the Centre for Integrated Urban Development (CIUD), who also delivered the intervention. For more details on how the intervention was developed, see Wilbur and Bright [16].

The Intervention and Its Delivery

The Bishesta campaign’s target group are adolescent and young people, aged 15–24 years, who menstruate, have an intellectual impairment, and live in the Kavre district and their carers. Three target behaviours were identified from the formative research for people with intellectual impairments (referred to as ‘young people’ hereafter): (1) Use a menstrual product, (2) use pain relief for menstrual discomfort, and (3) do not show menstrual blood in public. Three target behaviours were also identified for carers: (1) Provide enough clean menstrual products, (2) provide pain relief, and (3) show love and emotional support to the young person when she is menstruating. The campaign is based on two characters: Bishesta (meaning ‘extraordinary’ in Nepali), who has an intellectual impairment and menstruates, and Perana (meaning ‘motivation’ in Nepali), Bishesta’s carer. Both characters embody the target behaviours.

The intervention included ‘period packs’ for the young people. These contained: (1) A branded bag for storing clean menstrual pads at home; (2) a shoulder bag for carrying menstrual pads outside the home, with a plastic bag inside to transport used menstrual products; (3) a flip top bin, for disposing used menstrual pads at home; (4) a pain bangle with three strips of colour representing severity of menstrual discomfort—red for severe, orange for moderate, and yellow for mild; and (5) two visual stories about Bishesta menstruating and learning to manage as independently as possible, with Perana’s support. Carers received a menstrual calendar for tracking the young person’s menstrual cycle.

The campaign was delivered by five facilitators from the DSSN and the CIUD, under the guidance of the lead author and WaterAid Nepal. The campaign was implemented through group training sessions for participants and monitoring visits to the young person’s private or care home. The delivery process was monitored.

The aim of this study was to assess the feasibility of the Bishesta campaign in the Kavre district, Nepal, by investigating its acceptability, demand, implementation, and practicality [17].

2. Materials and Methods

2.1. Research Design

2.1.1. Feasibility Study

Process monitoring data were collected during implementation to understand (a) if the campaign was delivered as intended, (b) how many of the people attended every session and how often they were exposed to the campaign, and (c) the extent to which participants were using the campaign components.

Bowen et al.’s feasibility study framework identifies eight areas of focus: Acceptability, demand, implementation, practicality, adaptation, integration, expansion, and limited-efficacy testing [17]. This study applies this framework but only focuses on the first four areas of focus (see Table 1); the remaining areas are outside the parameters of this research and should be explored in the future (i.e., adaptability, integration, expansion, and limited-efficancy). Within the ‘practicality’ area of focus, this study also assessed behaviour change against the target behaviours. The feasibility study indicators and a summary of the results are included in Supplementary Materials Table S1, with results from the household monitoring indicators are captured under indicator 1.

Table 1. Bowen’s feasibility study framework.

Area of Focus	Topics to Investigate	Outcomes of Interest
Acceptability	How the participants and implementers react to the intervention	Satisfaction; Intent to continue use; Perceived appropriateness; Fit within organisational culture; Perceived positive or negative effects on organisation.
Demand	Estimated or actual use of intervention activities in a defined target group	Actual use; Expressed interest or intention to use; Perceived demand.
Implementation	The extent, likelihood, and manner in which an intervention can be fully implemented as planned and proposed	Degree of execution; Success or failure of execution; Amount and type of resources needed to implement; Factors affecting implementation ease of difficulty; Efficiency, speed, or quality of implementation.
Practicality	The extent to which an intervention can be delivered when resources, time, commitment, or a combination of these are constrained in some way	Positive/negative effects on target population; Ability of participants to carry out intervention activities; Cost analysis.

2.1.2. Study Site and Participants

Ethical approval was granted from the Nepal Health Research Council (code 39-2018) and the LSHTM Ethics Board (code 15703).

The feasibility study on the Bishesta campaign was conducted in December 2018. Participants were recruited from the formative research sample and through the DSSN's networks. Study participants were ten young people with an intellectual impairment, aged between 15–24 who menstruated. Six young people were from a residential care home, and four were from households in the Kavre district, Nepal. The Washington Group Short Set of questions were administered with carers and used to identify young people who experience 'a lot of difficulty' (70%, *n* = 7) or 'cannot do at all' (30%, *n* = 3) across the 'remembering and concentrating' functional domain [18]. People who 'cannot do at all' are classified as having a severe intellectual impairment in this article.

Eight of the young people's carers were recruited. These carers were professionals (50%, *n* = 4) who worked in a rural residential care home, or mothers (38%, *n* = 3) and sisters (13%, *n* = 1) living at home in urban areas with the young person.

Five facilitators who delivered the intervention and three members of WaterAid staff (Nepal and UK), with knowledge of active involvement in the intervention, were also included as research participants.

Informed consent was obtained from the carers and key informants before enrolment. Assent was sought from the young person, and consent was given by their carers. It was made clear to all participants that their involvement was voluntary.

2.1.3. Data Collection Tools

During the delivery of the intervention, the facilitation team administered process monitoring data collection tools to record (1) participants' attendance of the training sessions, (2) if the training sessions were delivered as intended (i.e., number of sessions delivered, if the correct number of facilitators delivered the sessions, if all the resources were available), and (3) household monitoring visit indicators (Table 2). If indicators 8 or 9 were achieved, the household was classified as a "Bishesta household".

Table 2. Household monitoring visit indicators.

Number	Indicator	Yes/No	Method
1	Shoulder bag near the young person's bed		Observe
2	Young person can identify the shoulder bag		Ask young person
3	Branded menstrual storage bag near young person's bed		Observe
4	Young person can identify where to get clean menstrual products		Ask young person
5	Branded menstrual storage bag is well stocked		Observe
6	Shoulder bag well stocked with menstrual products		Observe
7	Carers using menstrual calendar to track menstruation		Observe
8	This household has Yes against questions 1–7		
9	This household has Yes against questions 1, 3, 5–7		

Facilitators visited the young person and their carer after each group training session to gather the household monitoring data, re-emphasise information shared at the group training sessions, answer any questions participants may have, and support them to achieve the target behaviours.

The lead author, with support from and translation by Anita Sigdel (a woman with a visual impairment involved in the formative research data collection), administered the following mixed methods data collection tools during the feasibility study:

(a) Structured questionnaire exploring the target behaviours, administered before and after the intervention

(b) In-depth interviews and ranking campaign components with carers. Carers were asked to rank the campaign components according to which they used most to least often, what they liked and disliked about the components, and how they could be improved. Carers then ranked the components according to which (1) the young person used least to most and why, and (2) they felt led to the biggest change in the young person's target behaviours

(c) Observation of young people. In an attempt to encourage the young people to express how they viewed each campaign component, the lead author asked the young person to select an emoji ball (happy, neutral, or sad) that most closely represented their feelings about each campaign component. However, this was not understood, so faces with the same expressions were drawn on a piece of paper and the exercise repeated. This was not understood either, so the lead author passed one campaign component at a time to the young person, and the research team observed and recorded their responses, including recognition, affinity, and understanding. For instance, if a young person smiled when passed a visual story, flicked through it, and indicated what was happening on each page, the researchers assumed that she had a level of understanding of the story

(d) Key informant interviews were conducted by the lead author with all facilitators and WaterAid staff; facilitators also ranked the campaign components according to which they thought was the most useful within the group training sessions

2.1.4. Data Analysis

Data from observing the young people's reactions to the campaign components was discussed by the research team after each interaction, to reach a consensus about the findings and minimise researcher bias. After each day of fieldwork, interview notes were reviewed by the research team. This helped to identify gaps in the interview schedule and emerging themes. In-depth and key informant interviews were translated from Nepali into English and then transcribed. These transcriptions were checked by English speaking Nepali people. A thematic analytical approach was used to analyse findings. Drawing on Braun and Clarke [19], the lead author read the interview transcripts, coded data into emerging themes, and reviewed and refined them before finalising and naming the themes. Data was coded using NVivo 11 (QSR International, Warrington, UK); data were analysed to develop a fuller framework of themes and sub-themes. Relevant quotations are presented in this article. Data analysis of the quantitative data was conducted in Microsoft Excel (Microsoft, Washington, United States).

3. Results

3.1. Acceptability

Acceptability is the extent to which those delivering and receiving the intervention found it satisfying and appropriate [17].

3.1.1. Satisfaction

All facilitators reported that the training they received prepared them to deliver the campaign. The majority of facilitators (80%, $n = 4$) said that the level of detail in the campaign manual was helpful as it reminded and guided them to deliver the campaign as intended; it also increased their confidence and they did not find the detail overwhelming.

Young people benefited from the practical activities and visual methods, but these also benefited the carers, some of whom had limited levels of literacy.

> *"We were kind of afraid [. . . . . .]. If there were only theoretical sessions, I would have felt bored and would not have understand what they were trying to teach, but as they used pictures to explain, it was easier for me. Also, the things that I could not ask about, I could understand them from the pictures"*.
>
> (professional carer)

Facilitators reiterated training content and key messages to carers and young people during the monitoring visits, which carers found useful and motivating. Carers reported that the young people looked forward to the visits. Carers particularly appreciated that most of the facilitators were experienced in working with people who have intellectual impairments. A professional carer said that facilitators "*should like to work with our children, they should not be afraid of the children*".

3.1.2. Appropriateness

The appropriateness of the intervention was assessed through expressed intent to continue use and perceived fit within organisational context.

All carers of young people using the campaign components said that they would continue using the resources after the end of the programme.

> *"I think she will use [them]. They also think that these are very useful, they feel they are safe after using these"*.
>
> (professional carer)

Facilitators from DSSN also expressed a desire to continue implementing the campaign, and suggested ways to take it forward within their existing networks, day care centres, and schools. This is because facilitators felt that the Bishesta campaign filled an existing gap in their support to carers of people with intellectual impairments:

> *" . . . one of the biggest problems, when they have menstruation, some of the families they tie-up the girls at home, because the girl is running here and there. At that time, we didn't have any ideas of these type of trainings"*.
>
> (DSSN facilitator)

Key informant interviews with WaterAid revealed that the Bishesta campaign "add[s] new knowledge" to the WASH sector in Nepal and globally. Interviewees reported that their engagement in the research and campaign had been "inspiring", and that as WaterAid focuses on MHM and inclusion, the campaign should be continued.

3.2. Demand

Demand refers to the extent to which the campaign components are being used by the target group, their perceived level of impact in achieving the target behaviours, and an assessment on potential demand for the intervention.

3.2.1. Actual Use of the Campaign Components

During observation, young people demonstrated an understanding of the campaign components' purpose and how they should be used. Many felt a great sense of pride and ownership over the materials.

The branded menstrual storage bag was consistently used by carers and young people. All the young people enjoyed using the shoulder bag, which many viewed as a fashion accessory. Carers said that the shoulder bag meant that they were more likely to leave the home with the young person when they are menstruating.

> *"I think the [shoulder] bag was most useful for me, as if we need to go out, we don't have to carry the materials for the girls, they can carry them themselves in the bag. We didn't use[d] to carry the plastic [bag]. So, carrying the plastic is one of the things that I learnt from the training".*
>
> (professional carer)

The menstrual bin was well understood and used by all participants. It proved critical for improving the hygienic disposal of menstrual pads by young people and carers. The pain bangle was too complicated for the young people to understand. Only one young person was able to differentiate the colours on the pain bangle or understand how they relate to levels of pain. Additionally, some carers were unable to recall what the colours symbolised.

The visual stories and the Bishesta dolls were useful for improving communication on MHM and adopting the target behaviours. 'I Manage' visual story was cited a number of times by carers as a positive trigger for young people to use a menstrual product effectively (this relates to target behaviours: Use a menstrual product; do not to show blood in public). Carers regularly looked at the visual stories with the young people between the group training sessions. The visual stories were intended to be used to empower the young person, rather than as a teaching aid. For instance, the young person should hold the book and turn the pages themselves; carers should facilitate communication about the pictures but the young person should come up with their own ideas about what is happening. However, many carers used the books to direct the young person to manage their menstruation more hygienically. Some carers were concerned that the young people with severe intellectual impairments would rip or tear the books, so kept the books in a cupboard rather than next to the young person's bed.

The majority of carers found the menstrual calendar overly complicated and confusing. However, many were using it to track the start date of the young person's menstruation. The large and small Bishesta dolls were helpful in teaching the young people practical MHM skills and encouraging them to adopt the target behaviours. Outside the group training, a number of carers practiced changing the small Bishesta doll's pad with the young person, and some young people did this independently. When observing the young persons' reaction to the Bishesta doll, most demonstrated that they related to it. For instance, one young person pointed at the doll and then at herself during the observation. Others gestured that the doll is the same character as Bishesta in the visual stories; one person pointed at the campaign logo on the branded menstrual storage bag and then to the Bishesta doll, which the researchers assumed indicated brand awareness.

Carers were asked to rank the campaign components according to which they perceived to have the biggest and least impact on the young person's target behaviours (Table 3).

Table 3. Perceived levels of impact.

Variable	Component	Number of Carers
Most impactful	Large Bishesta doll	6
	Visual stories	2
	Shoulder bag	1
Least impactful	Pain bangle	8
	Shoulder bag	1

All facilitators identified the large Bishesta doll as the most impactful campaign component used during the group training sessions; this was followed by the branded menstrual storage bag. All facilitators graded the pain bangle as the least useful.

3.2.2. Perceived Demand

Three young people who live in the residential institution were not included in the intervention. After the group training sessions, the professional carers independently went through the training content with these young people, using the campaign materials. As the carers were not instructed to do this, it indicates that the campaign components and the way the training was delivered was appropriate, accessible, and demanded by carers.

All professional carers requested that all the young people in their care, and those who required more support to adopt the target behaviours, are involved in any future intervention. Family members asked for the same. These findings suggest that the carers see value in ensuring all the young people can manage their menstruation as independently as possible.

3.3. Implementation

Implementation refers to the degree to which the intervention can be delivered as intended within the context [17].

3.3.1. Delivered as Intended

Analysis of the process monitoring data shows that two of the three group training sessions were delivered by the correct number of facilitators (see results for indicator number 5 in Supplementary Materials- Table S1). The third was delivered by three facilitators instead of five. All other aspects of the campaign, such as all materials, were distributed, all elements of the sessions took place and were delivered as intended. All monitoring visits were carried out, but the facilitators did not visit participants in pairs due to competing work demands outside the campaign.

Carers were satisfied with one group training session per month and said that the length of time for the group training sessions was adequate. Many asked that the campaign could last longer than three months, so that the information could be repeated. Facilitators echoed this.

3.3.2. Amount and Type of Resources Needed to Implement

Working with people who have an intellectual impairment is resource intensive, because simple and clear information must be provided repetitively and people may require one-to-one support from facilitators.

In the Bishesta campaign, the number of facilitators required per young person was considered. For example, in the group training sessions, one facilitator worked with two young people at the same time: One of which had a severe intellectual impairment. This was not effective, as this person required one-to-one support.

3.4. Practicality

Practicality explores the extent to which the intervention can be carried out using existing resources [17].

Positive and Negative Effects on the Target Audience

(a) Key behaviours: Young person: Uses a menstrual product; Carers: Provide enough menstrual products

Over the short timeframe, two young people wore a menstrual product when they were not previously (see Supplementary Materials- Table S2 for the structured questionnaire results and analyses of the findings against the qualitative data). Qualitative data show that two participants with severe intellectual impairments had an increased understanding about the need to wear a menstrual product, though still required support to place them correctly. However, one young person with a severe intellectual impairment did not use a menstrual product. It is likely that a longer intervention is required to achieve total behaviour change within this sub-group.

Carers reported that the young people felt a greater level of comfort when menstruating and were willing to use a menstrual product because they understood why it was needed. Wearing a menstrual product also made a difference to how the carers perceive the young person. After one young person returned home for a festival, one professional carer explained how parents' view of their daughter had changed because she managed her menstruation with greater independence, and did not show her blood in public.

> *"Her parents told me that she did not do anything bad, they felt that she behaved like a grown up when she was taking care of the menstrual materials".*
>
> (professional carer)

Another carer, who before the intervention, used to restrict the young person's movements during menstruation because she was worried she would show her menstrual blood in public, took her on the bus with her because she was wearing a menstrual product.

> *"I didn't use to take her when I went somewhere. Because if she menstruates when we are out somewhere, like in a bus, she didn't put on the pads, then I would be in trouble. Now, we have dustbin, storage bag, shoulder bag. There have been many changes".*
>
> (family carer)

Carers reported a reduction in menstrual hygiene-related caring duties. For instance, there were less clothes and bedding to wash when the young person used a menstrual product. Carers reported that some young people knew where to get a clean menstrual product, and more independently fetched their own menstrual product from the storage bag, washed the used one and dried it in direct sunlight.

> *"She learnt many things, she knows where to keep her pads. When I tell her to change her pads and clothes, she does them by herself, and also washes them. She didn't use the menstrual products before, but after the three trainings, there has been good changes in her behaviour".*
>
> (family carer)

Carers reported preparing for the young person's menstruation by filling up the menstrual storage bags with clean menstrual products and underwear. In the past, young people either asked carers for a menstrual product, relied on carers to fetch a clean product, or did not use one. An unexpected outcome was carers' increased understanding of good menstrual hygienic practices.

> *"Before the training, though we used to dry [the menstrual product] in sunlight, we didn't let them dry properly, sometimes we used to dry them inside as well. We didn't care about killing the bacteria in the sun, we only cared about drying, sometimes we even used to give them the [menstrual] cloths even when it was not fully dried".*
>
> (professional carer)

(b) Key behaviours: Young person: Do not show blood in public

There was a marked improvement in the target behaviour of not showing blood in public. Carers explained that they now dispose of the used menstrual product in the menstrual bin instead of putting it in a plastic bag and throwing it in the open. Young people were also disposing of their used menstrual products in the menstrual bin.

> *"Sometimes they used to throw it behind the gate, sometimes they threw it from the hostel window. When we circled the building perimeter, we used to find many used pads. Now, they don't do that. They know how to dispose".*
>
> (professional carer)

The reason for focusing on this target behaviour was because some people with intellectual impairments in the formative research sample were abused by family members and the general public for showing their menstrual blood in public. This included walking around with blood on their clothes and removing their menstrual product and showing it to others. However, focusing on this behaviour in the Nepali context where menstrual blood is viewed as dirty, contaminating, and shameful, may have unintentionally reinforced these beliefs. Only one carer noted:

> *"The notion of shame is not seen much in our children. So, we tell them that they have to have some shame".*
>
> (professional carer)

(c) Key behaviours: Young person: Use pain relief; Carers: Provide pain relief; show love

According to the structured survey, 40% (*n* = 4) more young people always used pain relief after the intervention. The in-depth interviews revealed that young people have a greater understanding that menstruation can cause discomfort, which can be managed with pain relief options. One carer reported that the young person she looks after is now calmer during menstruation.

> *"She is upset sometimes when she is feeling pain, and I give her hot water drink and console her and tell her to rest. I don't let her sleep alone; I sleep with her".*
>
> (family carer)

Carers reported having an increased understanding of pre-menstrual and menstrual symptoms, which has led them to respond more compassionately when the young person is distressed during menstruation.

> *"Before, I used to get irritated when they got angry or upset during menstruation. I used to scold them, I thought they are not obeying me and creating problems for me...... But now after the training, I have realized that this is natural, getting angry and upset is natural".*
>
> (professional carer)

(d) Cost analysis

As this is the first intervention of its kind in Nepal and globally, it is difficult to benchmark the campaign costs. Table 4. presents the cost of the pilot study compared to the estimated cost of delivering the campaign at scale. The scale-up costs are based on 25 facilitators delivering 100 group training and monitoring visits to 1000 young people and 1000 carers.

Table 4. Bishesta campaign pilot study costs versus at scale costs (USD).

Activity	Detail	Total Cost: Pilot Study (*n* = 10 Young People)	Total Cost: Scale Up (*n* = 1000 Young People)
Production	Campaign components	$852	$40,410
Production	Training materials	$111	$2103
Salaries	Production team	$2100	$900
Salaries	Facilitators	$5034	$25,169
Training	Facilitators	$231	$750
Delivery	Group training and monitoring visits	$4068	$20,342
Grand total		$12,396	$89,674
Cost per young person		$1240	$90

It is estimated that the cost per young person will reduce from $1240–$90 if the campaign is delivered at scale. This could be achieved by (1) economies of scale, (2) a reduction in production salary costs, and (3) one off production costs for training materials, which can be reused across all group training sessions. The facilitators' salaries reflect the support required by the young people.

During the in-depth interviews, carers were asked if they would be willing to pay for any campaign components themselves, and if so, which? The rationale for this question was to explore how the campaign costs could be reduced. Some carers indicated that they would be willing to pay for the following campaign components: Menstrual pads (38% *n* = 3), shoulder bag (38% *n* = 3), menstrual bin (25% *n* = 2), branded menstrual storage bag (25% *n* = 2), and visual stories (13% *n* = 1). One carer recommended that carers buy the campaign components, and that they are given the Bishesta campaign logo so they can sew it onto the menstrual shoulder and storage bags they purchase. These suggestions were not taken into account in the at scale costs (Table 4).

4. Discussion

Findings demonstrate that the Bishesta campaign is acceptable and feasible. For instance, facilitators were satisfied with the training they received on how to deliver the intervention and the campaign manual, which guided their facilitation. This support helped the facilitators feel confident to deliver the campaign as it was intended. Carers and young people valued the visual and practical training methods, materials, campaign components and monitoring visits. MHM information was accessible for the young people and carers with limited literacy levels. Facilitators from the DSSN expressed a desire to continue delivering the Bishesta campaign, as they reported that it filled an existing gap in their self-care packages for people with intellectual impairments and carers. WaterAid staff also felt that the campaign could contribute positively to MHM knowledge in Nepal and globally.

Findings indicate a demand for the Bishesta campaign. Participants used 80% of campaign components; these components made the target behaviours attractive and enabled participants to carry them out with ease. The large Bishesta doll and the visual stories were identified as the most impactful campaign components for changing young people's target behaviours.

The campaign was largely implemented as planned. The number of facilitators to young people during the group training sessions worked well, as one-to-one support could be provided when required.

In terms of practicality, there were improvements across all target behaviours and participants were able to carry out the intervention activities. A possible negative effect on the target groups was the focus on 'do not show blood in public' target behaviour, as this may have inadvertently reinforced cultural beliefs that menstrual blood is dirty and shameful. The cost of producing the campaign components and training materials is arguably acceptable, although a benchmark is not available.

The focus of this study was feasibility, not limited-efficacy [17]. However, indicative outcomes from this small sample are that young people's levels of confidence, comfort, and autonomy during menstruation may have increased, which arguably leads to greater agency; carers' menstrual-related caring duties have reduced, meaning they feel less overwhelmed. Carers reported a greater level of understanding of the young person's pre-menstrual and menstrual symptoms, which meant they responded compassionately when the young person experienced these. Carers also expressed an ability to provide a higher quality of menstrual care as a result of the campaign.

A recent systematic review conducted to assess of MHM requirements of people with disabilities, and the barriers they face, revealed that (1) people with intellectual impairments face particular barriers to MHM and (2) limited MHM interventions exist for this group [14]. Specific barriers highlighted through the review is a dearth of MHM information, training, and support for people with intellectual impairments and their carers, limited carer's understanding of severity of pre-menstrual symptoms experienced by people with intellectual impairments and few MHM interventions for this group. The Bishesta campaign contributes to addressing these gaps by providing accessible and practical MHM information, training, and support for people with intellectual impairments and their carers in Nepal, with a focus on improving carers' understanding of pre-menstrual and menstrual symptoms experienced by the young people, and how to manage these.

4.1. Strengths and Limitations

A key strength of this research is that the development of the Bishesta campaign followed the behaviour-centred design model, so it is systematic, evidence based, and relevant for the context. The majority of the young people (80%, $n = 8$) and carers (75%, $n = 6$) were involved in the formative research, the intervention, and the feasibility study, so a strong level of trust and rapport was established between them and the lead author. This may have led carers to be overly positive in the evaluation, but the in-depth interviews with carers were complemented by the quantitative survey and observation of young people, which allays some concerns about researcher bias.

In terms of other limitations, the timeframe was tight. This meant that the data collection was conducted shortly after the completion of the last group training session, when the campaign's key messages were fresh in people's minds. Therefore, the findings should be viewed as indicators of behaviour change, rather than actual behaviour change. The sample size was small, so findings are not generalisable. The lead author led all aspects of the study, including developing the intervention and evaluating its feasibility and acceptability. Concerns of researcher bias were managed by close supervision provided by independent academic staff at the London School of Hygiene and Tropical Medicine, and triangulation of qualitative findings with quantitative data, as discussed above. Facilitators were interviewed as part of the feasibility and acceptability study. Their responses to questions may have been influenced by their desire for continued involvement in the intervention if it is scaled up. The lead author explained that the intervention might not be delivered further, but that if it is, the facilitators may not be involved in the scale up. This was reiterated throughout the key informant interviews.

4.2. Implications for Further Research

This study focused on assessing the Bishesta campaign against the first four of eight areas of focus in Bowen et al.'s feasibility study framework [17]. This section sets out the implications for further research against the remaining four areas.

(a) Adaptability: A number of changes should be made to the intervention: (1) The menstrual calendar should be simplified, (2) the pain bangle should be excluded, (3) the training provided to facilitators should include a greater emphasis on using positive language about menstruation, and (4) the cost of producing the reusable menstrual pads should be reduced by comparing the prices and quality of goods across a number of providers and selecting a more affordable option.

(b) Integration: Findings from this study indicate the importance of facilitators understanding the lived experiences of the young people and carers, beyond MHM. Within this area of focus, facilitators' skill set and previous experience of working with the target groups should be tested. Disability service providers could deliver the intervention within their wider self-care programmes, aimed at enabling people with intellectual impairments to live as independently as possible. This could be supported by WASH sector actors to ensure the MHM content is in line with wider efforts to promote effective MHM, including challenging harmful traditional beliefs, practices, and menstrual taboos, as well as ensuring access to WASH services to support menstrual hygiene management practices. The process of delivering the intervention should be monitored to assesses the level of organisational system change (e.g., organisational structure, strategies, operational methods, technologies) required to integrate the campaign into existing organisational commitments.

(c) Expansion: The Bishesta campaign was tested with a small sample size. Now it should be delivered at a wider scale with people who have an intellectual impairment and their carers living in different locations in Nepal.

(d) Limited-efficacy: An impact evaluation is needed to understand if the Bishesta campaign leads to sustained behaviour change. This could be designed as pre-post design study. A mixed methods baseline survey to understand current MHM behaviours related to the target behaviours should be conducted before the intervention. The campaign should be delivered and then evaluated using quantitative and qualitative methods to understand behaviour change outcomes.

5. Conclusions

The Bishesta campaign presents an opportunity to ensure that one of the groups most vulnerable to exclusion from MHM interventions is not left behind. The campaign begins to fill the documented gap in the sexual and reproductive health provision for people with intellectual impairments, and MHM information and support for their carers. It should now be tested with a larger sample and evaluated to understand its efficacy.

Supplementary Materials: The following are available online at http://www.mdpi.com/1660-4601/16/19/3750/s1: Table S1: Feasibility study indicators and results, Table S2: Structured questionnaire results and analyses of the findings against the qualitative data. The Bishesta campaign will be available for free download from December 2019 at https://washmatters.wateraid.org/.

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Disclaimer: The authors recognise that gender is a social construct, non-binary, and fluid. People who menstruate may identify themselves as male, female, or neither. Therefore, this article uses the terms 'person', or 'people' who menstruate rather than 'female', 'women', or 'girl'.

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Supporting information [see Appendix 7]

Table S1. Feasibility study indicators and results

Table S2. Structured questionnaire results and analyses of the findings against the qualitative data

Chapter 9 Discussion and conclusion

Participants of the Bishesta campaign

Photographer: WaterAid/Shruti Shrestha

9.1 *Overview*

This chapter includes a summary of research findings, implications for the conceptualisation of MHM within the Socio-ecological framework, the use of the BCD and Feasibility study framework, as well as considerations of methods implemented and approaches taken, the intervention developed and implications for future research.

9.2 *Summary of research findings*

This research aimed to develop an MHM behaviour change intervention for young people with disabilities in Nepal and assess its feasibility. The specific objectives to achieve this aim are set out below, with a summary of findings against each.

Objective 1: Systematically review the literature on the menstrual hygiene management (MHM) requirements of people with disabilities in different settings, and the barriers that they face

Chapter 3 presented evidence from a systematic review of relevant peer-reviewed literature that assesses the menstrual hygiene requirements of people with disabilities, the barriers they face, and the interventions that exist to address these. To date, this is the only systematic review to explore these issues. Results showed a dearth of evidence about the MHM requirements of people with disabilities. Across the included 22 studies, findings showed that people with intellectual impairments faced additional barriers to MHM. Pre-menstrual symptoms and related behaviours displayed by this group included fatigue, anger, withdrawal, self-injury and increased hyperactivity, and inappropriate handling of menstrual blood and materials. This group also faced difficulties understanding premenstrual syndrome (PMS) and communicating when experiencing menstrual discomfort. People with intellectual impairments were not systematically supported to understand menstruation or how to manage it as independently as possible. The review found no evidence that carers received support or guidance about managing the individual’s menstruation.

Additionally, MHM was considered a private issue, and carers did not speak to others about it, including medical professionals. Management strategies included restricting the person with intellectual impairment’s physical movements, suppressing their menstruation, and sterilisation. Findings also showed that people with mobility impairments were often not satisfied with the menstrual materials. Only one intervention was identified to support MHM for people with disabilities. This documented training in which people with intellectual impairments practised changing and disposing of a used menstrual material with a large doll (240).

Objective 2: Assess the inclusion of disability in Nepal’s policies and guidance relevant to WASH and MHM, and explore the implementation of policy commitments in the Kavre district

Chapter 4 investigates the inclusion of disability in Nepal’s policy and guidance related to WASH and MHM, and implementation, using the Kavre district as a case study. Results show that a lack of evidence about the MHM requirements of people with disabilities and the barriers they face led to an absence of MHM for people with disabilities in policy formulation, inadequate training and support for service providers, and a deficiency in professional understanding of the issues. When access to WASH for MHM was referred to in relation to disability, implementation focused on accessible infrastructure for people with mobility impairments. Service providers only discussed people with intellectual impairments when stating that they did not know how to support MHM for this group; no other impairment groups were mentioned. MHM interventions were delivered in schools, but children with disabilities were less likely to benefit as many were not enrolled in schools, and no outreach programmes were delivered. Like the results in the systematic review, carers were not identified as influencers for MHM for people with disabilities in policy formulation or implementation. Without any support or guidance, we found indications that carers sought to sterilise individuals to cease menstruation and mitigate unwanted pregnancies. Without consent, this violates individuals’ sexual and reproductive rights (251).

> **Objective 3: Undertake qualitative research to understand the specific MHM requirements of a) young people with disabilities, and the barriers they face in managing their menstruation hygienically and with dignity in the Kavre district, Nepal, and b) carers who support these people during menstruation.**

Chapter 5 presents results against this objective. In the Kavre district, we applied a selection of qualitative methods with 20 people with disabilities and 13 carers who provide menstrual support to these individuals. Results showed differences in barriers experienced by the different impairment groups, but the most substantial and unaddressed issues were for people with intellectual impairments. The issues facing this group were similar to those identified in the systematic review. MHM information was withheld from this group due to the belief that it would not be understood or remembered, and pre-menstrual symptoms and menstrual behaviours experienced were not well managed or understood by carers. Changes in behaviour before and during menstruation included withdrawal, increased hyperactivity, self-injury, feeling frightened and refusing to eat. Some refused to wear a menstrual product and left home with menstrual blood on their clothes or showed others their menstrual material. Within the Nepal context, where menstrual blood is commonly considered dirty and polluting, some people with intellectual impairments were subsequently abused by their families or members of the public.

Carers did not receive support or guidance about managing the individual’s menstruation. Difficulties leaving home because of caring duties also meant that they could not access MHM interventions delivered through the community. Carers did not speak to anyone else about the MHM duties they performed, which reflects evidence from other settings (1) (see Chapter 3). This isolation meant that carers often felt particularly overwhelmed when the individual was menstruating. Some people with disabilities reported that they were aware that their carers would like to sterilise them to cease their menstruation. Some carers and people with disabilities expressed interest when asked about sterilisation. I did not want to introduce that idea and inadvertently raise demand for the practice, so we stopped exploring the issue with this population. Due to the sensitive nature of this finding and its lack of triangulation, it was not included in Paper Three.

People with self-care limitations who were unable to manage menstruation independently felt shame when their carers handled their menstrual blood. People with disabilities who were not in schools were marginalised from MHM interventions delivered through school platforms, as documented in Chapter 4. Those with visual impairments highlighted challenges seeing blood on their clothes and washing stains from clothing and bedding, which they found stressful; people with mobility impairments reported inaccessible WASH facilities as the greatest challenge.

As noted in Chapter 1, section 1.2 Types of MHM, there is an implicit assumption that individuals manage their own menstruation. Findings from the systematic review and the formative research demonstrate that people with disabilities can be split into two groups: people who manage menstruation themselves, perhaps with great difficulty, and people who are reliant on carers for MHM. This marks one of the biggest differences between MHM for people with disabilities and for people without. MHM interventions for the latter focus on the person who menstruates, but for people with disabilities who are unable to manage menstruation independently, carers must be targeted and convinced to provide MHM care with dignity.

Interventions about making WASH infrastructure accessible for people with disabilities exist, as do MHM interventions for people with visual and hearing impairments (218, 252). However, an MHM behaviour change intervention could not be identified for people with intellectual impairments and their carers in LMICs, so an intervention was developed.

Objective 4: Develop an MHM behaviour change intervention that enables people with intellectual impairments to manage their menstruation more independently

Chapter 6 documents the process of developing complex interventions, using two case studies: 1) the application of the Behaviour Centred Design (170) to develop the MHM intervention in this PhD study, and 2) using the Medical Research Council Guidance for developing and evaluating complex interventions (180) to design an intervention to improve uptake and referral for hearing services in Malawi. The paper aimed to explain how these approaches could be applied to develop interventions with people with disabilities to encourage future initiatives for this group.

Only findings related to the application of the BCD in this PhD, and not the Malawi case study, are presented in this summary. The process begins with the *Assess* and *Build* steps, whereby a systematic review and formative research are conducted to explore behaviours before the intervention and what human motives drive these, and a Theory of Change is developed. A context-specific intervention that identifies relevant human motives to increase the reward associated with the target behaviour is collaboratively created within the Create step. Campaign components are developed to disrupt the behaviour setting and make the target behaviours more attractive and easier. Within the *Deliver* step*,* the intervention is piloted, and process monitoring data is gathered to understand if the campaign was delivered as intended as depicted in the Theory of Change. Finally, the *Evaluate* step is where an outcome and process evaluation is conducted.

Objective 5: Pilot the MHM behaviour change intervention in the Kavre district, and evaluate its feasibility and acceptability

Chapter 7 and Paper Five presents the Bishesta campaign: an MHM behaviour change intervention for young people with intellectual impairments and their carers in Nepal. It explains the target behaviours and human motives used to trigger behaviour change and the campaign components (called ‘period packs’) designed to make the target behaviours attractive and simple to adopt. The intervention was delivered by DSSN and CIUD staff, using participatory methods which encouraged open communication about MHM. Information was transferred repetitively through various formats: verbally, visually, role play and by demonstrating target behaviours using a large Bishesta doll. Contents of ‘period packs’ were introduced during group training sessions before participants took them home to use. Through the group training sessions, carers were encouraged to develop supportive networks.

The intervention sought to address barriers highlighted through the *Assess* and *Build* steps. These include providing simple and accessible MHM information to people with intellectual impairments to enable them to manage menstruation with greater comfort and confidence; guidance and support to carers, and encouraging a greater understanding of PMS, menstrual behaviours, and how to manage these, as well as to facilitate more open communication about menstruation.

Chapter 8 investigates the Bishesta campaign’s feasibility and acceptability to the target group, facilitators and WaterAid staff involved. Findings showed that the intervention was delivered with fidelity, that it was acceptable to the participants, facilitators and implementers and that there were improvements across all target behaviours. We concluded that the Bishesta campaign begins to fill a gap in MHM for people with intellectual impairments and their carers. However, the sample size was limited, so it should be tested at a larger scale to understand its efficacy.

9.3 *Implications for the conceptualisation of MHM: the Socio-ecological framework*

This PhD study findings have highlighted several areas in the Socio-ecological framework for MHM that must be strengthened to ensure it includes experiences of people with disabilities and their carers. The adapted Socio-ecological framework for MHM (presented in Chapter 3) aimed to address these gaps; however, after completing this PhD study, further revisions must be made to make it more inclusive. Table 6 presents the final revisions to the Socio-ecological framework for MHM, adapted for disability (the final edits are underlined).

Table 6. Final revisions to the Socio-ecological framework for MHM, adapted for disability

Factors that support MHM	Revisions to outcomes (underlined)
Societal and government policy factors	Policies, strategies and curriculum include targets, indicators and resources to address MHM needs and rights for people with disabilities, paying attention to different impairment groups; training standards and practices include disability and are delivered by people with and without disabilities; traditional norms, practices and cultural beliefs including those related to menstruation and disability
Environmental and resource availability factors	Fully accessible water and sanitation facilities including for solid waste management; availability of affordable, usable and culturally appropriate sanitary protection materials, assistive products (e.g. wheelchairs, lifting devices, tilting bathing chairs, incontinence products)
Interpersonal factors – person with disabilities	Relationship with family, carer (family and / or professional); relationships with healthcare workers, teachers and other people in authority; relationships with peers; perceptions of changes in gender roles for people with and without disabilities post-menarche
Interpersonal factors – Carer	Relationship with family, the person with disabilities; relationships with healthcare workers and other people in authority; relationships with the wider community; perceptions of changes in gender roles for people with and without disabilities post-menarche
Personal factors – person with disabilities	Knowledge about the biology of menstruation and MHM, information on menstruation and MHM in accessible formats (e.g. visual, sign language, audio, Easy Read, Braille, captioned media) and provided across existing platforms (e.g. schools) and outreach programmes; skills in coping and behavioural adaptions (including pain relief); attitudes, beliefs and feelings about menstruation (including sterilisation / long-term contraception); ability to manage menstruation independently, and support required, mental health and wellbeing
Personal factors – Carer	Knowledge about the biology of menstruation and MHM, information on menstruation and MHM provided across existing platforms (e.g. community interventions) and outreach programmes; skills in coping and behavioural adaptions (including pain relief, menstrual behaviours such as aggression, withdrawal, excessive sleeping); attitudes, beliefs and feelings about menstruation (including sterilisation / long-term contraception); ability to manage another person's menstruation independently, support required, and caring tasks related to MHM (e.g. bathing, changing the menstrual materials, providing pain relief, reminding the person what menstruation is and how to manage it hygienically and with dignity, supporting the person to manage as independently as possible, assisting a people with visual impairments to do laundry), pain caused by provision of care, mental health and wellbeing
Biological factors	Menstrual variations due to age and features of menstrual cycle (regular, irregular, heavy, light) and any other biological changes related to menstruation; intensity of menstruation (pain) and influences on behaviour, health and concentration; biological issues that impact on MHM, such as incontinence.

MHM needs for people with disabilities must be met, but this cannot be done in a silo as the wider life experiences of people with disabilities have a direct bearing on achieving this goal. This study has shown that MHM experiences will differ according to the impairment experienced, so consideration of what the outcomes for each impairment type are added in the revised effects against each Factor in Table 6. For instance, findings in this study show that people with mobility impairments and self-care limitations face barriers to accessing WASH facilities, so 'fully accessible water and sanitation facilities' have been added to *Environmental and resource availability factors.* In Vanuatu, a mixed-methods study exploring the menstrual experiences of people with and without disabilities in rural and urban areas found that the outcomes for people with disabilities were worse than those without disabilities, especially for people with mobility impairments and self-care limitations who are reliant on carers (83). This is because social restrictions dictate that individuals must collect their own water to bathe and wash the menstrual material and bathe independently during menstruation. Without potable water at home, inaccessible bathing facilities and laundry locations, this group experienced increased levels of pain and shame when menstruating.

As stated in the summary of research findings, there is a fundamental difference between people with and without disabilities as the former may be reliant on carers. Therefore, carers must also be included as a target group *(Personal factors – carers).* The focus should be on enabling carers to provide dignified and hygienic menstrual care, so the relationship between the two sets of factors (*Environmental and resource availability, Interpersonal factors and Personal factors*) must be understood. A person's ability to manage independently is also impacted by access to required assistive products (e.g. wheelchairs, hearing and memory aids, incontinence products (52, 83)). Carers must be equipped to assist without suffering physical pain and discomfort. Initiatives to increase access to lifting devices and bathing chairs are essential, so additions have been made to *Environmental and resource availability factors.*

The broader impacts of inadequate MHM on the well-being and mental health of people with disabilities and those who care for them have been integrated into the revised framework under *Personal factors – person with disabilities and carers.* Social exclusion and isolation, particularly experienced by people with intellectual impairments, are documented in Chapters 3 and 5. In Vanuatu, people with disabilities (data was not disaggregated by impairment type) were up to twice as likely to miss social events and three times more likely to eat alone than people without disabilities (83). Furthermore, people with disabilities were more likely to report 'suffering' than people without disabilities, and this was worse for women than men with disabilities (83). Menstrual experiences likely contributed to reasons for gender-based differences in results.

This PhD study has documented the mental health issues experienced by carers and how a lack of support and guidance about how to support a people with disabilities (particularly those with intellectual impairments), as well as isolation and despair, felt during the individual's menstruation, can result in violence. As reported in Chapters 3-5, this includes sterilisation and limiting physical movements during menstruation. Outcomes related to violence are reflected in the revisions to the Socio-ecological framework for MHM under *Personal factors – person with disabilities and carers*.

Underpinning any MHM efforts are *Societal and government policy factors.* The analysis of policies and guidance documents relevant to MHM in Nepal (Chapter 4, Paper Two) highlights an absence of attention to disability within MHM policies, guidance and subsequent training for implementers. It also demonstrates that when disability is included, there is a general focus on meeting the MHM needs of people with disabilities instead of their rights. For instance, where disability was referenced in relation to MHM in policies and guidance documents, references focused on ensuring WASH facilities were physically accessible. Attention was not given to enhancing people with disabilities' agency and autonomy. These findings reflect three other studies which applied the adapted EquiFrame for WASH and disability to assess the inclusion of disability core concepts of human rights in 1)

WASH policies and programme documents in Bangladesh and Cambodia (253), 2) guidance resources on WASH service provision in COVID-19 (254) and 3) an evaluation of 74 hygiene promotion programmes to prevent COVID-19 transmission, delivered in 37 LMICs (62). Across all studies, physical and information access to WASH services, with reasonable adjustments made to ensure accessibility where necessary, were prioritised. However, minimal to no attention was given to developing leadership, supporting carers and WASH accountability mechanisms, all of which are core concepts of human rights in the EquiFrame (230). Findings demonstrate a limited focus on disability, but where attention is given, it tends to be narrowly focused on meeting the needs of people with disabilities instead of progressively realising their rights across different settings. Consequently, *Societal and government policy factors* in the revised Socio-ecological framework for MHM include both needs and rights and investing in enhancing the capacities of people with disabilities.

Finally, to improve MHM for people with disabilities and incorporate all parameters detailed above, multi-sectoral engagement across disability, sexual and reproductive health, health, WASH and education policies and programmes are required for comprehensive efforts to improve the rights of people with disabilities. This is added to *Societal and government policy factors.*

9.4 *Considerations of methods implemented and approaches taken*

Participatory approaches

9.4..1 Ladder of participation

As outlined in Chapter 2, there are different participation levels, ranging from non-participation, co-produced to emancipatory research. Figure 8 depicts the ladder of participation for people with disabilities and carers on the left, with the participatory activities carried out in this PhD study on the right. These activities are separated across the different rungs to show how progressively participatory the efforts were.

Figure 8. The Ladder of participation applied in practice

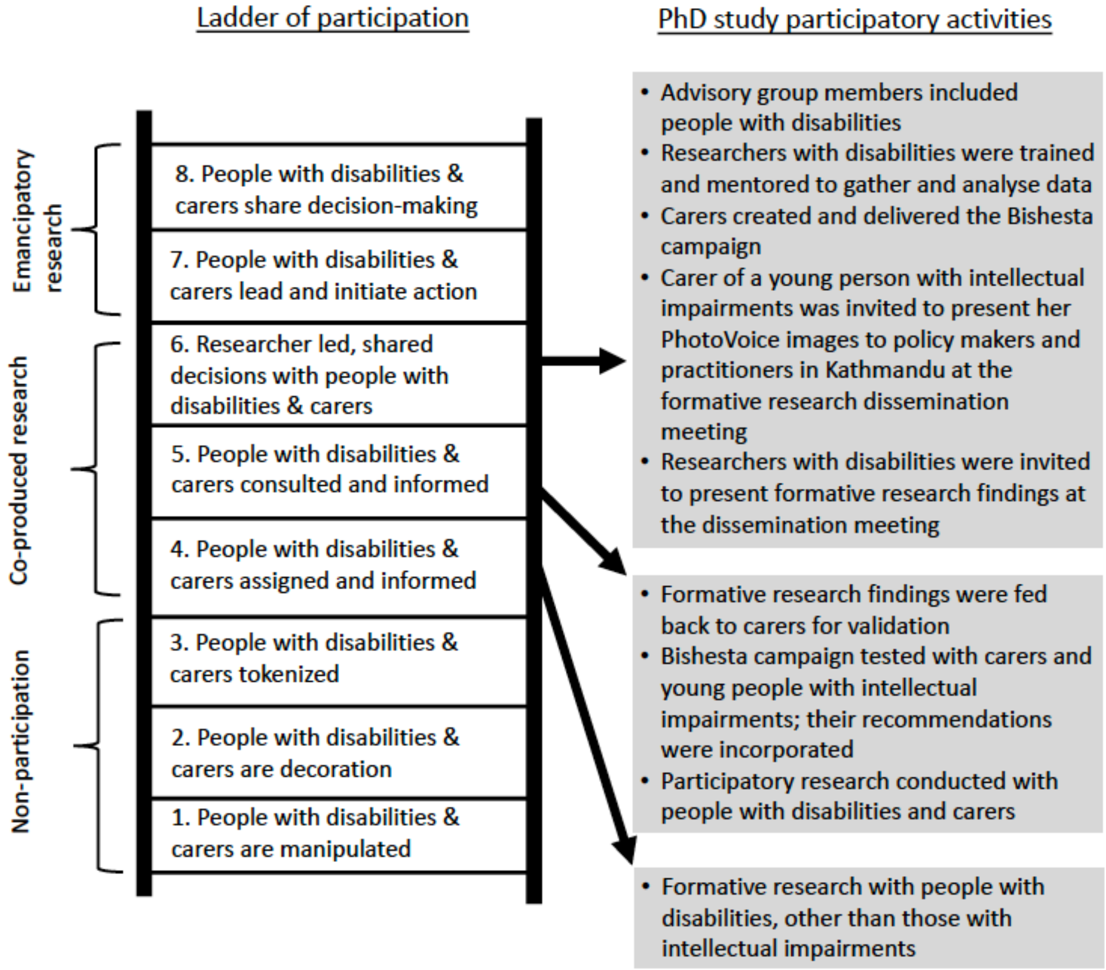


Figure 8 shows that all the participatory research activities are in rungs four to six, thereby demonstrating that this PhD study was co-produced but not emancipatory. PhD activities under the lower rung of co-produced research (number 4) relate to participants without intellectual impairments in the formative research. Arguably, this was appropriate because consulting with these populations on the creation of the Bishesta campaign could be considered unethical because they would have contributed their opinions and time without benefiting or receiving the intervention.

Though the participation ladder is a helpful construct, its progressive structure implies that emancipatory research, whereby people with disabilities have full ownership of the study (190), is the most desirable approach. Danieli and

Woodhams (255) note that those who advocate for emancipatory research believe that anything else ‘perpetuates the oppression of disabled people’ (p.283). Holland et al. (256) calls this the “right on” approach, which assumes that emancipatory research produces more ethical studies; that makes it challenging to scrutinise participatory approaches (pp.1-2). However, this ladder does not consider the potentially important role that non-disabled researchers can play in these studies. I have more than ten years of experience working on inclusive WASH and have deep knowledge and skills that can be applied to develop an inclusive MHM intervention, although I am not disabled myself. Of course, as Nind (257) points out, it is important to understand the motivations of researchers who undertake participatory research. A key driver in this PhD study to use participatory approaches was my political commitment to inclusive development, in line with ‘nothing about us without us’ (257, 258). However, as Conolly (259) explains, participatory approaches and methods can connect political and practical motivations. This is consistent with my experience as I found that participatory methods can be more accessible and encourage co-produced research (257), which is necessary for the BCD approach.

Another issue is that there would also have been ethical implications related to attempting to carry out emancipatory research with people with intellectual impairments in this PhD study. This includes selecting participants who can better understand concepts and communicate thoughts, thus excluding people with more profound impairments (257). As Danieli and Woodhams (255) stress, this equates to researchers using their power to exclude some people with disabilities. In conclusion, this PhD study presented four challenges to participatory research: 1) the study population were young people, with 2) intellectual impairments; 3) the study topic, menstruation, is a taboo topic, particularly in Nepal; and 4) it was conducted in a resource-poor setting. Consequently, emancipatory research was not possible nor desirable.

9.4..2 Participatory methods

Throughout the data collection, participatory research methods were applied to enable all participants to communicate their life experiences, including motive mapping, emoji balls, PhotoVoice and ranking, and the market survey and ranking. Participatory methods were also central to the Bishesta campaign so that information was accessible to everyone. This included the use of role-play, the Bishesta dolls, and visual stories.

PhotoVoice has been applied in other settings to explore 'intensely private' issues (47), including incontinence in Pakistan and Vanuatu (52, 260), sexual identities of people with physical disabilities in South Africa (47), and perimenopause in Ghana (196). Hunt et al. (47) explains that this method allows participants to 'look inside themselves' and draw on external stimuli to represent experiences about the topic explored. In this PhD study, this is demonstrated through Bishnu Sapkota's images of the worshipping site and kitchen inside her home (Fig. 10 and Fig. 11 in Chapter 5, Paper Three). These photos represent her fear that her daughter with intellectual impairments will not follow menstrual restrictions, which could result in the family being cursed by the gods.

PhotoVoice was carried out by people who could understand concepts and the task, which did not include people with intellectual impairments. However, Aldridge (261) did use participatory photographic research methods with people with learning difficulties. She found that it encouraged a focus on participants' capacities instead of their incapacities as it enabled people to depict their experiences in a visual rather than verbal way. With more time and resources, I believe I could have supported young people to carry out PhotoVoice during the feasibility study when communication on MHM had increased. However, participants who were more able to understand the consent process and understand and express abstract concepts, would have participated. This returns to the challenge discussed previously: researchers can exclude people with more profound impairments from participating in such approaches (257).

Though I explored several participatory methods to apply with people who have an intellectual impairment, including Body Mapping (192), Cue Cards (193), Talking Mats (194), and emoji balls and drama, I decided only to try emoji balls and acting as I felt that it would be the most understandable method. For instance, Body Mapping has been used successfully with people with intellectual impairments, but topics explored related to experiences that could be openly spoken about, such as ‘going on a trip’ or ‘moving out of home’ (262). Exploring MHM within the Nepali socio-cultural context is much more sensitive. It also required participants to understand abstract information, such as thoughts and feelings about the Bishesta campaign and menstruation, and then translate these into drawings. I tried using the emoji balls with happy, sad, and angry expressions, and drama with the participants (see Appendix 8: Feasibility Study topic guide: person with a disability). However, using emoji balls relies on the participant’s ability to recognise facial expressions, relate those to their feelings, and then apply that concept to reflect on the Bishesta campaign. In practice, the participants had never seen emoji balls before and were too distracted by them to engage in the activity. Instead, I handed one campaign component to the young person at a time; they reacted, we observed and recorded their response, and then inferred their ‘communicative intent’ (263) (see Chapter 6). This supports Ware’s belief that it is very difficult for people with ‘profound and multiple learning difficulties’ to intentionally communicate their views, beliefs and ideas (263). Ware explains that these populations are at the ‘pre-intentional’ stage whereby they react to stimuli, which others can observe and interpret. This is further discussed in the next section.

9.4..3 Working with carers

As explained in Chapter 2, carers who participated in the PhD study were a mix of paid professionals and female family members. However, these two groups’ experiences of providing MHM support to people with intellectual impairments were similar. For instance, in the qualitative study (Chapter 5, Paper Three), 11 carers were family members (10 mothers and one aunt), and two were professionals. All carers, regardless of position, reported that they were unsupported, felt overwhelmed and frustrated, and worried that the person would not adhere to the menstrual restrictions. Many withheld MHM information from the person with intellectual impairments because they did not believe they would understand it. Of the carers who participated in the Bishesta campaign, seven were professional carers, and three were family members (two mothers and one sister). Both groups reported satisfaction and demand for the Bishesta campaign (Chapter 8, Paper Six).

As introduced in Chapter 2 (*People with intellectual impairments* section), it can be challenging to hear the 'direct voice' (165) of a person with intellectual impairments because the participant might not fully understand the informed consent process, they might not engage in the interview process, or not for long, or they might be unresponsive. For these reasons, I was unable to interview people with intellectual impairments directly and instead relied on proxy responses. I tried to minimise potential research bias by 1) interviewing key informants who have existing relationships with carers during the policy analysis and the Feasibility study, 2) triangulating findings across different respondents, and 3) applying methods triangulation. I also tried to reduce possible bias when observing participants in the Feasibility study by asking the carer to sit behind the participant during our interaction. When the participant was engaged, this worked well. The approaches did not work with two participants who had very limited communication and language abilities, often repeated words or questions rather than answering them, and were hyperactive and restless. A greater focus on their emotional, bodily (such as gestures), nonverbal, and sensory forms of communication was required to understand these participants' reactions to the Bishesta campaign. This would have needed more time and support from carers to appreciate these behaviours and forms of communication. Such approaches could be applied in future studies.

9.4..4 Working with researchers with disabilities

The research team included two people with disabilities, Anita and Amrita, who had visual and mobility impairments, respectively, and who were mentored and coached throughout the data collection to develop their research skills. They also were involved in data analysis (e.g. at the end of each day, the research team met to discuss emerging findings) and were invited to disseminate findings to key stakeholders (though they declined). As depicted in Figure 8, these activities are on the seventh rung of the participation ladder within co-production, because the disabled researchers did not have key decision-making responsibilities, nor did they have full ownership of the study.

Key benefits related to including researchers with disabilities were identified. For instance, while analysing the transcriptions, Amrita showed a strong understanding of the situation of a participant who also had a spinal cord injury. One carer expressed surprise to be interviewed by Amrita, as she did not think that a person with disabilities could be educated or independent, so her assumptions were positively challenged. However, as a wheelchair user, Amrita could not get to every interview site in the formative research as the route was inaccessible. Sanitation facilities were also inaccessible during data collection and within our accommodation. Though the latter was rectified, the researcher limited her food and water intake so she would not have to use a toilet during data collection, and she became increasingly withdrawn and disengaged with the research. Such challenges have been documented in other studies, but these experiences raise important ethical and safeguarding issues which must be considered and carefully managed (264). Accessing households was less of a challenge for Anita as Shubha or I guided her across any rugged terrain.

Involving people with disabilities as researchers did not necessarily mean that all data gathered was improved or without bias. Disability is not homogenous, so people with the same impairment may experience menstruation very differently, or a person with a visual impairment may find it difficult to understand a person with an intellectual impairment’s experiences. During the research team training before formative research data collection, we discussed researcher bias and reflected on this at the end of each day's interviewing. However, as Bourke (257, 265) explains, acquiring research skills are important, but that is not enough to become a researcher. Therefore, a key concern was that the two researchers did not have rigorous academic training. Academics spend years learning how to design studies, formulate research questions, analyse data and produce articles, so arguably, it is unrealistic to think that people with disabilities without research backgrounds could be equipped within the timeframe of one project to lead and fully own a study (which would be emancipatory research). However, there is currently a dearth of skilled academics with disabilities, so training people with disabilities in research methods is an appropriate intermediate step.

The interview process

As explained in Chapter 2, Section 2.5, I did not attend all interviews because my presence as a white foreigner could influence the interviews and so that the Nepali research team could interact with participants without the need for translation. I observed several strengths and limitations related to this approach, which I reflect on in this section, as well as the potential effect my presence may have had on the interviews.

During interviews I conducted, sometimes the translator (a member of the research team) would listen to the participant's answers and then summarise their response instead of translating their words simultaneously. Thus they might have forgotten the richness of the exchange and therefore not have translated all the 'contextual information' (206), which gives meaning (e.g. humour, sarcasm) to words used. I managed this by reminding the team of the importance of striving for simultaneous interpretation (266) and reflecting on the interviews, potential research bias, and collaboratively analysing data at the end of each day. This is in line with Green and Thorogood's advice that translators "should not be just technical assistants, but a vital part of the research team" (206). In the future, I will spend more time explaining the importance of the translator's role and techniques during research team training before data collection.

Through reading interview transcripts, it was clear that a good level of rapport existed between the participants and Nepali researchers in several interviews led by them. It is likely that the lack of translation contributed to this and enabled the conversation to flow fluidly. However, when present at the interview, I could probe fully into pertinent issues. Occasionally, the less experienced Nepali researchers did not do this effectively, which only came to light when reading the transcripts after data collection. In subsequent studies in Cambodia and Bangladesh, I have requested that transcripts are sent to me during data collection so that I can mentor the team to probe more fully in future interviews.

My influence on interviews was important during the study. As participants may have viewed me as a foreign, privileged, educated woman, I was cognisant of 'social desirability bias', in which respondents underreport attitudes and behaviours that could be perceived as undesirable (267), and 'acquiescence bias', whereby participants are positive about whatever the researcher asks or presents (268). I attempted to manage this by taking time to understand the challenges, asking what a third party thinks of a particular issue so that the participant could project their own opinions onto others, as well as comparing responses across different participants and applying methods triangulation.

I also employed these approaches to policy makers who may have answered my questions to reflect WaterAid's policy influencing agenda. In one interview, the respondent was very generous with their time and gave extensive answers to my questions. Still, I thought some of their answers, such as those about the Government of Nepal's commitment to GESI and applying these principles in poverty reduction strategies, were politically astute. Therefore, I asked the same question in several different ways and probed extensively. To an extent, these strategies worked, but I left the interview feeling that the participant had projected the political reality that they wanted to convey. I discussed this thoroughly with WaterAid Nepal staff and explored the issues with other key informants to investigate multiple viewpoints and understand the context, challenges, and opportunities more fully. Findings are captured and discussed in Chapter Four, Paper Two.

In research, evidence is often generated to influence policy, so study participants may not directly benefit from sharing their experiences. Fortunately, I generated evidence and developed an intervention that addressed participants' requirements.

For instance, I noted growing trust and rapport between myself and the carers and one of the young people with intellectual impairments whom I interviewed and interacted with in the *Build* and *Evaluate* steps. I believe carers felt their views were listened to and enacted on through the intervention, and the young person's confidence increased through interacting with more people outside her home who spoke to her with respect and were interested in her opinions.

Finally, many participants with disabilities and carers asked for education or employment assistance during the qualitative study. At the start of the interview, the researchers explained that they represented WaterAid and the London School of Hygiene & Tropical Medicine. Hence, participants understood that we were all representing external organisations working on poverty reduction, regardless of nationality. As such I did not receive more requests for support than my Nepali counterparts.

The application of conceptual models of disability in Nepal

Despite existing definitions of disability (introduced in Chapter 1), disability is highly culturally variable (11). Though the Government of Nepal incorporates the ICF framework by including the UN CRPD's definition of disability in its Disability Rights Act (134, 135), this PhD study has revealed that this differs to the way individuals define disability. Key informants selected for the policy analysis focused on the impairment when discussing disability (2). Some people with disabilities and carers who participated in the qualitative study viewed disability as a curse: "I am already suffering like this and people say that my disability is a curse" (participant with a mobility impairment) (3). Thus demonstrating a prevailing focus on the individual's impairment across policy makers, people with disabilities, and carers, which is in line with the medical and charity model of disability rather than the more comprehensive ICF framework. As is seen in this PhD study, this can result in citizens not demanding their rights and the perception that the inclusion of disability in poverty reduction strategies is optional.

Encouraging a conceptual shift from the medical model of disability to the ICF framework is implicit within the Bishesta campaign. For instance, in the qualitative study carers reported withholding MHM information from people with intellectual impairments because they thought the young person did not have the intellectual capacity to understand it or manage menstruation. This aligns with the medical model of disability. Within the Bishesta campaign, activities aimed to improve the young person's confidence, autonomy, and inclusion through MHM; this contributes to enhancing 'participation' in the ICF framework (8). The target behaviour 'do not show blood in public' also relates to this: if a young person uses a menstrual material, changes it outside the home, and disposes of it hygienically, the carer may be less inclined to curtail the young person's participation during menstruation. The provision of 'period packs' that support MHM correlates to 'environmental factors' in the ICF framework. The carers' three target behaviours are intended to convey the importance of MHM and the provision of menstrual care, which relates to 'personal factors' in the ICF framework. However, potential changes in participants' perceptions of disability were not explored explicitly in the Feasibility study (Chapter 8, Paper Six).

Feasibility assessment

As stated in Chapter 2 (section 2.3), Bowen et al.'s Feasibility study framework complements the BCD by providing a more detailed approach to assessing an intervention's feasibility. For instance, outcome indicators were identified for the adoption of key target behaviours (which is in line with the BCD) and each of the areas of focus in the Feasibility study framework. Outcome indicators included '85% of participants attended three group training sessions' (*Demand*) and 'a desire to expand the intervention into other areas of Nepal' (*Practicality*) (Appendix 7 presents the outcome indicators). Findings from the *Evaluate* step showed that the Bishesta campaign is feasible in the small sample size, but challenges to feasibility did arise. These issues are discussed in Chapters 7 (Papers Five) and 8 (Chapter Six) and in 'Implications for scale and practice' within this section.

A limitation of Bowen et al.’s Feasibility study framework became apparent through its application in this PhD study. There is no guidance on how to weight challenges to feasibility across each area of focus. For instance, if costs are high (*Practicality*), is that less or more critical than unused campaign components *(Demand)*?

Other authors have also identified concerns in the use of Feasibility studies. Hallinberg et al. (269) conducted a systematic review of guidance about whether and how to proceed from a feasibility study to a full-scale evaluation, which includes Bowen et al.’s framework and 29 other resources. The authors argue that many public health interventions move too quickly to evaluation but fail because of issues which should have been identified and addressed during a feasibility study. The review concluded that inadequate guidance to assess which issues must be resolved before investing in a full-scale evaluation was prevalent across all included studies. Where efforts were made, approaches ranged from using a traffic light system with scales of acceptability (270, 271), subjective assessments of what was deemed feasible and acceptable for specific groups and contexts (272), to favouring qualitative over quantitative methods to explore reasons for the issues (271, 273). Authors of studies which suggest such methods recommended returning to the pilot study stage if ‘major modifications’ are necessary, but this term was not defined (274-276). Eldridge et al*.* (270, 271) went further and proposed using a traffic light system to indicate the seriousness of the challenges to feasibility. The authors suggest that measures ‘below a lower threshold indicate that the intervention is not feasible [red], above a higher threshold that it is feasible [green], and between the two that it might be feasible if appropriate changes can be made [amber]’ (text within brackets are added). However, ascertaining the measurement is subjective.

I subjectively assessed the components of the Bowen Feasibility study as it applied to the Bishesta campaign to identify elements that warranted revision before progression to an evaluation in collaboration with my PhD supervisors. The results are presented in Table 7. The traffic light system is applied to show the level of concern against each ‘challenge to feasibility’ of the study, and ‘actions required to address the challenge’ are presented. The most significant concerns (marked orange) are implementation (need for a one-to-one facilitator for the intervention) and practicality (high cost per head of the intervention). These are discussed more fully in the ‘Implications for scale and practice’ section in this Chapter.

Table 7. Enablers and challenges to feasibility of the Bishesta campaign

Area of focus	Outcome indicator	Enablers of feasibility	Challenges to feasibility	Actions required to address the challenge
Acceptability	• 50% of young people and carers recognised as Bishesta households • Carers reporting that they and / or the young person positively benefited from the involvement in the Bishesta programme	• Facilitators were happy with the training and campaign manual • Carers were satisfied with campaign content, delivery and facilitators • Carers said the young people would continue using campaign components • DSSN facilitators and WaterAid wished to continue delivering the Bishesta campaign and expand it into other areas of Nepal	• None	• N/A
Demand	• 85% of participants attended three group training sessions • 50% of young people and carers recognised as Bishesta households • Carers reporting that they and / or the young person positively benefited from the involvement in the Bishesta programme	• 80% of campaign components were used • Professional carers independently repeated the campaign content with young people who were not enrolled in the campaign • Carers (family members and professionals) requested to be involved in a future intervention	Menstrual calendar and pain bangle were too complicated and were not used	Delete menstrual calendar and pain bangle from campaign components
Implementation	• All group training delivered as planned	• Two of the three group training sessions delivered as planned	One group training session was delivered	N/A because it did not have a negative impact

	• Cost per head is in line with the food hygiene behaviour change pilot study in Nepal (181)	• All campaign materials and content delivered as intended • Household monitoring visits were delivered as planned	with three instead of five facilitators	on changing target behaviours
			Young people with severe intellectual impairments require one-to-one facilitator support	Advocate for disability inclusive MHM interventions to raise awareness about the importance of resourcing the support requirements for people with severe intellectual impairments
Practicality	• 50% of young people and carers recognised as Bishesta households • Carers reporting that they and / or the young person positively benefited from the involvement in the programme • Intervention could be delivered alongside general MHM interventions or existing disability programmes • Desire to expand the programme into other areas of Nepal	• Improvements across all target behaviours • Participants were able to carry out all the intervention activities	High cost per head - $1240 (estimated reduction to $90 if delivered to 1000 young people)	Reduce campaign components (see *Demand*), increase sample size to reduce campaign component production costs, compare costs with interventions for people with disabilities and their care

	• Facilitators reporting effective delivery of the group training sessions	🟨

Other key strengths and limitations of the approach

In addition to the key strengths detailed in the individual papers, this PhD study included the development of the first MHM behaviour change intervention for people with intellectual impairments and their carers. This is important as MHM is a neglected topic globally; people with intellectual impairments are more disadvantaged than people with sensory or physical impairments and are at risk of exclusion from development interventions (12).

Within the *Deliver* step, the campaign is delivered through ‘touchpoints’ identified in the *Create* step. Gathering process monitoring data and conducting a process and outcome evaluation (*Evaluate*), which was guided by Bowen et al.’s Feasibility study framework, allowed a systematic, evidence-based and step-wise approach.

I brought practical knowledge to this research study and MHM intervention development with nearly two decades’ experience in WASH and international development and mainstreaming disability inclusion and gender equality within WASH policies and programmes. I understood the WASH sector, its actors, and the challenges facing practitioners and policymakers, so I was informed to develop an intervention that might be acceptable.

Several limitations should be considered when interpreting the results in this PhD thesis. Due to funding requirements, the study's intervention development and data collection were conducted within 15 months, between September 2017 (formative research) and December 2018 (feasibly study). This tight timeframe meant that the feasibility study was conducted one month after the intervention ended. Consequently, there may have been an overestimation of the feasibility of the intervention, although there is limited consensus about how to define ‘sustained’ or ‘maintained’ behaviour change. For instance, Prochaska & DiClemente (277) and Prochaska et al. (278) suggest timeframes, Birian et al. (176) use six months in their handwashing behaviour change campaign in India, as does Greenland et al. (279) in their behaviour change intervention to prevent diarrhoea in Zambia. However, Kwasincka et al. (280) completed a systematic review of theoretical explanations for sustained behaviour change across 100 included articles and found a variety of measurements depending on the context, behaviour, and individual factors. In this PhD study, the young person's ability to repeat behaviours without being reminded will vary from person to person and, therefore, must be considered within 'individual factors'. Consequently, setting a timeframe to measure sustained behaviour change may be meaningless.

This study contributes to filling the gap in MHM behaviour change interventions for people with intellectual impairments and their carers. However, within this vacuum, participants may have welcomed any intervention that supported MHM improvement for this population. Limitations related to generalisability, sample size and selection are discussed in section 9.5 under 'generalisability of the intervention' and 'implications for scale and practice'.

Implications for future research

Three key implications for future research arise from the thesis.

More research is required to evaluate the effectiveness of participatory approaches with people with disabilities in low-and middle-income settings. Though studies documenting and critiquing participatory approaches with people with disabilities in LMICs are increasing (281), most of the literature on the concept of participation is from high-income countries (257). These settings have vastly different socio-cultural contexts, so research on this topic in LMICs is needed.

Ware Field (263) identifies an evidence gap in terms of participatory methods, whereby efforts to evaluate participatory methods have not focused on people with multiple and complex intellectual impairments. Therefore, more research is needed to evaluate the use of different participatory methods to support these populations to communicate their views intentionally. Ethical, methodological and practical parameters should be explored throughout the study. For ease, the topic explored should be openly discussed within the study population, such as friendship or going to the shops. Once learning is generated, applying the participatory methods to more private topics, such as MHM could then be explored with this population.

Turning to the feasibility assessment, the Bishesta campaign should be assessed against the remaining four focus areas in Bowen et al.'s (171) Feasibility study framework. These are discussed in section 9.5, under 'generalisability of the intervention', which captures how the Bishesta campaign is being adapted for the humanitarian context in Vanuatu, and within 'implications for scale and practice', where an impact evaluation of the Bishesta campaign in Nepal is presented.

9.5 *Intervention developed*

Appropriateness of the Behaviour Centred Design

The Behaviour Centred Design approach provides a systematic and logical way of generating evidence sequentially to design an intervention: *Assess, Build, Create, Deliver* and *Evaluate* (ABCDE). Here, I consider whether this approach was appropriate for the intervention design and study undertaken and what can be learnt for future research and practice and scaling of the programme.

9.5..1 Use of the BCD to explore a taboo topic

Information was gathered and generated through the Assess and Build steps to understand the current behaviours, the physical, biological, social-environmental settings, and drivers for behaviours, including human motives. Formative research methods recommended within the BCD focus on observing behaviours to understand drivers rather than self-reported data because behaviours are often non-conscious (282). These methods include observation, demonstrations, transect walks, motive mapping, PhotoVoice, identity mapping, and infrastructure monitoring.

The BCD has been used to develop interventions to improve personal hygiene, including handwashing with soap, oral hygiene, food hygiene, and nutrition (176, 181, 182, 184, 185, 282-285). Before this study, the BCD was not used to explore incredibly private topics, such as MHM or develop interventions with and for people with disabilities.

In many LMICs, menstrual blood is believed to be ritually impure or polluting (65). Nepal is often cited as the country that practices the most extreme form of exclusion, Chauupadi, arguably making Nepal one of the most challenging settings to explore menstrual experiences and deliver MHM interventions (286). In this context, observing menstrual behaviours was challenging. For instance, no participant agreed to show the research team their clean reusable menstrual material in the formative research. Consequently, I explored these behaviours through in-depth interviews because rapport and trust could be developed through the interaction. To manage potential bias and weaknesses related to self-reporting behaviours, I conducted more participatory activities (observation, PhotoVoice and ranking, WASH infrastructure monitoring) within or alongside in-depth interviews to triangulate findings (287).

9.5..2 Engagement of creative professionals

The involvement of a creative team in intervention design led to an imaginative, theory-driven campaign with visuals that captured people's attention. I also applied gamification (using game elements such as competition or point scoring to real-world contexts to motivate the adoption of new behaviours or social norms) (288, 289) and the distribution of free campaign components, which both motivated and triggered behaviour change. However, this process was expensive as creative professionals tend to work in the commercial sector, so they typically require high levels of remuneration. Additionally, different campaign components were produced to trigger each target behaviour making the production costly.

Generalisability of intervention

The BCD supports understanding behaviours and what drives those within a specific context and target group. This knowledge contributes to developing a strong possible theory of change for the target behaviour and the development of the intervention for that setting (170). This chimes with Moore et al. (290), who state that public health issues and interventions are very sensitive to context, so implementation in a new setting without adaptation is less likely to result in positive outcomes.

As detailed in Chapter 7, Paper Five, I am piloting the Bishesta campaign with World Vision in the humanitarian sector within Vanuatu. We are following the Behaviour Centred Design's ABCDE approach. We will adapt the intervention based on findings from 1) a systematic review about MHM for people with and without disabilities in emergency settings and 2) formative research with young people, their carers, and key informants to understand if and how the intervention should be adapted before delivering and assessing its feasibility. We are applying Bowen et al.'s Feasibility study but will also follow the ADAPT guidance on adapting and transferring interventions to new contexts (290). The ADAPT guidance provides a framework for involving stakeholders, selecting appropriate interventions, making adaptations, taking decisions on challenges to feasibility (thereby addressing the weakness observed in Bowen et al.'s Feasibility study framework) and reporting.

Unpublished data from our ongoing systematic review highlights an absence of a disability lens in most MHM interventions in humanitarian settings. Emerging findings from the formative research show that over half use pain relief when they have menstrual discomfort, but a few have 'shown blood in public'. More than half of carers provide pain relief, and many report showing love and understanding when the young person is menstruating. Almost half of the carers keep the young person at home during menstruation. This is connected to protecting young people from ridicule if they go out with menstrual blood on their clothes. It is also linked to high levels of gender-based violence in the country, which has the highest rates of violence against women and girls globally (291). In this context, parents keep their daughters at home to protect them. In relation to the contents of hygiene kits distributed during humanitarian emergencies, participants requested a greater choice of menstrual materials and instructions about how to use them. During Cyclone Harold, participants also explained that they could not dry reusable menstrual materials quickly enough because of the high rainfall, so they recommended including more menstrual materials in hygiene kits.

Compared to study findings from Nepal, there is greater communication about MHM within families in Vanuatu, including men, who also provide menstrual care for the individual if required. Carers react less negatively if the young person does not adhere to menstrual restrictions. However, in Vanuatu, 70% of young people use a menstrual material, and 64% know when to change it (compared to 80% and 80%, respectively in Nepal). Additional gaps highlighted in the Vanuatu study were unhygienic disposal of menstrual materials, limited information about MHM, inadequate support to people with intellectual impairments to understand how to manage more independently, and an absence of guidance for carers.

These findings demonstrate the value of taking a BCD approach to understand the context fully, MHM behaviours performed, and the human motives driving these. Beyond changing the Bishesta campaign visuals to suit the Vanuatu context, other adaptations to the intervention include 1) depicting the involvement of men and women in promoting MHM, 2) storing menstrual hygiene kits (which include more menstrual hygiene materials and a greater variety of types with instructions for use), ready for distribution by humanitarian agencies in Vanuatu in the next emergency, 3) including an image of Veivanua (the ni-Vanuatu Bishesta), Vetahenavanua (Perana), and her father leaving home with the menstrual hygiene kit during a cyclone evacuation, and 4) greater emphasis on regularly changing the menstrual material in the visual story.

Implications for other impairment types

In the Bishesta campaign, information is communicated audibly and visually. It is also based on the experiential learning theory (292), (which states that people learn best through experience), as participants learn how to manage their menstruation using the Bishesta dolls. Therefore, the campaign may need to be adapted for people with hearing and visual impairments.

Robles-Bykbaev et al. (293) reports that information on cultural, social and health-related topics for people with hearing impairments is increasingly being delivered online using captioned media and sign language. As sign language is regional, these interventions focus on specific geographical areas. Robles-Bykbaev et al. (293) drew on existing interventions to develop a web-based platform to deliver SRH information through sign language. The authors noted that a major challenge was a lack of Ecuadorian Sign Language of signs for SRH concepts. During the research team training workshop in Nepal (see Chapter 5), we experienced similar limitations. There were no signs for the biology of menstruation and MHM concepts, so we spent a long time explaining these to participants with hearing impairments. Therefore, the first stage of revising the Bishesta campaign for people with hearing impairments would be translating the content into Nepali Sign Language. If signs for MHM terms and concepts are missing, these could be developed between OPDs and professionals working on MHM. The campaign delivery would then incorporate training on these. Group training 1, which includes the Game of Life and the Bishesta Doll sessions, and Group training 3, that covers the visual stories, would be most easily adapted for this population (see Paper Five, Table 2 'outline of group training modules' for more information).

Furthermore, the Water and Sanitation Collaborative Council (WSSCC) developed a tactile book, *As We Grow Up,* to increase understanding about and information on MHM (238, 239); this could be delivered alongside Group training 1 for people with visual impairments.

The formative research findings (Chapter 5, Paper Three) revealed that people with mobility impairments faced difficulties due to a lack of appropriate menstrual materials and inaccessible WASH facilities. These issues are presented in Chapter 1, Table 1. However, an in-depth assessment of the types of menstrual materials available, used and preferred by people with mobility limitations was not explored, so a new menstrual material was not developed in this study. Regarding addressing accessibility of WASH infrastructure, guidance for this already exists (59, 218, 236, 237). Practitioners should be supported to implement these in partnership with people with disabilities.

Implications for scale and practice

This section will discuss the following topics: how to simplify the Bishesta campaign and reduce its costs, the proposed future feasibility assessment, and how the intervention could be delivered in Nepal.

9.5..1 Intervention simplification and cost reduction

The Bishesta campaign has proved acceptable and feasible at a small scale. Within Chapter 8 (Paper Six), it was recommended that the following changes were made to the campaign components: 1) simplify the menstrual calendar, 2) exclude the pain bangle, 3) include a greater emphasis on positive menstrual-related language in the facilitators training and 4) reduce the cost of producing reusable menstrual materials by comparing quality and price across several providers and choosing a more affordable option. Since the pilot study was completed, recommendations one, two, and three have been addressed (294).

As indicated in Table 7, the cost of delivering the pilot study was a concern. A cost-benefit analysis was not conducted as part of this PhD study. However, a comparison of cost per young person to deliver the pilot study was compared against the estimated cost to deliver the campaign to 1000 young people was documented in Chapter 8 (Paper Six), which was $1240 and $90, respectively.

It is difficult to compare the cost of this intervention with other behaviour change interventions in Nepal. Budgets are presented differently across projects, and the target groups differ. For instance, a food hygiene behaviour change campaign pilot study in Nepal cost £103.54 per household ($142.27 at a $1.37 exchange rate) (295). The food hygiene campaign was delivered by local health workers and volunteers through community events attended by six households. It included the production of campaign components designed to trigger behaviour change and ensure these were easy to adopt, which is like the Bishesta campaign (see Chapter 7, Paper Five).

“Juntos” (meaning ‘together’ in Portuguese) is a community-based intervention for children with Congenital Zika Syndrome, which aims to better enable families to support the development of their children with Congenital Zika Syndrome (296). A feasibility study of the Juntos pilot study reported that it cost $440 per participant to attend ten sessions (249). Costs included training facilitators, salaries, and group activities (venue, transport, refreshments and materials). The authors stated that costs could be further reduced by increasing the group sizes and thereby reducing training costs. Neither the food hygiene campaign nor Juntos worked directly with people with intellectual impairments, who required one-to-one or one-to-two facilitation support during the Bishesta campaign delivery.

In conclusion, additional work is required to reduce the cost and assess the cost-effectiveness of the Bishesta campaign.

9.5..2 Proposed future feasibility assessment

As the pilot study focused on the first four areas of focus in Bowen et al.'s feasibility study framework, an assessment of the remaining four is now needed (171). This requires adapting the Bishesta campaign for a new setting (currently underway in Vanuatu) and an assessment of the remaining three areas of focus through an impact evaluation in Nepal (171).

The Bishesta campaign Feasibility study indicated that the intervention could lead to increased confidence, participation, and autonomy of young people with intellectual impairments, as well as a reduction in stress and frustration experienced by some carers (6). Evidence demonstrates that improved mental health and wellbeing can improve immune functioning, physical health, and productivity (297-300). Therefore, the future feasibility assessment will incorporate a cost-benefit analysis to explore these potential wider benefits.

The impact evaluation study population would be young people with intellectual impairments, aged 15-24, who menstruate and live in the Kavre district and Kathmandu Valley, and their carers. Table 8 presents the four areas of focus, with the research questions that the feasibility assessment will answer.

Table 8. Bowen et al.'s feasibility study framework

Area of focus	Topics to investigate	Outcomes of interest	Research questions
Adaptability	To what extent does the Bishesta campaign change target behaviours when amendments are made to the campaign components, and it is delivered in a different setting?	• Level to which similar outcomes are achieved in revised format	• Is the adapted Bishesta campaign suitable for the humanitarian context in Vanuatu?
Integration	To what extent do organisation's systems need to change to integrate the Bishesta campaign in an existing programme in Nepal?	• Perceived fit with organisation's systems • Perceived sustainability • Costs to organisation	• To what extent has the intervention been delivered as intended? • What organisation should deliver the intervention? • How can the intervention be integrated within the delivery organisation's existing self-care programmes? • Is the campaign cost-effective? • What effect does the campaign have on participants' mental health and wellbeing?
Expansion	To what extent can the Bishesta campaign be expanded with a different population or in a different setting in Nepal?	• Fit within organizational culture and vision • Positive or negative effects on organisation • Disruption caused by expansion	• What are the subsequent positive or negative effects on the delivery organisation? • To what extent did the delivery organisation's systems change to integrate the Bishesta campaign in an existing programme, and what were the positive or negative effects on the organisation? • Could the Bishesta campaign be scaled up across the Central Development Region of Nepal?
Limited-efficacy	Does the Bishesta campaign show promise of behaviour change in the target population in Nepal?	• Intended effects of the campaign on target behaviours • Level of sustained behaviours	• What mechanisms for measuring sustained behaviour change for people with intellectual impairments are appropriate? • To what extent have the target behaviours been adopted, and how sustained is the behaviour change?

9.5..3 Proposed future intervention delivery

This section considers the key features required for delivering the intervention in Nepal, based upon the study findings for this PhD. Here, I consider the mode of delivery, the partners, and the key future research needs.

The twin-track approach

In Chapter 1, the twin-track approach, which combines disability-specific interventions and mainstreaming disability inclusion across efforts to increase access to WASH, was introduced. Several organisations and donors promote the twin-track approach in humanitarian and development interventions, focused on WASH, education and health (301-304). However, few evaluations of the approach have been conducted.

From a search of three online databases (PubMed, Medline and EMBASE) for evaluating twin-track approaches for disability-inclusive development, only one relevant peer-reviewed article was found, and none were on WASH (302). Dadun et al. (302) reviewed a socio-economic development intervention that used the twin-track approach to reduce stigma related to leprosy in Indonesia. Authors found that including people with leprosy in microcredit (mainstreaming) without making adjustments (targeting) to meet specific needs was inappropriate. They concluded that applying the twin-track approach contributed to inclusion and sustainability (303).

Some good practice examples exist for using the twin-track approach in WASH, although they have not been formally evaluated. For instance, WaterAid and World Vision have made concerted efforts to apply the twin-track approach. WaterAid committed to reducing WASH inequalities in their global strategy (210), and approaches included recruiting equity and inclusion advisors, investing in staff capacity enhancement, and developing inclusive WASH interventions (304). The latter included the Undoing Inequity project, which aimed to develop an inclusive WASH intervention that addresses barriers to WASH faced by people with disabilities, older adults and people with chronic illnesses in Uganda and Zambia

(305), and the Bishesta campaign in this PhD study. A challenge highlighted in a review of WaterAid's work is moving from seeing inclusive WASH as an 'add-on' to an integral part of the organisation's work (221). World Vision Vanuatu is currently delivering the Laetem Dak Kona project: an inclusive WASH programme targeting people with disabilities and women in the TORBA and SANMA Provinces (306). This includes mainstreaming disability inclusion within MHM interventions. As documented in Chapter 7, Paper Five, and 'Generalisability of the intervention' section above, World Vision and the LSHTM are also piloting the Bishesta campaign in humanitarian settings, which is the targeting aspect of the twin-track approach.

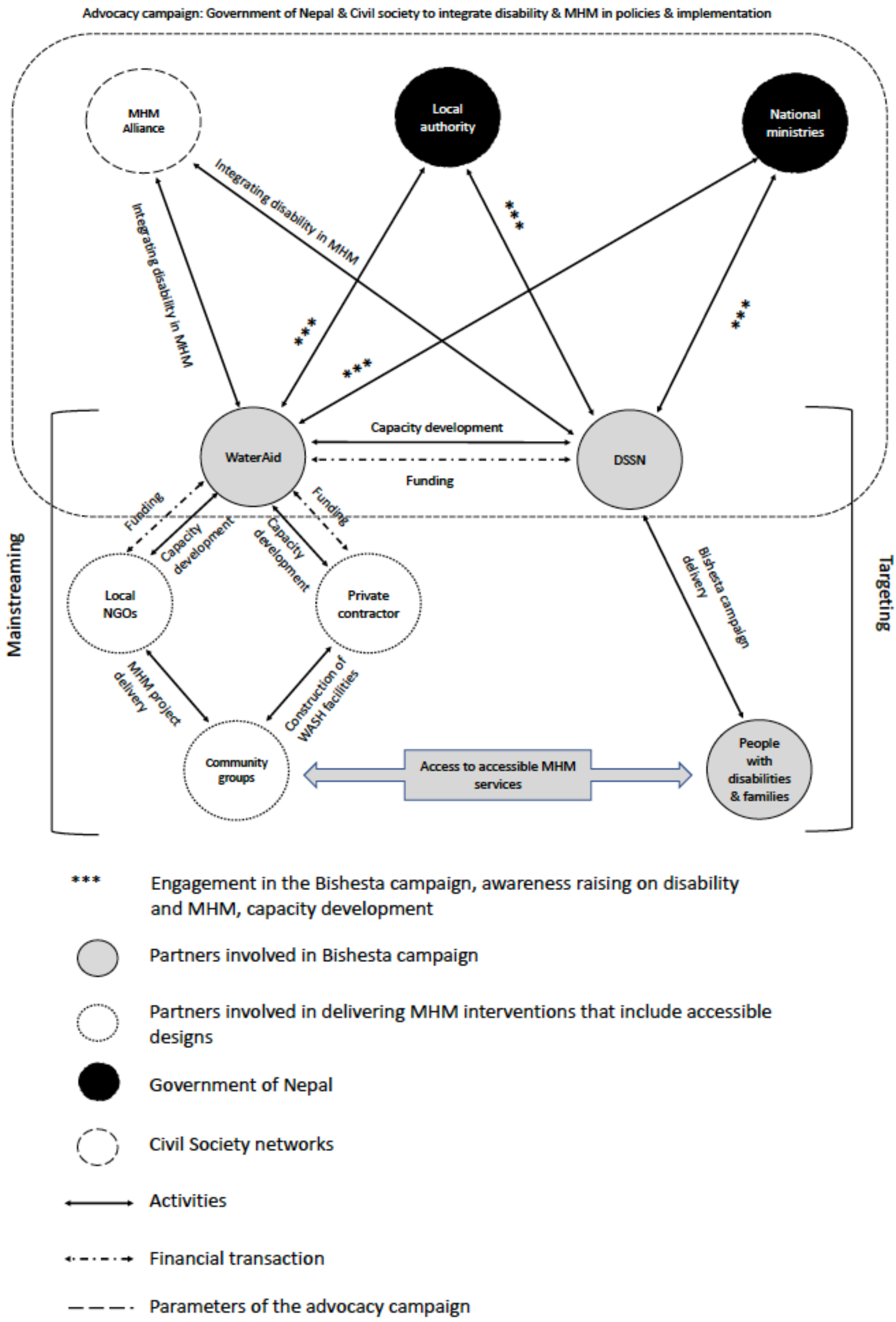
Based on existing evidence, the Bishesta campaign should be the targeted component of an organisation's twin-track approach to embedding disability within their MHM efforts (discussed further below).

Delivery organisations

The Bishesta campaign should be delivered by an organisation that has experience in working with young people with intellectual impairments and their families. Drawing on early childhood development studies, researchers note the importance of situating people with disabilities within their 'existing learning environments', such as residential institutions or daycare centres, and families when designing research and interventions (307, 308). The Juntos intervention is an example of such an approach as it was implemented by mothers of children with Congenital Zika Syndrome (296). A feasibility study of Juntos found it to be acceptable for participants and facilitators and in high demand (249). Additionally, Altundağ and Cakırer Calbayram assessed an intervention delivered by staff in 'special education institutions' in Turkey, which aimed to improve people with intellectual impairments' ability to correctly place a menstrual product in their underwear (240) (see Paper One, Chapter 3). They concluded that the programme improved students' skills.

As explained in Chapter 1 ('MHM intervention delivery' section), MHM efforts are implemented by various stakeholders, ranging from government bodies, international government organisations, and non-government organisations directly and through implementing partner organisations. Pulling together delivery mechanisms of MHM and disability interventions, Figure 9 presents a proposed twin-track approach for WaterAid, which includes the delivery of the Bishesta campaign.

Figure 9. Delivering the Bishesta campaign within the twin-track approach



Within the “mainstream” branch of the proposed WaterAid twin-track approach, WaterAid should continue to work with local NGOs and private contractors to deliver MHM interventions and construct WASH facilities. Information and infrastructure would be fully accessible for people with different impairments. The Bishesta campaign would be delivered through WaterAid’s targeting component, by DSSN, under the CBR approach. Financial investment and capacity development from WaterAid would enhance the sustainability of DSSN and contribute to strengthening disability service providers. DSSN would also strengthen WaterAid’s capacity to understand disability issues more fully. Both outcomes would contribute to filling gaps identified in policy implementation in Nepal (Chapter 4, Paper Two). The Bishesta campaign would be incorporated into DSSN’s existing self-care programmes to enable people with intellectual impairments to live as independently as possible. These are delivered by DSSN staff through their daycare centres. WaterAid’s mainstream MHM intervention would ensure participants of the Bishesta campaign have access to WASH facilities for MHM.

WaterAid and DSSN would work with local authorities and national ministries across the Ministry of Physical Planning and Works, Health and Population, Urban Development, Education, and Water Supply and Sanitation Sector Efficiency Improvement Unit to affect long-term change. They would work to increase government officials’ understanding of disability and MHM issues, inform them of the Bishesta campaign and support the inclusion of disability in MHM relevant policies and guidance documents. These efforts will contribute to addressing gaps identified in Paper Two, Chapter 4 (limited inclusion of disability in policies and guidance relevant to MHM and increasing professional understanding of disability and MHM). This approach draws on the study design of Prasad Gautam’s trial of a food hygiene behaviour change campaign in Nepal (295). This study began with a pilot, which involved relevant Nepal ministries and is now being rolled out by the Ministry of Health and Population, with technical support from WaterAid, through its routine immunisation programme in four districts (309).

Furthermore, a more comprehensive advocacy campaign to influence the Government of Nepal and Civil Society actors to integrate disability within MHM would need to be conducted in the proposed work. Content will draw on evidence generated through this PhD study and WaterAid's twin-track approach as an example of how to mainstream disability within MHM interventions and implement a targeted programme with a disability service provider to facilitate MHM for people with intellectual impairments and their carers. The advocacy campaign should be delivered with and through Nepal's Menstrual Health Management Alliance (310). This has over 50 members; this Alliance works on MHM (including wider sexual and reproductive health), education, awareness, policy development, research and innovation. It advises the Government of Nepal on MHM, promotes MHM at the national and sub-national levels, and facilitates MHM learning and knowledge management.

Further research would need to be conducted to develop Inclusive MHM Checklists and thereby support the integration of disability within MHM efforts in Nepal. These will draw on the development of a COVID-19 Inclusive WASH Checklist, which is based on the EquiFrame, adapted for WASH and was designed to provide guidance for WASH practitioners to integrate disability and ageing in COVID-19 WASH responses (311). However, the two MHM checklists would be based on the EquiFrame adapted for disability and gender and focusing on WASH and MHM, published in Paper Two, Chapter 4. One will focus on supporting policy makers to integrate core concepts of human rights related to disability within relevant MHM policies and guidance documents. The second will contain details on how to ensure disability is included within MHM interventions.

9.6 *Conclusion*

MHM is a recognised global public health issue (175), yet this PhD thesis highlights barriers to MHM for people with disabilities at the global, national, district and household levels. There is a dearth of evidence on disability and MHM at the macro level, meaning MHM interventions targeting this group are not prioritised or resourced. A lack of evidence also exists within Nepal; this leads to limited awareness of the issue and its importance, as well as its absence in national policies. Consequently, MHM for people with disabilities and support for carers is not resourced, so this group is marginalised from existing MHM interventions. The impacts are extreme and encompass isolation, shame and violence, including sterilisation.

This PhD thesis has begun to build an evidence base and has documented the development of the first MHM behaviour change campaign for people with intellectual impairments and their carers. The Behaviour Centred Design was an appropriate approach to systematically developing a complex behaviour change intervention that improved MHM practices within the sample population. It has also shown that if people with intellectual impairments are provided with clear and repetitive MHM information in an engaging way, most appear to be better able to manage menstruation. Furthermore, it demonstrates the benefits of supporting carers to understand menstruation and how to support another individual manage it hygienically and with dignity.

Future research is required to test its efficacy before scaling up. If successful, the Bishesta campaign could be delivered at a larger scale, thus ensuring that a population who is at heightened risk of marginalisation is not habitually excluded from important public health efforts.

Appendix 1. Comparison between the Socio-ecological framework for MHM and the BCD checklist

Socio-ecological framework for MHM		**BCD checklist**	
Factors	Sub factors	Factors	Sub factors
Societal and government policy factors	Policies, strategies and curriculum; training standards and practices; traditional norms, practices and cultural beliefs	Context	Political, programmatic, social
		Behaviour setting	Norms
Environmental and resource availability factors	Water and sanitation facilities including for solid waste management; availability of affordable, usable and culturally appropriate sanitary protection materials	Environment	Physical, biological
		Behaviour setting	Stage
		Context	Economic
Interpersonal factors – disabled person	Relationship with family, carer, healthcare workers, teachers and other people in authority; relationships with peers; perceptions of changes in gender roles post-menarche	Behaviour setting	Roles
		Environment	Social
Interpersonal factors – Carer	Relationship with the family, the disabled person, healthcare workers and other people in authority; relationships with the wider community ; perceptions of changes in gender roles post-menarche	Behaviour setting	Roles
		Environment	Social
Personal factors – disabled person	Knowledge about the biology of menstruation and MHM, information on menstruation and MHM; skills in coping and behavioural adaptions (including pain relief); attitudes, beliefs and feelings about menstruation; ability to manage menstruation independently, and support required	Brains	Executive, motivated, reactive
		Behaviour setting	Roles
Personal factors – Carer	Knowledge about the biology of menstruation and MHM, information on menstruation and MHM; skills in coping and behavioural adaptions (including pain relief); attitudes, beliefs and feelings about menstruation; ability to manage another person's menstruation independently, support required and caring tasks related to MHM	Brains	Executive, motivated, reactive
		Behaviour setting	Roles

Biological factors	Menstrual variations due to age and features of menstrual cycle; intensity of menstruation (pain) and influences on behaviour, health and concentration	Body	Traits, physiology, senses

Appendix 2. Supporting information for Paper One

S1 Checklist. PRISMA Checklist

PRISMA 2009 Checklist – Wilbur et al. 2019

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2,3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4 - 6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	6
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	7, 15 Table 2 Table 3, Table 4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	1, 7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	7-8
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	8-9
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	9, Table 1
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	10, 24, Appendix 2

PRISMA 2009 Checklist – Wilbur et al. 2019

Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Appendix 2
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	9, Table 1

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	16, Table 4, Appendix 2
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Appendix 3
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 3
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Table 4, Appendix 3
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	10 - 22
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Table 4, Appendix 3
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	22 – 24, Figure 1
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	25
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	24 - 25
FUNDING			

Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	26

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

S1 Table. Search String for PubMed

1	developing countr*[MH] OR developing countr*[TIAB] OR developing nation*[TIAB] or developing world[TIAB]
2	least developed countr*[TIAB] OR least developed nation*[TIAB] OR least developed world[TIAB] OR least-developed countr*[TIAB] OR least-developed nation*[TIAB] OR less-developed countr* OR less-developed nation*[TIAB] OR less developed countr*[TIAB] OR less developed nation*[TIAB]
3	under-developed countr*[TIAB] OR under developed countr*[TIAB] OR underdeveloped countr*[TIAB] OR under-developed nation*[TIAB] OR under developed nation*[TIAB] OR underdeveloped nation*[TIAB] OR under-developed world[TIAB] OR under developed world[TIAB] OR underdeveloped world[TIAB] OR under-developed econom*[TIAB] OR under developed econom*[TIAB] OR underdeveloped econom*[TIAB]
4	third world countr*[TIAB] OR third world nation*[TIAB] OR third-world countr*[TIAB] OR third-world nation*[TIAB]
5	low- and middle-income countr*[TIAB] OR low and middle income countr*[TIAB] OR low- and middle-income nation*[TIAB] OR low and middle income nation*[TIAB] OR low- and middle-income world[TIAB] OR low and middle income world[TIAB] OR low- and middle-income econom*[TIAB] OR low and middle income econom*[TIAB] OR low income countr*[TIAB] OR middle income countr*[TIAB] OR low-income countr*[TIAB] OR middle-income countr*[TIAB]OR low income nation*[TIAB] OR middle income nation*[TIAB] OR low-income nation*[TIAB] OR middle-income nation*[TIAB] OR low income world[TIAB] OR middle income world[TIAB] OR low-income world[TIAB] OR middle-income world[TIAB] OR low income econom*[TIAB] OR middle income econom*[TIAB] OR low-income econom*[TIAB] OR middle-income econom*[TIAB]
6	LIC[TIAB] OR LICs[TIAB] OR MIC[TIAB] OR MICs[TIAB] OR LMIC[TIAB] OR LMICs[TIAB] OR LAMIC[TIAB] OR LAMICs[TIAB] OR LAMI countr*[TIAB]
7	Transitional countr*[TIAB] OR Transitional econom*[TIAB] OR Transition countr*[TIAB] OR Transition econom*[TIAB]
8	Asia[MH] OR Africa[MH] OR South America[MH] OR Caribbean region[MH] OR Central America[MH]
9	Afghanistan[TIAB] OR Albania[TIAB] OR Algeria[TIAB] OR American Samoa[TIAB] OR Angola[TIAB] OR Antigua[TIAB] OR Barbuda[TIAB] OR Argentina[TIAB] OR Armenia[TIAB] OR Azerbaijan[TIAB] OR Bangladesh[TIAB] OR Belarus[TIAB] OR Byelarus[TIAB] OR Byelorussia[TIAB] OR Belorussia[TIAB] OR Belize[TIAB] OR Benin[TIAB] OR Bhutan[TIAB] OR Bolivia[TIAB] OR Bosnia[TIAB] OR Herzegovina[TIAB] OR Hercegovina[TIAB] OR Bosnia-Herzegovina[TIAB] OR Bosnia-Hercegovina[TIAB] OR Botswana[TIAB] OR Brazil[TIAB] OR Brasil[TIAB] OR Bulgaria[TIAB] OR Burkina[TIAB] OR Upper Volta[TIAB] OR Burundi[TIAB] OR Urundi[TIAB] OR Cambodia[TIAB] OR Republic of Kampuchea[TIAB] OR Cameroon[TIAB] OR Cameroons[TIAB] OR Cape Verde[TIAB] OR Central African Republic[TIAB] OR Chad[TIAB] OR Chile[TIAB] OR China[TIAB] OR Colombia[TIAB] OR Comoros[TIAB] OR Comoro Islands[TIAB] OR Comores[TIAB] OR Congo[TIAB] OR DRC[TIAB] OR Zaire[TIAB] OR Costa Rica[TIAB] OR Cote d'Ivoire[TIAB] OR Ivory Coast[TIAB] OR Cuba[TIAB] OR Djibouti[TIAB] OR Obock[TIAB] OR French Somaliland[TIAB] OR Dominica[TIAB] OR Dominican Republic[TIAB] OR Ecuador[TIAB] OR Egypt[TIAB] OR United Arab Republic[TIAB] OR El Salvador[TIAB] OR Eritrea[TIAB] OR Ethiopia[TIAB] OR Fiji[TIAB] OR Gabon[TIAB] OR Gabonese Republic[TIAB] OR Gambia[TIAB] OR Georgia[TIAB] OR Ghana[TIAB] OR Gold Coast[TIAB] OR Grenada[TIAB] OR Guatemala[TIAB] OR

	Guinea[TIAB] OR Guinea-Bissau[TIAB] OR Guiana[TIAB] OR Guyana[TIAB] OR Haiti[TIAB] OR Honduras[TIAB] OR India[TIAB] OR Indonesia[TIAB] OR Iran[TIAB] OR Iraq[TIAB] OR Jamaica[TIAB] OR Jordan[TIAB] OR Kazakhstan[TIAB] OR Kenya[TIAB] OR Kiribati[TIAB] OR Republic of Korea[TIAB] OR North Korea[TIAB] OR DPRK[TIAB] OR Kosovo[TIAB] OR Kyrgyzstan[TIAB] OR Kirghizstan[TIAB] OR Kirgizstan[TIAB] OR Kirghizia[TIAB] OR Kirgizia[TIAB] OR Kyrgyz[TIAB] OR Kirghiz[TIAB] OR Kyrgyz Republic[TIAB] OR Lao[TIAB] OR Laos[TIAB] OR Latvia[TIAB] OR Lebanon[TIAB] OR Lesotho[TIAB] OR Basutoland[TIAB] OR Liberia[TIAB] OR Libya[TIAB] OR Lithuania[TIAB] OR Macedonia[TIAB] OR Madagascar[TIAB] OR Malagasy Republic[TIAB] OR Malawi[TIAB] OR Nyasaland[TIAB] OR Malaysia[TIAB] OR Malaya[TIAB] OR Malay[TIAB] OR Maldives[TIAB] OR Mali[TIAB] OR Marshall Islands[TIAB] OR Mauritania[TIAB] OR Mauritius[TIAB] OR Mayotte[TIAB] OR Mexico[TIAB] OR Micronesia[TIAB] OR Moldova[TIAB] OR Moldovia[TIAB] OR Mongolia[TIAB] OR Montenegro[TIAB] OR Morocco[TIAB] OR Mozambique[TIAB] OR Myanmar[TIAB] OR Burma[TIAB] OR Namibia[TIAB] OR Nepal[TIAB] OR Nicaragua[TIAB] OR Niger[TIAB] OR Nigeria[TIAB] OR Pakistan[TIAB] OR Palau[TIAB] OR Palestine[TIAB] OR Panama[TIAB] OR Papua New Guinea[TIAB] OR Paraguay[TIAB] OR Peru[TIAB] OR Philippines[TIAB] OR Romania[TIAB] OR Rumania[TIAB] OR Roumania[TIAB] OR Russia[TIAB] OR Russian Federation[TIAB] OR USSR[TIAB] OR Soviet Union[TIAB] OR Union of Soviet Socialist Republics[TIAB] OR Rwanda[TIAB] OR Ruanda-Urundi[TIAB] OR Samoa[TIAB] OR Samoan Islands[TIAB] OR Sao Tome[TIAB] OR Principe[TIAB] OR Senegal[TIAB] OR Serbia[TIAB] OR Montenegro[TIAB] OR Yugoslavia[TIAB] OR Seychelles[TIAB] OR Sierra Leone[TIAB] OR Solomon Islands[TIAB] OR Somalia[TIAB] OR South Africa[TIAB] OR Sri Lanka[TIAB] OR Ceylon[TIAB] OR Saint Kitts[TIAB] OR St Kitts[TIAB] OR Saint Christopher Island[TIAB] OR Nevis[TIAB] OR Saint Lucia[TIAB] OR St Lucia[TIAB] OR Saint Vincent[TIAB] OR St Vincent[TIAB] OR Grenadines[TIAB] OR Sudan[TIAB] OR Suriname[TIAB] OR Surinam[TIAB] OR Swaziland[TIAB] OR Syria[TIAB] OR Syrian Arab Republic[TIAB] OR Tajikistan[TIAB] OR Tadzhikistan[TIAB] OR Tadjikistan[TIAB] OR Tanzania[TIAB] OR Thailand[TIAB] OR Timor-Leste[TIAB] OR East Timor[TIAB] OR Togo[TIAB] OR Togolese Republic[TIAB] OR Tonga[TIAB] OR Tunisia[TIAB] OR Turkey[TIAB] OR Turkmenistan[TIAB] OR Turkmenia[TIAB] OR Tuvalu[TIAB] OR Uganda[TIAB] OR Ukraine[TIAB] OR Uruguay[TIAB] OR Uzbekistan[TIAB] OR Vanuatu[TIAB] OR New Hebrides[TIAB] OR Venezuela[TIAB] OR Vietnam[TIAB] OR Viet Nam[TIAB] OR West Bank[TIAB] OR Gaza[TIAB] OR Yemen[TIAB] OR Zambia[TIAB] OR Zimbabwe[TIAB] OR Rhodesia[TIAB]
10	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9
11	Developed countr*[MH] or developed countr*[TIAB] OR developed nation*[TIAB] OR developed world[TIAB] OR first world[TIAB] OR first-world[TIAB] OR first world countr*[TIAB] OR first-world countr*[TIAB]
12	most developed countr*[TIAB] OR most developed nation*[TIAB] OR most developed world[TIAB] OR most-developed countr*[TIAB] OR most-developed nation*[TIAB] OR more-developed countr* OR more-developed nation*[TIAB] OR more developed countr*[TIAB] OR more developed nation*[TIAB]
13	over-developed countr*[TIAB] OR over developed countr*[TIAB] OR overdeveloped countr*[TIAB] OR over -developed nation*[TIAB] OR over developed nation*[TIAB] OR overdeveloped nation*[TIAB] OR over-developed world[TIAB] OR over developed world[TIAB] OR overdeveloped world[TIAB] OR over-developed econom*[TIAB] OR over developed econom*[TIAB] OR overdeveloped econom*[TIAB] OR advanced econom*[TIAB] OR advanced econom*[TIAB]

14	first world countr*[TIAB] OR first world nation*[TIAB] OR first-world countr*[TIAB] OR first-world nation*[TIAB]
15	High-income countr*[TIAB] OR high income countr*[TIAB] OR high-income nation*[TIAB] OR high-income world[TIAB] OR high income world[TIAB] OR high econom*[TIAB] OR high income econom*[TIAB] OR high-income econom*[TIAB]
16	HIC[TIAB] OR HICs[TIAB] OR HIN[TIAB] OR HINs[TIAB] OR HIW[TIAB] OR HE[TIAB] OR HEs[TIAB] OR HIE[TIAB] OR HIEs[TIAB] OR MDC[TIAB] OR MDCs[TIAB]
17	Middle east[MH] OR North Africa[MH] OR Europe[MH] OR Central Asia[MH] OR North America[MH] OR East Asia[MH] OR West Asia[MH] OR Australasia[MH]
18	Andorra[TIAB] OR Gibraltar[TIAB] OR Oman[TIAB] OR Antigua[TIAB] OR Barbuda[TIAB] OR Greece[TIAB] OR Aruba[TIAB] OR Greenland[TIAB] OR Portugal[TIAB] OR Australia[TIAB] OR Guam[TIAB] OR Puerto Rico[TIAB] OR Austria[TIAB] OR Hong Kong[TIAB] OR Qatar[TIAB] OR The Bahamas[TIAB] OR Hungary[TIAB] OR San Marino[TIAB] OR Bahrain[TIAB] OR Iceland[TIAB] OR Saudi Arabia[TIAB] OR Barbados[TIAB] OR Ireland[TIAB] OR Seychelles[TIAB] OR Belgium[TIAB] OR Isle of Man[TIAB] OR Singapore[TIAB] OR Bermuda[TIAB] OR Israel[TIAB] OR Sint Maarten[TIAB] OR British Virgin Islands[TIAB] OR Italy[TIAB] OR Slovak Republic[TIAB] OR Brunei Darussalam[TIAB] OR Japan[TIAB] OR Slovenia[TIAB] OR Canada[TIAB] OR Korea Republic[TIAB] OR Spain[TIAB] OR Cayman Islands[TIAB] OR Kuwait[TIAB] OR Saint Kitts and Nevis[TIAB] OR Channel Islands[TIAB] OR Latvia[TIAB] OR Saint Martin[TIAB] OR Chile[TIAB] OR Liechtenstein[TIAB] OR Sweden[TIAB] OR Croatia[TIAB] OR Lithuania[TIAB] OR Switzerland[TIAB] OR Curaçao[TIAB] OR Luxembourg[TIAB] OR Taiwan[TIAB] OR Cyprus[TIAB] OR Macao[TIAB] OR Trinidad and Tobago[TIAB] OR Special Administrative Region China[TIAB] OR Czech Republic[TIAB] OR Malta[TIAB] OR Turks and Caicos Islands[TIAB] OR Denmark[TIAB] OR Monaco[TIAB] OR United Arab Emirates[TIAB] OR Estonia[TIAB] OR Nauru[TIAB] OR United Kingdom[TIAB] OR England[TIAB] OR Ireland[TIAB] OR Scotland[TIAB] OR Wales[TIAB] OR Faroe Islands[TIAB] OR Netherlands[TIAB] OR United States[TIAB] OR Finland[TIAB] OR New Caledonia[TIAB] OR Uruguay[TIAB] OR France[TIAB] OR New Zealand[TIAB] OR Virgin Islands[TIAB] OR French Polynesia[TIAB] OR Northern Mariana Islands[TIAB] OR Germany[TIAB] OR Norway[TIAB]
19	11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18
20	Disabled person[MH] OR disabled person*[TIAB] OR person with disabilit* [TIAB] OR persons with disabilit*[TIAB] OR people with disability*[TIAB] OR handicapped person*[TIAB] OR handicapped people[TIAB]
21	Physical impair*[TIAB] or physically impair*[TIAB] OR physical deficien*[TIAB] OR physically deficien*[TIAB] OR physical disab*[TIAB] OR physically disab*[TIAB] OR physical handicap*[TIAB] OR physically handicap*[TIAB] OR physically challeng*[TIAB]
23	Cerebral palsy[MH] OR Cerebral pals*[TIAB] OR spinal dysraphism[MH] OR Spina bifida[TIAB] OR muscular dystrophies[MH] OR Muscular dystroph*[TIAB] OR Arthritis[MH] OR Arthriti*[TIAB] OR Osteogenesis imperfecta[TIAB] OR Musculoskeletal Abnormalities[MH] OR Musculoskeletal abnormalit*[TIAB] OR Musculo-skeletal abnormalit*[TIAB] OR Muscular abnormalit*[TIAB] OR Skeletal abnormalit*[TIAB] OR limb abnormalit*[TIAB] OR Chronic Brain Injury[MH]OR Amputation*[TIAB] or Amputee[TIAB] OR Clubfoot[TIAB] OR Poliomyelitis[MH] OR Polio*[TIAB] OR Paraplegia[MH] OR Paraplegi*[TIAB] OR Paralys*[TIAB] OR Paralyz*[TIAB] OR Hemiplegia[MH] OR Hemiplegi*[TIAB]

24	Hearing loss[MH] OR Hearing loss*[TIAB] OR hearing impair*[TIAB] OR hearing deficien*[TIAB] OR hearing disable*[TIAB] OR hearing disabili*[TIAB] OR hearing handicap*[TIAB] OR acoustic loss*[TIAB] OR acoustic impair*[TIAB] OR acoustic deficien*[TIAB] OR acoustic disable*[TIAB] OR acoustic disabili*[TIAB] OR acoustic handicap*[TIAB] OR Deaf*[TIAB] or hearing loss[TIAB]
25	Blindness[MH] OR vision loss*[TIAB] OR vision impair*[TIAB] OR vision deficien*[TIAB] OR vision disable*[TIAB] OR vision disabili*[TIAB] OR vision handicap*[TIAB] OR visual loss*[TIAB] OR visual impair*[TIAB] OR visually impair*[TIAB] OR visual deficien*[TIAB] OR visually deficien*[TIAB] OR visual disable*[TIAB] OR visually disable*[TIAB] OR visual disabili*[TIAB] OR visually disabili*[TIAB] OR visual handicap*[TIAB] OR visually handicap*[TIAB] OR low vision[TIAB] OR reduced vision[TIAB] OR (blind*[TIAB] NOT double blind*[TIAB] NOT blinding[TIAB] NOT triple blind*[TIAB])
26	Mental disorder*[TIAB] OR Schizophreni*[TIAB] OR Psychosis[TIAB] OR psychoses[TIAB] OR Psychotic Disorder*[TIAB] OR Schizoaffective Disorder*[TIAB] OR Schizophreniform Disorder*[TIAB] OR schizophrenia and disorders with psychotic features[MH] OR Dementia*[TIAB] OR Alzheimer*[TIAB]
27	intellectual illness*[TIAB] OR intellectual impair*[TIAB] OR intellectual deficien*[TIAB] OR intellectual disable*[TIAB] OR intellectual disabili*[TIAB] OR intellectual handicap*[TIAB] OR intellectual retard*[TIAB] OR mental ill[TIAB] OR mentally ill[TIAB]OR mental illness*[TIAB] OR mental impair*[TIAB] OR mentally impair*[TIAB] OR mental deficien*[TIAB] OR mentally deficien*[TIAB] OR mental disable*[TIAB] OR mentally disable*[TIAB] OR mental disabili*[TIAB] OR mental handicap*[TIAB] OR mentally handicap*[TIAB] OR developmental impair*[TIAB] OR developmentally impair*[TIAB] OR developmental deficien*[TIAB] OR developmentally deficien*[TIAB] OR developmental disable*[TIAB] OR developmentally disable*[TIAB] OR developmental disabili*[TIAB] OR developmentally disabili*[TIAB] OR developmental handicap*[TIAB] OR developmentally handicap*[TIAB] OR developmental retard*[TIAB] OR developmentally retard*[TIAB] OR psychological ill[TIAB] OR psychologically ill[TIAB] OR psychological illness*[TIAB] OR psychological impair*[TIAB] OR psychologically impair*[TIAB] OR psychological deficien*[TIAB] OR psychologically deficien*[TIAB] OR psychological disable*[TIAB] OR psychologically disable*[TIAB] OR psychological disabili*[TIAB] OR psychological handicap*[TIAB] OR psychologically handicap*[TIAB]
28	Learning disorders[MH] OR learning disorder*[TIAB] OR communication disorders[MH] OR communication disorder*[TIAB] OR language disorder*[TIAB] OR speech disorder*[TIAB] OR speech disorder*[TIAB]
29	Pervasive Child Development Disorders[MH] OR autistic[TIAB] OR autism[TIAB] OR asperger*[TIAB] or dyslexi*[TIAB] OR Down’s Syndrome[TIAB] OR Down Syndrome[TIAB] OR Mongolism[TIAB] or Trisomy 21[TIAB]
30	21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29
Menstrual Hygiene Management	
31	Menstrua* OR menses OR menarche OR catamenia OR vagiosis OR candidiasis OR hygiene
32	10 OR 19 AND 30 AND 31
33	Limit 32 to English language, publication type=conference paper, journal article, non-peer reviewed publications, annual report, journal issue, thesis, miscellaneous, case reports, comparative study, evaluation studies, government publications, meta-analysis, review, systematic reviews

S2 Table. Quality assessment of all studies

	Altundag 2015	Carnaby 2002	Charlifue 1992	Chou 2009	Chou 2012	Patage 2015	Goldstein 1988	Hamilton 2011	Ibralic 2010	Kirkham 2013	Kyrkou 2005	Lin 2011	Lin 2011	Mason 2007	Obaydi 2008	Perrin 1976	Ranganath 2012	Rodgers 2005	Thapa 2017	Van der Merwe 1987	van Schrojenstein Lantman-deValk 2011	White 2016
Quantitative studies																						
1. Sampling methods																						
1.1 Was the sample representative of the broader population?	3	N/A*	3	2	N/A	3	2	3	2	3	2	3	3	N/A	2	N/A	1	2	N/A	3	3	N/A
1.2 Was recruitment of participants appropriate to the study question?	3	N/A	3	3	N/A	3	3	3	2	3	3	3	3	N/A	3	N/A	2	3	N/A	3	3	N/A
1.3 Adequate sample size (>100 or sample size calculation undertaken)	2	N/A	3	2	N/A	2	2	1	2	3	2	3	3	N/A	2	N/A	1	3	N/A	1	3	N/A
1.4 Response rate reported and acceptable (≥70%)	2	N/A	3	3	N/A	1	1	1	2	2	2	3	3	N/A	2	N/A	1	2	N/A	1	3	N/A
1.5 Control group is appropriate, clearly defined (if applicable)	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A
2. Data collection																						
2.1 Sample characteristics clearly described	1	N/A	3	3	N/A	3	3	3	2	3	1	3	3	N/A	2	N/A	1	3	N/A	3	3	N/A
2.2 Means of collecting data (e.g. assessment tool, questionnaire, etc) valid, reliable	2	N/A	3	3	N/A	3	3	3	3	3	2	3	3	N/A	3	N/A	3	2	N/A	2	2	N/A
3. Data analysis / interpretation																						
3.1 Potential confounders	1	N/A	1	2	N/A	2	2	1	2	2	2	2	2	N/A	2		1	1		1	2	

taken into account during the analysis and interpretation																						
3.2 Tests for statistical significance undertaken, presented	2	N/A	3	3	N/A	1	3	3	3	3	1	3	3	N/A	3		1	3		1	3	
Qualitative studies (adapted from RATS)																						
1. Study design																						
1.1 Study design is appropriate to the research question	N/A	1	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	2	N/A	N/A	3	N/A	N/A	3
1.1.2 Could a quantitative approach have worked better?	N/A	1	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	2	N/A	N/A	3	N/A	N/A	3
1.1.3 Justified why a particular method was chosen, e.g.: a)Interviews: experience, perceptions, behaviour, practice; b) Focus groups: group dynamics, convenience, non-sensitive topics; c) Ethnography: culture, organizational behaviour, interaction	N/A	1	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	2	N/A	N/A	3	N/A	N/A	3
2. Sampling methods																						
2.1 Criteria for selecting study sample is appropriate, e.g. purposive (diversity of opinion), random (generalizable	N/A	2	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	2	N/A	N/A	3	N/A	N/A	3

to broader population), volunteer (hard to reach groups)																						
2.2 Details given of how recruitment was conducted and by whom	N/A	2	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	3	N/A	N/A	3	N/A	N/A	3
2.3 Details given on who chose not to participate and why	N/A	2	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	2	N/A	2	N/A	N/A	3	N/A	N/A	2
3. Data collection																						
3.1 Collection of data is comprehensive and appropriate. E.g. a) Was the study setting appropriate? E.g. protection of confidentiality for sensitive discussions; b) Is the role of the researcher(s) appropriate? How might they bias the study and results? e.g. Do researchers occupy dual roles (clinician and researcher	N/A	2	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	2	N/A	2	N/A	N/A	3	N/A	N/A	3
4. Data analysis/interpretation																						
4.1 Are interpretations clearly presented and supported adequately by evidence?	N/A	3	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	2	N/A	3	N/A	N/A	3	N/A	N/A	3
4.2 Indicators of quality																						
- Description of how themes were derived from the data	N/A	2	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	2	N/A	N/A	3	N/A	N/A	3

(inductive or deductive)																						
- Semi quantification when appropriate	N/A	3	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	2	N/A	N/A	3	N/A	N/A	3
- Quote use appropriate, effective	N/A	3	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	3	N/A	N/A	3	N/A	N/A	3
-Analysis /presentation of negative/deviant cases, alternative explanations	N/A	2	N/A	N/A	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	2	N/A	2	N/A	N/A	2	N/A	N/A	2
-Method of reliability check (e.g. triangulation, independent review of data to contest themes)	N/A	1	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	1	N/A	N/A	2	N/A	N/A	2
4.3 Are findings generalizable to a broader population?	N/A	2	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	N/A	1	N/A	N/A	3	N/A	N/A	3
	16	27	22	21	41	18	22	18	18	22	15	23	23	38	22	29	11	19	40	15	22	39
Grading	+	++	++	++	++	+	++	+	+	++	+	++	++	++	++	+	-	+	++	-	++	++

*N/A marked under quantitative criteria for qualitative studies and vice versa.

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++	Low risk of bias: All or almost of the above criteria were fulfilled, and those that were not fulfilled were thought unlikely to alter the conclusions of the study.
+	Medium risk of bias: Some of the above criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study.
-	High risk of bias: Few or no criteria were fulfilled, and the conclusions of the study were thought likely or very likely to alter with their inclusion.

S3 Table. Summarised data extraction table

Citation	Title	Study location	Study design	Source of participants	Disability group	Means of assessing disability	Disabled person (n)	Carer (n)	Carer type	Theme	Overview of results
Altundag et al (2015)	Teaching menstrual care skills to intellectually disabled female students	Turkey (LMIC)	Quasi-experiment	Institution	Intellectual	Clinical	54	Number not specified in paper	Not specified in paper	1. MHM training and support for people with intellectual impairments	1. MHM training using a doll helped people with ID manage more independently
Carnaby et al (2002)	Getting personal: an exploratory study of intimate and personal care provision for people with profound and multiple intellectual disabilities	UK (HIC)	Qualitative	Residential home	Intellectual		15	Number not specified in paper	Professional	1. Concerns of carers of people with intellectual impairments 2. MHM training and support for carers	1. Day care staff disliked menstrual care tasks most. Residential service staff rated menstrual care just behind giving enemas (day care staff don't give enemas). Intimate care carries social taboos. 2. Carers noted a lack of training / standards of care for intimate and personal care tasks and requested formalised guidance.
Charlifue et al (1992)	Sexual issues of women with spinal cord injuries	HIC	Quantitative	Hospital	Physical	Clinical	231	Number not specified in paper	Not specified in paper	1. Menstrual product acceptability for people with physical impairments	1. 19% users reported problem using a menstrual product. 2. >50% needed assistance MHM 3. 43% reported bowel / bladder changes when menstruating
Chou et al (2009)	Prevalence and severity of menstrual symptoms among institutionalised women with an intellectual disability	Taiwan (HIC)	Quantitative	Welfare institution	Intellectual	Means of assessing disability not specified in paper	92	Number not specified in paper	Not specified in paper	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments	1. Level of ID is significantly associated with the domain of Water Retention (p 5 .01) and Negative Affect (p 5 .001); and women with mild/moderate ID - more likely to have a higher level of Water Retention and Negative Affect than women with severe/profound ID
Chou et al (2012)	Caring for a daughter with intellectual disabilities in managing menstruation: a mother's perspective	Taiwan (HIC)	Qualitative	Household	Intellectual	Means of assessing disability not specified in paper	13	12	Parent	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments 2. Concerns of carers of people with intellectual impairments 3. MHM training and support for carers 4. Menstrual suppression	1. Mothers who can't communicate with daughters rely on changes in behaviour to predict period / PMS. 2. Carers reported challenges of sourcing appropriate sanitary protection and getting daughters to use them. Mens product: expensive, not effective, daughters take them off 3. No mother had had access to information about how to manage menstruation. Mens care viewed as a private issue. Mothers used fate as a coping strategy instead of seeking assistance from professionals. 2. Most mothers were advised to sterilise their daughters by medical practitioners, health practitioners, professionals from a service agency. Reasons given for suggesting sterilisation: eliminating menstrual care ('tedious task'), hygiene, preventing pregnancy if daughter raped. Mothers viewed regular menstruation positively - sign of good health
Goldstein (1988)	Menarche, menstruation, sexual relations and contraception of adolescent females with Down syndrome	Denmark (HIC)	Quantitative	Households and hospital	Intellectual	Clinical	15	Number not specified in paper	Not specified in paper	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments	1. 20% of DS did not change their sanitary pads themselves. All controls did this independently. 2. No significant differences between test and control across: average menarche age, regularity of menstruation, duration of bleeding, length of menstrual cycle, PMS.
Hamilton et al (2011)	Autism spectrum disorders and menstruation	America (HIC)	Quantitative	Household	Intellectual	Self-reported	124	Number not specified in paper	Not specified in paper	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments	Differences between Asperger syndrome (AS) and autistic spectrum disorder (ASD) groups: ASD reported more hygiene issues; ASs reported more dysmenorrhea symptoms than ASD (could be ability to understand and communicate)
Ibralic (2010)	Age at menarche and premenstrual syndrome in adolescent girls with intellectual disability in Bosnia and Herzegovina	Bosnia and Herzegovina (LMIC)	Quantitative	Hospital	Intellectual	Clinical	31	Number not specified in paper	Not specified in paper	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments	1. No statistical difference between mean age of menarche between ID and control; no overall difference in physical symptoms between test and control. 2. Greater variability in the age at menarche between test and controls

Citation	Title	Study location	Study design	Source of participants	Disability group	Means of assessing disability	Disabled person (n)	Carer (n)	Carer type	Theme	Overview of results
Kirkham et al (2013)	Trends in menstrual concerns and suppression in adolescents with developmental disabilities	Canada (HIC)	Quantitative	Hospital	Intellectual	Clinical	300	Number not specified in paper	Professional and parent	1. Concerns of carers of people with intellectual impairments	Menstruation - one of top 3 concerns for carers; menstrual suppression was the most common concern of carers
Kyrkou (2005)	Health issues and quality of life in women with intellectual disability	Australia and New Zealand (HIC)	Quantitative	Household	Intellectual	Means of assessing disability not specified in paper	24	Number not specified in paper	Parent	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments	1. Period pain: 62.5% women/w autism; 75% of women/w DS, 100% AS appear to have pain, compared to 50% of the general population. 2. Ability to report pain: 8 women/ DS could point to or state where they have pain, even those with limited communication skills. Zero women/w autism could; 1 woman/w AS could even though all women/w AS had good communication skills. 3. Behaviour / symptoms of PMS: facial pallor, restlessness, excessive talking, sleep and appetite disturbance, wanting to be left alone, or exaggeration of the usual symptoms of their disability 4. PMS rates: General population 20-80% have mild–moderate PMS, 2-10% have PMS that interferes with usual lifestyles. Over 75 % of women/w DS complained of increased irritability. Over 75 % of women/w autism complained of irritability and lethargy.
Lin et al (2011a)	Predictors of caregiver supportive behaviors towards reproductive health care for women with intellectual disabilities	Taiwan (HIC)	Quantitative	Welfare institution	Intellectual	Means of assessing disability not specified in paper	0	1152	Professional	1. MHM training and support for carers	Caregiver supportive behavioural score towards reproductive health care for women with ID: menstrual issues = 8.03 3.98; sex education = 8.18 4.14; menopause issues = 7.81 4.61; preventive health services = 6.07 4.64.
Lin et al (2011b)	Caregiver awareness of reproductive health issues for women with intellectual disabilities	Taiwan (HIC)	Quantitative	Welfare institution	Intellectual	Means of assessing disability not specified in paper	0	1152	Professional	1. MHM training and support for carers	1. Almost 1/4 of carers unfamiliar with menstruation. Respondents responded incorrectly to statements such as “menstrual pain is one of the symptoms of reproductive diseases” (36.7%); “it is abnormal to menstruate before 16 years of age” (37.1%).
Mason et al (2007)	An Exploration of Issues around Menstruation for Women with Down Syndrome and their Carers	England (HIC)	Qualitative	Household	Intellectual	Means of assessing disability not specified in paper	6	53	Parent	1. Concerns of carers of people with intellectual impairments 2. Menstrual product acceptability for people with intellectual impairments 3. MHM training and support for people with intellectual impairments	1. Women/w DS who'd been given info re MHM before puberty were better able to cope. 2. People with ID: limited / confused understanding re the reproductive function of menstruation (could be because they've never been taught). Often menstruation means stomach ache and medication to the ppl with DS. Many mothers didn't know how much their daughter's knew about MHM. Lack of understanding / information leads to fear, shock and distress. Mother's surprised when daughters started periods 2. Ppl with IDs didn't like wearing a mens product. Some mothers reported daughter's mens being heavier, ie 'flooding', needing 'supersized pads' (but there's no control group) 3. Daughter's dislike for wearing a mens product. Some mothers found mens leakages distressing. Worried daughters won't follow social norms (ie showing mens blood in public) 4. Some mothers tracked mens with daughter on calendar - this helped some daughters to prepare for mens. Mothers who made MHM a routine (ie changing pad at specific times in the day irrespective of need) helped daughter's awareness and reduced leakages. Many people with ID needed constant reminding re MHM

Citation	Title	Study location	Study design	Source of participants	Disability group	Means of assessing disability	Disabled person (n)	Carer (n)	Carer type	Theme	Overview of results
Obaydi et al (2008)	Prevalence of premenstrual syndrome in autism: a prospective observer-rated study	England (HIC)	Qualitative	Households and hospital	Intellectual	Clinical	26	Number not specified in paper	Professional	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments	1. PMS rates: 92% in the autism group; 11% in the control group; difference is highly statistically significant (P<0.000 001) 2. Symptoms which had a marked increase autistic spectrum disorder group: affective lability; anger or irritability; clumsiness; anxiety or tension; depressed mood; impairment of work, performance, social activities or relationships; social withdrawal, isolation and decreased interest in usual activities; decreased concentration; temper tantrums; physical aggression; self harm; stereotypies or repetitive movements; destructive behaviour; hypersomnia; insomnia; a change in appetite or a specific food craving; and headache.
Patage et al (2015)	Reproductive and sexual health needs among differently abled individuals in the rural field practice area of a medical college in Karnataka, India	India (LMIC)	Quantitative	Household	Mixed	Government lists	198	Number not specified in paper	Not specified in paper	1. Menstrual product acceptability for people with intellectual impairments	MH product used: Sanitary napkin: 54.67; Cloth: 38.67%
Perrin et al (1976)	A considered approach to sterilization of mentally retarded youth	America (HIC)	Qualitative	Hospital	Intellectual	Clinical	20	Number not specified in paper	Not specified in paper	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments 2. Menstrual suppression	1. Mens 'behaviours': increased hyperactivity, withdrawal, fear, refusing to eat 2. Inability to cope during mens so girls were excluded from school during mens 3. Carers coping strategies: keep daughters at home during mens 4. Lack of definitive laws on sterilsation: Human rights should be extend to the disabled person and the parents; Clear laws are needed for the protection of all involved including medical practitioners who could be sued.
Ranganath et al (2012)	Menstrual history in women with Down Syndrome - A review	India (LMIC)	Quantitative	Hospital (outpatients)	Intellectual	Self-reported	0	10	Parent	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments 2. Menstrual product acceptability for people with intellectual impairments	1. 77.5% needed help changing sanitary pads. 2. None reported pain, PMS
Rodgers et al (2005)	The nature and extent of help given to women with intellectual disabilities to manage menstruation	UK (HIC)	Quantitative	Household and hospital	Intellectual	Self-reported	452	217	Professional and parent	1. MHM training and support for people with intellectual impairments	1. 29% no one had ever tried to teach ppl with an ID. No relationship between the level of IQ and whether anyone had tried to teach them. 2. Menstrual care provided does not correlate to severity of ID: Mild ID – carer does the task: Keeping clean during period: 23%; Obtaining sanitary pads / tampons: 13%; Changing sanitary pads / tampons: 7%; Disposing of sanitary pads / tampons: 7%. Severe / profound IDs – carer does not do the task: Keeping clean during period: 9%; Obtaining sanitary pads / tampons: 6%; Changing sanitary pads / tampons: 16%; Disposing of sanitary pads / tampons: 14%

Citation	Title	Study location	Study design	Source of participants	Disability group	Means of assessing disability	Disabled person (n)	Carer (n)	Carer type	Theme	Overview of results
Thapa et al (2017)	Lost in transition: menstrual experiences of intellectually disabled school-going adolescents in Delhi, India	India (LMIC)	Qualitative	Institutions (schools)	Intellectual	Clinical	0	23	Parent	1. Concerns of carers of people with intellectual impairments 2. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments 3. MHM training and support for people with intellectual impairments 4. MHM training and support for carers 5. Menstrual suppression	1.Daughters refusal to wear mens product and constantly coercing daughters to wear; limited ability to follow social / cultural norms. All cause stress, frustration, anxiety. Carers coping strategies: limit their daughter's physical movements because they need to be nearby to manage their menstruation, and to protect them from walking around with soiled clothes. 2. Carers said difficulties communicating is a major barrier. Ppl with IDs are unable to understand menstrual cramps or explain when in pain. Result in irritability, anger 3. Assumption that ppl with IDs can't understand anything so they don't get training in MHM. Ppl with IDs didnt' know how to maintain hygiene during mens, or the importance of it. 4. No training given to mothers. Leads to feelings of being overwhelmed. Mothers are the sole carers for MH. View it as a private issue 5. Reasons for sterilising daughters: drudgery of MH tasks, fear for who will care for her daughter in the future, seeing no benefit for daughters, fear of unwanted pregnancies. Levels of satisfaction with sterilisation was high. Mothers (are in high income brackets) live in urban areas with access to private medical centres and can afford the operation
Van der Merwe (1987)	Sterilization of mentally retarded persons	South Africa (LMIC)	Quantitative	Hospital	Mixed	Means of assessing disability not specified in paper	152	Number not specified in paper	Not specified in paper	1. Menstrual suppression	After the hysterectomy carers reported: 92% felt it was good that she isn't menstruating anymore; 98% would repeat the operation
van Schrojenstein Lantman-deValk et al (2011)	The use of contraception by women with intellectual disabilities	Netherlands (HIC)	Quantitative	Service provider	Intellectual	Government lists	234	Number not specified in paper	Not specified in paper	1. Pre-menstrual symptoms and communication difficulties experienced by people with intellectual impairments 2. Menstrual suppression	48% (n = 112) of women used contraception. Reasons: problems with menstruation, behaviour and/or prevention of pregnancy. Mens related reasons for using contraception include PMS, irregular mens, heavy mens, dymenorrhoea, metrorrhagia (57% n=35). 39% n=24 women took contraception becuase of problems with behaviour. This includes 38% n=9 of those becuase of mood changes before and during mens
White et al (2016)	A qualitative study of barriers to accessing water, sanitation and hygiene for disabled people in Malawi	Malawi (LMIC)	Qualitative	Household	Mixed	Self-reported	36	15	Parent	1. Menstrual product acceptability for people with physical impairments 2. MHM training and support for people with intellectual impairments	1. Challenges for people with visual impairments: may be unable to: respond to the visual cues of menstruation making it harder to manage, identify when their period began and ended. 2. Challenges for wheelchair users: discomfort from always being seated; blood can stain clothes. 3. Challenges for ppl with IDs: often unable to manage mens independently 4. Mens - source of shame, worry, discomfort and embarrassment 5. Girls don't go to school for 1-2 weeks during mens, or drop out when they start menstruating

Abbreviations

AS	Asperger Syndrome
ASD	Autistic Spectrum Disorder
DS	Down Syndrome
HIC	High income country
ID	Intellectual disability
LMIC	Low and middle income country
PMS	Pre-menstrual symptoms
Ppl	People
Mens	Menstruation
MHM	Menstrual hygiene management

Appendix 3. Supporting information for Paper Two

Additional File 1. Adapted EquiFrame for WASH, MHM and Disability

Core concept	Disability & WASH		Disability & MHM	
	Key question	**Key language**	**Key question**	**Key language**
Non-discrimination	Does the policy support the rights of people with disabilities with equal opportunity in accessing WASH services?	People with disabilities are not directly or indirectly discriminated against within the WASH system.	Does the policy support the rights of people with disabilities with equal opportunity in accessing MHM services?	People with disabilities are not directly or indirectly discriminated against within the MHM system.
Individualised services	Does the policy support the rights of people with disabilities with individually tailored WASH services to meet their needs, choices and impairments?	People with disabilities receive specific, appropriate and effective WASH services, with reasonable adjustments made/supported, when necessary.	Does the policy support the rights of people with disabilities with individually tailored MHM services to meet their needs, choices and impairments?	People with disabilities receive specific, appropriate and effective MHM services, with reasonable adjustments made/supported, when necessary. Including: 1. Clean menstrual materials 2. Private and accessible place to change these materials (e.g. toilet) 3. Accessible soap and water for washing the body 4. Safe, accessible and convenient facilities to dispose of used materials 5. Accessible, accurate

				information on the menstrual cycle
Entitlement/ affordability	Does the policy indicate entitlements for people with disabilities (e.g. respite grant or reduced user fee) and how they may qualify for specific benefits relevant to them?	People with disabilities who have limited resources are entitled to some services free of charge or may be entitled to a sliding scale tariff.	Does the policy indicate entitlements for people with disabilities (e.g. respite grant, reduced fee or no tax for menstrual products) and how they may qualify for specific benefits relevant to them?	People with disabilities who have limited resources are entitled to menstrual products free of charge or at a reduced cost.
Capability based services	Does the policy recognise the capabilities of people with disabilities in implementation and management of WASH activities, at an organisational level?	For instance, peer support, group advocacy, OPDs.	Does the policy recognise the capabilities of people with disabilities in relation to MHM?	For instance, peer support, group advocacy, OPDs focused on MHM. People with disabilities are meaningfully represented in MHM management committees
Participation	Does the policy support the right of people with disabilities to participate in the decisions that affect their lives and	People with disabilities can exercise choices and influence decisions affecting their life. They are included and consulted in the planning, development,	Does the policy support the right of people with disabilities to participate in the decisions related to MHM that affect	People with disabilities can exercise choices and influence decisions affecting their life. Such consultation may include planning, development,

	enhance their empowerment?	implementation, and evaluation of WASH activities	their lives and enhance their empowerment?	implementation, and evaluation related to MHM.
Coordination of services	Does the policy support assistance of people with disabilities in accessing services from within a single provider system (interagency/utility) or more than one provider system (intra-agency/utility) or more than one sector (inter-sectoral)?	People with disabilities know how services should interact where inter-agency, intra-agency, and inter-sectoral collaboration is required. This includes coordination between health services, schools, households and public places, with regards to WASH. Additional coordination opportunities include WASH sector with the private sector, civil society and rights groups.	Does the policy support assistance of people with disabilities in accessing MHM services from within a single provider system (interagency/utility) or more than one provider system (intra-agency/utility) or more than one sector (inter-sectoral)?	People with disabilities know how MHM services should interact where inter-agency, intra-agency, and inter-sectoral collaboration is required. This includes coordination between health services, schools, households and public places, with regards to MHM. Additional coordination opportunities include WASH / MHM actors with the private sector, civil society and rights groups.
Protection from harm	People with disabilities are protected from harm during their interaction with WASH and related services	People with disabilities are protected from harm during their interaction with WASH services, as well as health related system and from families and the community who may have negative	People with disabilities are protected from harm during menstruation and related services	People with disabilities are protected from harm during menstruation and their interaction with related services, as well as health related system and from families and the community who may have negative

		attitudes about WASH for people with disabilities. This includes the right to private, secure WASH facilities.		attitudes about menstruation and people with disabilities.
Liberty	Does the policy support the right of people with disabilities to be free from unwarranted physical or other confinement?	People with disabilities are protected from unwarranted physical or other confinement while in the custody of the service system/provider. This includes at home and a healthcare service.	Does the policy support the right of people with disabilities to be free from unwarranted physical or other confinement during menstruation?	People with disabilities are protected from unwarranted physical or other confinement during menstruation. This includes at home, boarding schools and a healthcare service.
Autonomy	Does the policy support the right of people with disabilities to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to her or him?	People with disabilities can express “independence” or “self-determination”. For instance, person with an intellectual disability will have recourse to an independent third party regarding issues of consent and choice.	Does the policy support the right of people with disabilities to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to them when menstruating?	People with disabilities can express “independence” or “self-determination” in relation to menstruation. For instance, person with an intellectual disability will have recourse to an independent third party regarding issues of consent and choice over the menstrual product used, method to manage menstrual discomfort.
Privacy	Does the policy address the need for information	Information regarding people with disabilities	Does the policy address the need for information	Information regarding people with disabilities who

	regarding people with disabilities to be kept private and confidential?	need not be shared among others.	regarding people with disabilities who menstruate to be kept private and confidential?	menstruate need not be shared among others.
Integration	Does the policy promote the use of mainstream services by people with disabilities?	People with disabilities are supported to use the services that are provided for general population.	Does the policy promote the use of mainstream MHM services by people with disabilities?	People with disabilities are supported to use the MHM services that are provided for general population.
Contribution	Does the policy recognise that people with disabilities can be productive contributors to society and the WASH sector?	People with disabilities make a meaningful contribution to society and the WASH sector. They are recognised as important contributors to programmes and activities	Does the policy recognise that people with disabilities can be productive contributors to society during menstruation?	People with disabilities who are menstruating make a meaningful contribution to society.
Family resource	Does the policy recognise the value of the family members of people with disabilities in addressing WASH needs?	The policy recognises the value of all family members of people with disabilities, in supporting WASH needs and activities	Does the policy recognise the value of the family members of people with disabilities in addressing MHM needs?	The policy recognises the value of family members of people with disabilities as a resource for addressing MHM needs.
Family support	Does the policy recognise individual members of people with disabilities may have an impact on the family members	Caring for persons with disabilities may have mental health effects on other family members, such that these family members	Does the policy recognise individual members of people with disabilities may have an impact on the family members	Caring for persons with disabilities who menstruates may have mental health effects on other family members, such that these

	requiring additional support from WASH services?	themselves require support.	requiring additional support from MHM services?	family members themselves require support.
Cultural responsiveness	Does the policy ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic, or linguistic, aspects of the person, as well as personal safety and dignity?	i) People with disabilities are consulted on the acceptability of the service provided ii) Hygiene facilities, goods and services must be respectful of ethical principles and culturally appropriate, i.e. respectful of the culture of people with disabilities	Does the policy ensure that MHM services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic, or linguistic, aspects of the person, as well as personal safety and dignity?	i) People with disabilities who menstruate are consulted on the acceptability of the MHM service provided ii) Hygiene facilities, goods and services must be respectful of ethical principles and culturally appropriate, i.e. respectful of the culture of people with disabilities
Accountability	Does the policy specify to whom, and for what, services providers are accountable?	People with disabilities have access to internal and independent professional evaluation or procedural safe guard. Do laws/regulations provide mechanisms that ensure complaints are effectively heard? Are there effective complaint mechanisms? Are there judicial bodies that can resolve conflicts? This	Does the policy specify to whom, and for what, MHM services providers are accountable?	People with disabilities have access to internal and independent professional evaluation or procedural safe guard related to MHM. Do laws/regulations provide mechanisms that ensure complaints regarding MHM are effectively heard? Are there effective complaint mechanisms? Are there judicial bodies that can resolve conflicts? This is evident for both public and private institutions.

		is evident for both public and private institutions.		
Prevention	Does the policy support people with disabilities in seeking primary, secondary and tertiary prevention of health conditions associated with WASH?	Includes WASH related illnesses and details on how people with disabilities can seek primary, secondary and tertiary prevention of health conditions associated with WASH, e.g. Trachoma, Soil-Transmitted Helminthes – intestinal worms, Lymphatic Flariasis, Leprosy	Does the policy support people with disabilities in seeking primary, secondary and tertiary prevention of health conditions associated with menstruation?	Includes complications related to menstruation e.g. reproductive tract infections such as bacterial vaginosis, candidia, and Trichomonas vaginalis (including genital itching, back pain, abdominal pain, pustules over genitalia and abnormal genital discharge)
Capacity building	Does the policy support the capacity building of health workers and of the system that they work in addressing WASH needs of people with disabilities?	Includes awareness raising among communities and families on disability and barriers faced by people with disabilities.	Does the policy support the capacity building of health workers and of the system that they work in addressing MHM needs of people with disabilities?	Includes awareness raising among communities and families on disability and barriers to MHM faced by people with disabilities.
Access	Does the policy support people with disabilities – physical and information access to WASH services?	People with disabilities have accessible and safe WASH services within, or in the immediate vicinity, of household, health and	Does the policy support people with disabilities – physical and information access to MHM services?	People with disabilities have accessible and safe MHM facilities within, or in the immediate vicinity, of household, health and educational institution, public

		educational institution, public institutions and places and workplace. All information must be understandable and in appropriate format.		institutions and places and workplace. Includes: 1) Private and accessible place to change these materials (e.g. toilet), 2. Accessible soap and water for washing the body, 3. Safe, accessible and convenient facilities to dispose of used materials. All MHM information must be understandable and in appropriate format.
Quality	Does the policy support quality services to people with disabilities through highlighting the need for evidence-based and professionally skilled practice? Does the policy promote innovation in WASH services for people with disabilities (e.g. technology)? Does the policy support water that is safe for consumption and other personal uses,	People with disabilities are assured of the quality of water supply for consumption and other personal uses; that sanitation facilities are hygienically and technically safe to use by people with disabilities and that water for hygiene (cleansing, handwashing) is accessible at critical times (i.e. during menstruation, after defecation, changing diapers/nappies, before preparing food	Does the policy support quality MHM services to people with disabilities through highlighting the need for evidence-based and professionally skilled practice? Does the policy promote innovation in MHM services for people with disabilities? E.g. menstrual product type, information exchange, accessibility of	People with disabilities are assured that disposal facilities are hygienically and technically safe to use by people with disabilities and that water for menstrual hygiene is accessible during menstruation. Services are based on best practice/evidence and support innovative strategies/technology

	so that it presents no threat to human health for people with disabilities; that sanitation facilities must be hygienically and technically safe to use for people with disabilities and ensure hygiene, access to water for cleansing and hand washing for people with disabilities at critical times.	and before eating). Services are based on best practice/evidence and support innovative strategies/technology. This includes guidelines.	water for washing the body/menstrual product used; safe, private and accessible place to change the menstrual product; accessible methods to dispose of the used menstrual product)?	
Efficiency	Does the policy support efficiency by providing a structured way of matching WASH system resources with service demands in addressing WASH needs of people with disabilities?	Are WASH services sustainable for people with disabilities: Will services still be available in times of financial crisis? Are technology choices appropriate? Do contracts with providers take into account operation and maintenance? Are funds from donors sustainable?	Does the policy support efficiency by providing a structured way of matching MHM system resources with service demands in addressing MHM needs of people with disabilities?	Are MHM services sustainable for people with disabilities: Will services still be available in times of financial crisis? Are technology choices and menstrual products appropriate? Do contracts with providers take into account operation and maintenance? Are funds from donors sustainable?

Additional File 2. Adapted EquiFrame for WASH, MHM and Gender

Core concept	Gender & WASH		Gender & MHM	
	Key question	**Key language**	**Key question**	**Key language**
Non-discrimination	Does the policy support the rights of women/girls with equal opportunity in receiving WASH services?	Women/girls are not directly or indirectly discriminated against within the WASH system.	Does the policy support the rights of people with equal opportunity in receiving MHM services?	People (women/girls, LGBTI people) are not directly or indirectly discriminated against within the MHM system.
Individualised services	Does the policy support the rights of women/girls with individually tailored WASH services to meet their needs and choices?	Women/girls receive specific, appropriate and effective WASH services, for example services specific to menstrual hygiene management	Does the policy support the rights of people who menstruate with individually tailored MHM services to meet their needs and choices?	People who menstruate receive specific, appropriate and effective MHM services, for example WASH services specific to menstrual hygiene management. Including: 1. Clean menstrual materials 2. Private place to change these materials (e.g. toilet) 3. Soap and water for washing the body 4. Safe and convenient facilities to dispose of used materials 5. Accurate information on the menstrual cycle

Entitlement/ affordability	Does the policy indicate entitlements for women/girls (e.g. respite grant or reduced user fee), and how they may qualify for specific benefits relevant to them?	Women/girls may be entitled to a respite grant or sliding scale tariff, especially if in unpaid work	Does the policy indicate entitlements for people who menstruate (e.g. respite grant, reduced fee or no tax for menstrual products) and how they may qualify for specific benefits relevant to them?	People who menstruate who have limited resources are entitled to menstrual products free of charge or at a reduced cost.
Capability based services	Does the policy recognise the capabilities of women/girls in implementation and management of WASH activities, at an organisational level??	For instance, peer support, mentoring, group advocacy. Women are meaningfully represented in WASH committees.	Does the policy recognise the capabilities of people who menstruate in relation to MHM?	For instance, peer support, mentoring, group advocacy focusing on MHM.
Participation	Does the policy support the right of women/girls to participate in the decisions that affect their lives and enhance their empowerment?	Women/girls can exercise choices and influence decisions affecting their life. They are included and consulted in the planning, development, implementation, and evaluation of WASH activities	Does the policy support the right of people who menstruate to participate in the decisions related to MHM that affect their lives and enhance their empowerment?	People who menstruate can exercise choices and influence decisions affecting their life. Such consultation may include planning, development, implementation, and evaluation related to MHM.

Coordination of services	Does the policy support assistance of women/girls in accessing services from within a single provider system (interagency) or more than one provider system (intra-agency) or more than one sector (intersectoral)?	Women/girls know how services should interact where inter-agency, intra-agency, and inter-sectoral collaboration is required. This includes coordination between health services and schools with regards to WASH. Additional coordination opportunities include WASH sector with the private sector, civil society and rights groups.	Does the policy support assistance of people who menstruate in accessing MHM services from within a single provider system (interagency/utility) or more than one provider system (intra-agency/utility) or more than one sector (intersectoral)?	People who menstruate know how MHM services should interact where inter-agency, intra-agency, and inter-sectoral collaboration is required. This includes coordination between health services, schools, households and public places, with regards to MHM. Additional coordination opportunities include WASH / MHM actors with the private sector, civil society and rights groups.
Protection from harm	Women/girls are protected from harm during their interaction with WASH and related services	Women/girls are protected from harm during their interaction with WASH services, as well as health related systems, including sexual violence. Also protection from harm from families and the community who may have negative attitudes about specific WASH topics for women/girls (e.g. menstrual	People who menstruate are protected from harm during menstruation and related services	People who menstruate are protected from harm during menstruation and their interaction with related services, as well as health related system and from families and the community who may have negative attitudes about menstruation.

		hygiene). This includes the right to private, secure WASH facilities.		
Liberty	Does the policy support the right of women/girls to be free from unwarranted physical or other confinement?	Women/girls are protected from unwarranted physical or other confinement while in the custody of the service system/provider. This includes at home and a healthcare service.	Does the policy support the right of people who menstruate to be free from unwarranted physical or other confinement during menstruation?	People who menstruate are protected from unwarranted physical or other confinement during menstruation. This includes at home, boarding schools and a healthcare service.
Autonomy	Does the policy support the right of women/girls to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to her or him?	Women/girls can express “independence” or “self-determination”. For instance, a husband is not to make decisions for his wife.	Does the policy support the right of people who menstruate to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to them when menstruating?	Women/girls can express “independence” or “self-determination” in relation to menstruation. For instance, a wife is able to use the household budget to buy menstrual products or relief for menstrual discomfort.

Privacy	Does the policy address the need for information regarding women/girls to be kept private and confidential?	Information regarding women/girls need not be shared among others.	Does the policy address the need for information regarding people who menstruate to be kept private and confidential?	Information regarding people who menstruate need not be shared among others.
Integration	Does the policy promote the use of mainstream services by women/girls?	Women/girls are supported to use the services that are provided for general population.	Does the policy promote the use of mainstream services by people who menstruate?	People who menstruate are supported to use the services that are provided for general population.
Contribution	Does the policy recognise that women/girls can be productive contributors to society and the WASH sector?	Women/girls make a meaningful contribution to society and the WASH sector. They are recognised as important contributors to programmes and activities	Does the policy recognise that people who menstruate can be productive contributors to society during menstruation?	People who are menstruating make a meaningful contribution to society.
Family resource	Does the policy recognise the value of the family members of women/girls in addressing WASH needs?	The policy recognises the value of all family members of women/girls, in supporting WASH needs and activities	Does the policy recognise the value of the family members of people who menstruate in addressing MHM needs?	The policy recognises the value of family members of people who menstruate as a resource for addressing MHM needs.

Family support	Does the policy recognise individual members of women/girls may have an impact on the family members requiring additional support from WASH services?	For example, caring for women/girls with chronic illness may have mental health effects on other family members, such that these family members themselves require support.	Does the policy recognise people who menstruate may have an impact on the family members requiring additional support from MHM services?	For example, caring for menstruating women/girls with chronic illness may have mental health effects on other family members, such that these family members themselves require support.
Cultural responsiveness	Does the policy ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic, or linguistic, aspects of the person, as well as personal safety and dignity?	i) Women/girls are consulted on the acceptability of the service provided ii) Hygiene facilities, goods and services must be respectful of ethical principles and culturally appropriate, i.e. respectful of the culture of women	Does the policy ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic, or linguistic, aspects of the person, as well as personal safety and dignity?	i) People who menstruate are consulted on the acceptability of the MHM service provided ii) Hygiene facilities, goods and services must be respectful of ethical principles and culturally appropriate, i.e. respectful of the culture of women/girls, LGTBI

Accountability	Does the policy specify to whom, and for what, services providers are accountable?	Women/girls have access to internal and independent professional evaluation or procedural safe guard. Do laws/regulations provide mechanisms that ensure complaints are effectively heard? Are there effective complaint mechanisms? Are there judicial bodies that can resolve conflicts? This is evident for both public and private institutions.	Does the policy specify to whom, and for what, MHM services providers are accountable?	People who menstruate have access to internal and independent professional evaluation or procedural safe guard related to MHM. Do laws/regulations provide mechanisms that ensure complaints regarding MHM are effectively heard? Are there effective complaint mechanisms? Are there judicial bodies that can resolve conflicts? This is evident for both public and private institutions.
Prevention	Does the policy support women in seeking primary, secondary and tertiary prevention of health conditions associated with WASH?	Includes gendered WASH related illnesses and details on how women/girls can seek primary, secondary and tertiary prevention of associated health conditions, e.g. urinary tract infections	Does the policy support people who menstruate in seeking primary, secondary and tertiary prevention of health conditions associated with menstruation?	Includes complications related to menstruation e.g. reproductive tract infections such as bacterial vaginosis, candidia, and Trichomonas vaginalis (including genital itching, back pain, abdominal pain, pustules over genitalia and abnormal genital discharge)

Capacity building	Does the policy support the capacity building of health workers and of the system that they work in addressing WASH needs of women?	Includes awareness raising among communities and families on the specific WASH issues facing women/girls and potential barriers.	Does the policy support the capacity building of health workers and of the system that they work in addressing MHM needs of people who menstruate?	Includes awareness raising among communities and families on the specific MHM issues facing people who menstruate and potential barriers.
Access	Does the policy support women/girls – physical and information access to WASH services?	Women/girls have accessible and safe WASH services within, or in the immediate vicinity, of household, health and educational institution, public institutions and places and workplace. This means that they have separate WASH facilities from men/boys. All information provided on WASH must be understandable and in appropriate format. Does the policy address the needs of both girls and women?	Does the policy support people who menstruate – physical and information access to MHM services?	People who menstruate have accessible and safe MHM facilities within, or in the immediate vicinity, of household, health and educational institution, public institutions and places and workplace. Includes: 1) Private place to change these materials (e.g. toilet), 2. Accessible soap and water for washing the body, 3. Safe and convenient facilities to dispose of used materials. All MHM information must be understandable and in appropriate format.

Quality	Does the policy support quality services to women/girls through highlighting the need for evidence-based and professionally skilled practice? Does the policy promote innovation in WASH services for women/girls (e.g. technology)? Does the policy support water that is safe for consumption and other personal uses, so that it presents no threat to human health for women/girls; that sanitation facilities must be hygienically and technically safe to use for women/girls and ensure hygiene, access to water for cleansing and hand	Women/girls are assured of the quality of water supply for consumption and other personal uses; that sanitation facilities are hygienically and technically safe to use by women/girls and that water for hygiene (cleansing, handwashing) is accessible at critical times (i.e. during menstruation, after defecation, changing diapers/nappies, before preparing food and before eating). Services are based on best practice/evidence and support innovative strategies/technology. This includes guidelines	Does the policy support quality MHM services to people who menstruate through highlighting the need for evidence-based and professionally skilled practice? Does the policy promote innovation in MHM services for people? E.g. menstrual product type, information exchange, water for washing the body/menstrual product used; safe and private place to change the menstrual product; methods to dispose of the used menstrual product)?	People who menstruate are assured that disposal facilities are hygienically and technically safe to use and that water for menstrual hygiene is available during menstruation. Services are based on best practice/evidence and support innovative strategies/technology

	washing at critical times

Efficiency	Does the policy support efficiency by providing a structured way of matching WASH system resources with service demands in addressing WASH needs of women/girls?	Are WASH services sustainable for women/girls: Will services still be available in times of financial crisis? Are technology choices appropriate? Do contracts with providers take into account operation and maintenance? Are funds from donors sustainable?	Does the policy support efficiency by providing a structured way of matching MHM system resources with service demands in addressing MHM needs of people who menstruate?	Are MHM services sustainable: Will services still be available in times of financial crisis? Are technology choices and menstrual products appropriate? Do contracts with providers take into account operation and maintenance? Are funds from donors sustainable?

Additional file 1. Adapted EquiFrame for WASH, MHM and Disability

Additional file 2. Adapted EquiFrame for WASH, MHM and gender

Appendix 4. Supporting information for Paper Three

In Depth Interview Question Guide for Carers

Materials and supplies for in depth interview

- One digital recording device
- Spare Battery for recording device
- Notebook for note-taking and pens
- Camera
- Refreshments

Use of these questions

These questions are a guide only. In practice, field staff should familiarise themselves with these questions and adapt them to suit the participant and their responses. This responsiveness is important to ensure that the participant feels at ease and able to talk about these topics. The interview should feel more like a conversation rather than a question and answer session. It is important to establish a rapport with participants, so begin with some general questions about their family and their interests before delving into what are quite private topics relating to menstrual hygiene management. Questions should be added where a participant mentions something of interest or touches on something that needs further clarification. Questions can be skipped where a participant answers the question in a previous response. You may not need to go through all questions.

Risks

If there is a concern that the Carer does not understand what informed consent entails, do not interview him / her.

To be completed for each interview

Name of Interviewer	FIRST NAME	SURNAME	
Name of note taker	FIRST NAME	SURNAME	
District	Village / Metropolitan area / Municipality	Household number	
Name of the parent / carer	FIRST NAME	SURNAME	
Age			
Caste			
What is your main source of income?	*Circle only one answer* 1. Agriculture / livestock 2. Trader (food / non-food items) 3. Craftsperson 4. Small business / shop owner 5. Manual labourer 6. Other (specify)		
Name of Primary Participant	FIRST NAME	SURNAME	
Has written informed consent been obtained from the primary participant?	Yes	No	N/A
If the parent / carer has a communication / intellectual disability, have they been given the choice about who they want to be interviewed with if they prefer not to be interviewed by themselves?	Yes	No	N/A

2

Date of interview		Start time:	End time:
Interview number		Audio interview recording number:	
Additional information			

INSTRUCTIONS: INTERVIEWER TURN ON THE TAPE RECORDER AND SAY CLEARLY THE DATE, TIME, LOCATION, AND THE INTERVIEWER'S NAME

3

Opening/ rapport building questions

- Who do you live with?
- Who do you care for?
- Do you go to school / work? Tell me about that.

KEY QUESTIONS

Now we are going to move on to our discussion of more specific questions about menstruation.

1. **Could you tell me a bit about the disability that [primary participant's name] has?**

2. **How long have you been caring for [primary participant's name]?**

3. **What support do you give [primary participant's name]?**

    - What are the main tasks?
    - Are any of these related to self-care (i.e. toileting, washing her body, washing her clothes and bedding, fetching water for her)?

4. **Does [primary participant's name] ever have difficulty controlling when they urinate or defecate?**

    - How do you deal with that?
    - What are the challenges (i.e. getting her to the toilet, washing her, cleaning her clothes / bedding, taking her out of the house)?
    - Do you use products (i.e. cloth, pad, nappy)? What are these? Where do you get them?

5. **Can you tell me about the first time [primary participant's name] got her period?**

Context:
- Where was [primary participant's name]?
- What did she do?
- What did you do?
- How did you help her manage it?

Attitudes/emotions:
- What was your immediate reaction or feeling?
- How did [primary participant's name] react?
- How did that make you feel?

Knowledge:
- Did you know how to help [primary participant's name] manage?

- Could you explain what was happening to [primary participant's name]?
- What did you say?
- Did she understand?
- Did anyone tell you how to help [primary participant's name] manage her period?
- Who? (Family, friends, teachers, health worker)?
- What did they tell you?
- Did anyone help you care for [primary participant's name] when she had her period?

Resources/management/practices:

- What did you use (pads, cloth, tissues, etc.)?
- Who/where did you get materials from?
- Where did you go to change / wash her menstrual material (latrine, separate room, outside, etc.)?
- Do you remember if there was water, soap, privacy?
- Did you have any challenges using the place where you helped her wash / change her menstrual material? Please explain?
- Where did you go to help her wash her body?
- How did you feel about helping [primary participant's name] manage their first period?

Support:

- Did you tell anyone when [primary participant's name] got their period for the first time? Please explain.
- If yes, who did you talk with? Why?
- What did you talk about?
- Did you try to hide it or keep it a secret? Why?
- Who did you not want to know? Why?

6. **Can you tell me about the most recent time [primary participant's name] got her period?**

Context:

- Where were you both?
- Was [primary participant's name] prepared for it? How?
- Were you prepared for it? How were you prepared?

Attitudes/emotions:

- How did you feel about helping [primary participant's name] manage their period (proud, pleased, scared, worried, frustrated, no negative or positive feelings at all)? Why?
- Has this changed since [primary participant's name] first period? Why?

Knowledge:

- Did you know how to help [primary participant's name] manage?
- Could you explain what was happening to [primary participant's name]?
- What did you say?

- Did she understand?
- Do you have more information now about how to help [primary participant’s name] manage her period?
- What information is that? Who gave that to you information?
- Did anyone help you care for [primary participant’s name] when she had her period?

Resources/management/practices:

Instructions: you may want to complete the Product Attribute Assessment now and run through the following probing questions, or you can complete the Product Attribute Assessment at the end of the IDI questions.

- What material / product did you use (pads, cloth)?
- Does [primary participant’s name] normally use those?
- Do you use different supplies for different days of [primary participant’s name] period (light or heavy menstrual flow)?
- Is it difficult for the [primary participant’s name] to use them? Why?
- Do you use different materials / products to manage your own period? Why?
- Who/where did you get [primary participant’s name’s] menstrual material / product from?
- How often do you change them?
- Where do you change them?
- Where do you go to wash her menstrual materials (if not disposable)?
- Where do you dry her re-usable materials? (Inside? Outside? In sun? In shade?)
- Where do you store her materials when you do not have your period?
- Where would you dispose of her menstrual materials (if not re-usable)? Is this method of disposal OK or would you prefer other options?
- Where did you and [primary participant’s name] go to wash her body?
- Does [primary participant’s name] disability make it hard to wash her body?
- Do you feel safe in the place you clean her?
- Do you have more washing to do when [primary participant’s name] has her period (i.e. clothes, bedding)?
- If you do, how many more times do you do this than when [primary participant’s name] does not have her period?
- Does [primary participant’s name] have pain? How do you help her manage the pain (e.g. massage, warm cloth, paracetamol)?
- What’s your biggest worry or challenge when [primary participant’s name] has her period (i.e. leaking, heavy bleeding, availability of water for washing)?

Support:

- Does anyone ever provide materials or supplies for [primary participant’s name]? Who?
- If someone provides materials for [primary participant’s name], where do they get the materials? Do they cost something?

- Who did you not want to know that [primary participant's name] had her period? Why?

7. **Has anyone ever spoken to you about lightening [primary participant's name's] menstrual flow?**

If yes:
- Explore if this is sterilization or lightening the menstrual flow.
- Why have you considered that?
- How did you hear about that?
- Who did you speak to about it?
- What did they tell you?
- What did you do?
- Did [primary participant's name] understand what was happening? Did they agree to it? Can you tell me about that?
- What difference has it made to you and [primary participant's name]? How do you both feel about that?

If no, move to the next question.

8. **Has anyone ever spoken to you about lightening [primary participant name's] menstrual flow? Can you tell me about that?**

- Who spoke to you?
- What did they tell you?
- What options did they give you?
- What happened? Explore reasons for lightening the menstrual flow; who made the decision; if the primary participant knew what was happening; did she consent?
- What difference has it made to you and [primary participant's name]? How do you both feel about that?

If no, move to the next question.

9. **Are there any activities you don't want [primary participant's name] doing when she has her period? Why?**

- How does [primary participant's name] feel about that?

10. **Are these restrictions different for her to females who do not have a disability? How?**

11. **Looking back at your experiences, what have you learned about how to help [primary participant's name] manage her period?**

Management/practices:
- Do you know when [primary participant's name's] period is coming? How?
- How do you normally prepare for her period?

12. **Do you know when [primary participant name’s] period is coming?**

    - How does that help you prepare and manage her period?

13. **What would help you to better support [primary participant’s name] to manage her period? (i.e. information, products, a private place to wash her body, her menstrual material and dry it)?**

14. **Of the information you received (if any), what has been the most useful? Why was it useful?**

    - Who gave you that information?
    - Of the support you have received (if any), what has been the most useful? Why?
    - Who provided that support?
    - How would you like to receive information about how you can help [primary participant’s name] manage her period (radio, television, newspaper, healthcare centre)? Why?
    - Who would you like to receive that information from (healthcare worker, friend, family member)? Why?

15. **Are there any advantages to caring for [primary participant’s name] when they have their period (ie knowledge that she has a good menstrual cycle)? Please explain.**

16. **If you had a relative or friend whose daughter has a disability, what advice would you give her before her daughter starts menstruating? What would you say?**

17. **We are going to come up with recommendations for organisations and healthcare professionals that could help improve menstrual hygiene management for people with a disability. What advice would you like us to pass along to them that you think would make things better for you when [primary participant’s name] has her period?**

Product Attribute Assessment

I would like to see menstrual products you use. Please can you set out all the menstrual hygiene products you use?

1. Ask about each item displayed:
    a. What are its good qualities (probe into physical accessibility, acceptability, affordability, appropriateness and quality)?
    b. What are its less good qualities (probe into physical accessibility, acceptability, affordability, appropriateness and quality)?
    c. How long has this product been used?
    d. Have you tried using any other product?

2. Introduce other products that are available on the local market (obtained through the market survey). Ask the participant if they have ever used any of the products? *State what these are into the audio voice recorder.*

3. Ask participants what they feel about these products. *State which product are being discussed into the audio voice recorder.*
    a. Would you be willing to pay the price of this? Show the costs of each product (displayed on the bottom of the packaging)?
    b. What would your personal preference be? Why? (Probe into physical accessibility, acceptability, affordability, appropriateness and quality)?
    c. How would other people perceive these products?
    d. Could you use, wash and dispose of these products independently and privately? If not, why not?

4. Give the shop bought products and the products currently used to the participant. *State what these are into the audio voice recorder.* Ask the participant to:
    a. Put all the products in a line
    b. Reorder the products in preference order. Left being the least preferred option. Right being the most preferred option
    c. Ask the participant why they have ordered them in that way
    d. *Take a photo of the product line and state the order into the audio voice recorder.*

Accessibility and safety audit

Ask the user to show you where she manages her menstruation / where the Carer manages the menstruation of the person s/he is caring for.	
Type of facility (i.e. latrine, wash room, behind a bush/tree):	
Location:	
General description of the facility:	
Ask the user to into and show how they can/cannot use the facility. Make a note of any features that make it difficult to use.	
Getting there (observe):	
Checklist • Distance from house to facility. • Is the path wide enough for the primary participant? • Is the path level and firm, with nothing to trip up? • Is the path surface slippery when either dry or wet? • Are there obstacles that block the path, or make it easy to trip especially for visually impaired people? • Are slopes too steep? • If used at night, is the path lit? • Are there any parts of the path which make people feel unsafe when using it? If so why?	
Getting in/on/out (observe):	

<table>
<tr><td></td><td></td></tr>
<tr><td colspan="2"><i>Checklist</i>
Steps:
• Are they even or uneven, firm or broken, non-slip or slippery?
• Is there a handrail for support?
Entrance:
• Is it wide enough for the user to enter?
• Is the door easy to open?
• Is the door easy to lock and unlock?
• If someone faced harassment or other safety risks when using the facility would they be able to safely get away from the facility?</td></tr>
<tr><td>Safety of use (ask the participant)</td><td></td></tr>
<tr><td colspan="2"><i>Checklist</i>
• Do you feel safe when using the facility?
• Are there any particular times of day or night when you feel less safe?
• Is there any way that anyone can easily see inside the facility?</td></tr>
<tr><td>Inside (observe)</td><td></td></tr>
</table>

11

Checklist • Is there enough space inside for a participant and her Carer (if she needs support) to move around easily? • When the door is closed is there enough light to see? • Do the roof / window (if applicable) provide adequate privacy for user/s?	
Water (observe and ask the participant)	
Checklist • Is there an internal water point? Describe. • Can the water be used to wash the body and the menstrual cloth? • Is soap or ash available? • Can the water and soap be easily reached by all users?	
Disposal: Is there a place where washed reusable menstrual cloths be dried, or where it can be thrown away (observe / ask the participant)?	
Checklist • Can the cloth be hung up? • Is it in sunlight to dry the cloth? • Is there a bin with a lid for sanitary disposal? • Is there a safe location for the final disposal of the sanitary waste (i.e. incinerator, a place to bury it or disposal into municipal waste collection systems)?	
Any additional information or comments	

Annex 1: Algorithm outlining referral options offered or actions taken in response to disclosures of violence

Referral Type	Age	Discloses	Defined as:	Primary course of action/person notified	Time frame for action	Finish to interview
Mandatory	Any age	Use of severe physical or sexual violence against a child	Burning, choking, stabbing, whipping, beating up, or any similar act; physically forcing or coerced sex	Research supervisor notifies project manager same day. Project manager notifies <<named individual>> the same day.	Discussion of each case and a plan for any further action within one day of receipt of the case.	[INTERVIEWER]: "Because of some of what you've told me, I am concerned that a child in your care may be at risk and I have a professional responsibility to let somebody else know. What I'm going to do is talk to my research team supervisor and they will pass your details to <<named individual>>. I am not going to pass anything you said to me in this room to anybody else. Is there anything you'd like to ask me?"
Optional	Age over 18 years	Forced sexual intercourse within the past week, or obvious untreated physical injuries	In **past week**: threatened or pressured into sex; physically forced sexual intercourse or doing sexual things; suffered cuts, loss of consciousness; dislocated, sprained, fractured or broken bones; untreated injuries or severe injuries (requiring medical attention) reported as a result of physical or sexual violence; signs of acute malnutrition /neglect	With consent of participant: research team supervisor telephones <<named individual>> immediately from the field. Immediate transport to health centre is arranged by <organisation> in consultation with research team supervisor; concurrent arrangements made for other support as necessary by <organisation>, other adults notified at request of child. Transport arrangements may involve the research team, 3rd parties, or staff of <organisation> depending on the time frame and particulars of the case.	Participant taken to health centre immediately/same day/next day depending on the particulars of the case.	[INTERVIEWER]: "Because of what you've told me today, I am concerned about your health and safety. What this means is that if you want me to, I will to arrange to bring you to the health centre, to make sure that you are OK. If you agree, what will happen next is that I will talk to my friend <<named individual>>, who works at <organisation> in child protection. She will arrange for you to visit the local health centre, and will want to speak with you. It's part of <<named individual>>'s job to help make sure that young people in your community are safe and taken care of. She/he is very experienced and has helped many young people. You can ask me what is going on and what is going to happen

						next at any time. How do you feel about that? Are there any other adults you would like me to help you get in touch with about the things you have told me? Would you like me to inform your parents/caregivers? It is your choice. What is the best way for <<named individual>> to get in touch with you about this, for example, at school, or at home, or some other way?”
Mandatory	Under age 18 years	Forced sexual intercourse within the past week, or obvious untreated physical injuries	In **past week**: threatened or pressured into sex; physically forced sexual intercourse or doing sexual things; suffered cuts, loss of consciousness; dislocated, sprained, fractured or broken bones; untreated injuries or severe injuries (requiring medical attention) reported as a result of physical or sexual violence; signs of acute malnutrition /neglect	With or without consent of participant: research team supervisor telephones <<named individual>> immediately from the field. Immediate transport to health centre is arranged by <organisation> in consultation with research team supervisor; concurrent arrangements made for other support as necessary by <organisation>, other adults notified at request of child. Transport arrangements may involve the research team, 3rd parties, or staff of <organisation> depending on	Participant taken to health centre immediately/same day/next day depending on the particulars of the case.	[INTERVIEWER]: “Because of what you’ve told me today, I am concerned about your health and safety. What this means is that I will to arrange to bring you to the health centre, to make sure that you are OK. What will happen next is that I will talk to my friend <<named individual>>, who works at <organisation> in child protection. She/he will arrange for you to visit the local health centre, and will want to speak with you. It part of <<named individual>>’s job to help make sure that young people in your community are safe and taken care of. She is very experienced and has helped many young people. You can ask me what is going on and what is going to happen next at any time.

				the time frame and particulars of the case.		Are there any other adults you would like me to help you get in touch with about the things you have told me? Would you like me to inform your parents/caregivers? It is your choice. What is the best way for <<named individual>> to get in touch with you about this, for example, at school, or at home, or some other way?”
Optional	Any age	All other disclosures causing concern	For example, other less severe forms of violence, mental health issues	Researcher offers to contact <organisation>; <<named individual>> will then provide list of agencies which may be able to provide support, and facilitates contact according to wishes of the participant	Discussion of each case and documentation of further action within three weeks of receipt of the case.	“Thank you for sharing those things with me. If you want, I can recommend somebody who might be able to help you. If you say yes, I would like to put you in touch with my friend <<named individual>>, who works at <organisation>. She/he may be able to help put you in touch with other organisations that can assist you. Do you think you would like me to contact <<named individual>> for you? <<if participant says yes>> “What is the best way for <<named individual>> to get in touch with you?”

In Depth Interview Question Guide for people with disabilities

Materials and supplies for in depth interview

- One digital recording device
- Spare Battery for recording device
- Notebook for note-taking and pens
- Camera
- Refreshments

Use of these questions

These questions are a guide only. In practice, field staff should familiarise themselves with these questions and adapt them to suit the participant and their responses. This responsiveness is important to ensure that the participant feels at ease and able to talk about these topics. The interview should feel more like a conversation rather than a question and answer session. It is important to establish a rapport with participants, so begin with some general questions about their family and their interests before delving into what are quite private topics relating to menstrual hygiene management. Questions should be added where a participant mentions something of interest or touches on something that needs further clarification. Questions can be skipped where a participant answers the question in a previous response. You may not need to go through all questions.

Risks

If there is a concern that the Primary Participant does not understand what informed consent entails, ask for her Carer's consent. If consent is given, interview the primary participant and the carer.

To be completed for each interview

Name of interviewer	FIRST NAME	SURNAME	
Name of note taker	FIRST NAME	SURNAME	
District	Village / Metropolitan area / Municipality	Household number	
Name of Primary Participant	FIRST NAME	SURNAME	
Age			
Caste			
What is your main source of income?	*Circle only one answer* 1. Agriculture / livestock 2. Trader (food / non-food items) 3. Craftsperson 4. Small business / shop owner 5. Manual labourer 6. Other (specify)		
Has written informed consent been obtained from the participant?	Yes	No	N/A
If participant is under 18 years old and / or has an intellectual disability has parental/Carer consent been obtained?	Yes	No	N/A
If the participant has a communication / intellectual disability, have they been given the choice about who they want to be interviewed with if	Yes	No	N/A

they prefer not to be interviewed by themselves?			
Name of Carer, family member or guardian of Primary Participant	FIRST NAME	SURNAME	
Date of interview		Start time:	End time:
Interview number		Audio interview recording number:	
Additional information (whether the Carer may need to assist in answering the questions with reasons for this).			

INSTRUCTIONS: INTERVIEWER TURN ON THE TAPE RECORDER AND SAY CLEARLY THE DATE, TIME, LOCATION, AND THE INTERVIEWER'S NAME

Opening/ rapport building questions (probes in italics)

- Who do you live with? Siblings, parents / grandparents?
- Do you have friends nearby?
- Do you go to school or work? Tell me a bit about that.

I'm now going to ask you a few questions about any difficulties you have.

Washington Group short set questions (circle the answer)

	Functional domain	**No difficulty**	**Some difficulty**	**A lot of difficulty**	**Cannot do it at all**
A	Do you have difficulty seeing, even if you are wearing glasses?	1	2	3	4
B	Do you have difficulty hearing, even if you are using a hearing aid?	1	2	3	4
C	Do you have difficulty walking or climbing steps?	1	2	3	4
D	Do you have difficulty remembering or concentrating?	1	2	3	4
E	Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4
F	Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?	1	2	3	4

KEY QUESTIONS

Now we are going to move on to our discussion of more specific questions about menstruation.

1. **Does someone in your family help you with daily activities, like washing and eating?**

    - Who supports you?
    - What support do they give you?

2. **What are words that girls and women use to talk about menstruation?**

    - What words are used with friends?
    - What do they mean?
    - Are 'secret' words used so nobody else will know what is discussed?

3. **Can you tell me about the first time you got your period?**

Context:
- How old were you?
- Did you know what to do?
- Did you have supplies to manage?

Attitudes/emotions:
- Can you remember how you felt at that time?

Knowledge:
- Did you know what it was when you got it? How?
- Who told you about it (family, friends, teachers, health worker)?
- What did they tell you?

Resources/management/practices:
- What did you use (pads, cloth, tissues, etc.)?
- Who/where did you get materials from?
- Where did you go to manage your period (latrine, separate room, outside, etc.)?
- Do you remember if there was water, soap, privacy where you managed your period?

Support:
- Did you tell anyone? Please explain.
- If yes, who did you talk with? Why?
- Did you try to hide it or keep it a secret? Why?
- What did you talk about?
- Who did you not want to know? Why?

4. Can you tell me about the most recent time you got your period?

Context:

- Where were you?
- Were you prepared for it? How were you prepared?

Attitudes/emotions:

- How did you feel (pleased, scared, worried, no negative or positive feelings at all)? Why?

Resources/management/practices:

Instructions: you may want to complete the Product Attribute Assessment now and run through the following probing questions, or you can complete the Product Attribute Assessment at the end of the IDI questions.

- What did you do?
- What material / product did you use (pads, cloth)?
- Do you normally use those materials?
- Do you use different supplies for different days (light or heavy menstrual flow)?
- Do you find them difficult or easy to use? Why?
- Who/where did you get them from?
- How often do you change them?
- Where do you change them?
- Where do you go to wash your menstrual materials (if not disposable)?
- Where do you dry re-usable materials? (Inside? Outside? In sun? In shade?)
- Where do you store the materials when you do not have your period?
- Where would you dispose of materials (if not re-usable)? Is this method of disposal OK or would you prefer other options?
- Where did you go to clean yourself when you have your period?
- Do you feel safe in the place you clean yourself?
- How often do you clean yourself when you have your period? How often do you clean yourself when you do **not** have your period?
- Do you find it hard or easy to change the menstrual material, dry the menstrual cloth / dispose of the menstrual product, wash yourself? Please explain.
- Do you have pain? How do you manage the pain (e.g. massage, warm cloth, paracetamol)?
- What are the worst problems?
- Do you think these challenges would be the same for females that do not have disability?

Support:

- Does someone support you manage your period (a carer)? How do they help you?
- Does anyone ever provide materials or supplies for you? Who?

- If someone provides materials for you, where do they get the materials? Do they cost something?
- Who did you not want to know you had your period? Why?

5. **Do you know when your period is coming? How?**

Management/practices:

- How does that help you prepare and manage your period?
- Do you know when it has started and finished?
- How do you normally prepare for your period?

6. **When you are menstruating now, who do you talk to about it (if anyone)?**

Support:

- Friends/family/teacher/boyfriend?
- Why do you talk to this person?
- Why not others?

7. **Is there anywhere you're not allowed to go when you are menstruating?**

- Are there restrictions placed on you? Mobility? Cooking? Eating? Religious? Why?
- Are there things you prefer not to do?
- Do you leave the house? Where do you go (work, school, friends)?

8. **Are these restrictions different for you to females who do not have disability? How?**

- Who treats you differently?
- If yes, how do they treat you differently?

9. **Are there any advantages to menstruating? Please explain.**

- Rest from regular housework/school work?
- Respect from others?

10. **Has anyone ever spoken to you about lightening your menstrual flow?**

If yes:

- Who has spoken to you about that?
- What did they say?
- What happened?
  - Explore if this is sterilization or lightening the menstrual flow.
  - Explore reasons for these discussions, who made the decision; if the primary participant knew what was happening; did she consent? Explore if someone has spoken to her about sterilization.
- How do you feel about this?

If no, move to the next question.

11. **Are you able to control when you urinate or defecate?** *If yes, skip to the next question.*

    - How do you deal with that?
    - What are the challenges (i.e. getting to the toilet, washing, cleaning clothes / bedding, going out of the house)?
    - Do you use products (i.e. cloth, pad, nappy)? What are these? Where do you get them?

12. **If you had a little sister/cousin who had disability, what advice would you give her before she starts menstruating to help her, what would you say?**

13. **What could parents/families/careers do to support their girls with disability when they are menstruating?**

14. **We are going to come up with recommendations for organisations that could help improve menstrual hygiene management for people have a disability. What advice would you like us to pass along to them that you think would make things better for you when you are menstruating?**

Product Attribute Assessment

I would like to see menstrual products you use. Please can you set out all the menstrual hygiene products you use?

1. Ask about each item displayed:
    a. What are its good qualities (probe into physical accessibility, acceptability, affordability, appropriateness and quality)?
    b. What are its less good qualities (probe into physical accessibility, acceptability, affordability, appropriateness and quality)?
    c. How long has this product been used?
    d. Have you tried using any other product?

2. Introduce other products that are available on the local market (obtained through the market survey). Ask the participant if they have ever used any of the products? *State what these are into the audio voice recorder.*

3. Ask participants what they feel about these products. *State which product are being discussed into the audio voice recorder.*
    a. Would you be willing to pay the price of this? Show the costs of each product (displayed on the bottom of the packaging)?
    b. What would your personal preference be? Why? (Probe into physical accessibility, acceptability, affordability, appropriateness and quality)?
    c. How would other people perceive these products?
    d. Could you use, wash and dispose of these products independently and privately? If not, why not?

4. Give the shop bought products and the products currently used to the participant. *State what these are into the audio voice recorder.* Ask the participant to:
    a. Put all the products in a line
    b. Reorder the products in preference order. Left being the least preferred option. Right being the most preferred option
    c. Ask the participant why they have ordered them in that way
    d. Take a photo of the product line and state the order into the audio voice recorder.

10

Accessibility and safety audit

Ask the user to show you where she manages her menstruation / where the Carer manages the menstruation of the person s/he is caring for?	
Type of facility (i.e. latrine, wash room, behind a bush/tree):	
Location:	
General description of the facility:	
Ask the user to into and show how they can/cannot use the facility. Make a note of any features that make it difficult to use.	
Getting there (observe):	
Checklist • Distance from house to facility. • Is the path wide enough for the primary participant? • Is the path level and firm, with nothing to trip up? • Is the path surface slippery when either dry or wet? • Are there obstacles that block the path, or make it easy to trip especially for visually impaired people? • Are slopes too steep? • If used at night, is the path lit? • Are there any parts of the path which make people feel unsafe when using it? If so why?	
Getting in/on/out (observe):	

Checklist Steps: • Are they even or uneven, firm or broken, non-slip or slippery? • Is there a handrail for support? Entrance: • Is it wide enough for the user to enter? • Is the door easy to open? • Is the door easy to lock and unlock? • If someone faced harassment or other safety risks when using the facility would they be able to safely get away from the facility?	
Safety of use (ask the participant)	
Checklist • Do you feel safe when using the facility? • Are there any particular times of day or night when you feel less safe? • Is there any way that anyone can easily see inside the facility?	
Inside (observe)	

Checklist • Is there enough space inside for a participant and her Carer (if she needs support) to move around easily? • When the door is closed is there enough light to see? • Do the roof / window (if applicable) provide adequate privacy for user/s?	
Water (observe and ask the participant)	
Checklist • Is there an internal water point? Describe. • Can the water be used to wash the body and the menstrual cloth? • Is soap or ash available? • Can the water and soap be easily reached by all users?	
Disposal: Is there a place where washed reusable menstrual cloths be dried, or where it can be thrown away (observe / ask the participant)?	
Checklist • Can the cloth be hung up? • Is it in sunlight to dry the cloth? • Is there a bin with a lid for sanitary disposal? • Is there a safe location for the final disposal of the sanitary waste (i.e. incinerator, a place to bury it or disposal into municipal waste collection systems)?	
Any additional information or comments	

Annex 1: Algorithm outlining referral options offered or actions taken in response to disclosures of violence

Referral Type	Age	Discloses	Defined as:	Primary course of action/person notified	Time frame for action	Finish to interview
Mandatory	Any age	Use of severe physical or sexual violence against a child	Burning, choking, stabbing, whipping, beating up, or any similar act; physically forcing or coerced sex	Research supervisor notifies project manager same day. Project manager notifies <<named individual>> the same day.	Discussion of each case and a plan for any further action within one day of receipt of the case.	[INTERVIEWER]: "Because of some of what you've told me, I am concerned that a child in your care may be at risk and I have a professional responsibility to let somebody else know. What I'm going to do is talk to my research team supervisor and they will pass your details to <<named individual>>. I am not going to pass anything you said to me in this room to anybody else. Is there anything you'd like to ask me?"
Optional	Age over 18 years	Forced sexual intercourse within the past week, or obvious untreated physical injuries	In **past week**: threatened or pressured into sex; physically forced sexual intercourse or doing sexual things; suffered cuts, loss of consciousness; dislocated, sprained, fractured or broken bones; untreated injuries or severe injuries (requiring medical attention) reported as a result of physical or sexual violence; signs of acute malnutrition /neglect	With consent of participant: research team supervisor telephones <<named individual>> immediately from the field. Immediate transport to health centre is arranged by <organisation> in consultation with research team supervisor; concurrent arrangements made for other support as necessary by <organisation>, other adults notified at request of child. Transport arrangements may involve the research team, 3rd parties, or staff of <organisation> depending on the time frame and particulars of the case.	Participant taken to health centre immediately/same day/next day depending on the particulars of the case.	[INTERVIEWER]: "Because of what you've told me today, I am concerned about your health and safety. What this means is that if you want me to, I will to arrange to bring you to the health centre, to make sure that you are OK. If you agree, what will happen next is that I will talk to my friend <<named individual>>, who works at <organisation> in child protection. She will arrange for you to visit the local health centre, and will want to speak with you. It's part of <<named individual>>'s job to help make sure that young people in your community are safe and taken care of. She/he is very experienced and has helped many young people. You can ask me what is going on and what is going to happen

						next at any time. How do you feel about that? Are there any other adults you would like me to help you get in touch with about the things you have told me? Would you like me to inform your parents/caregivers? It is your choice. What is the best way for <<named individual>> to get in touch with you about this, for example, at school, or at home, or some other way?”
Mandatory	Under age 18 years	Forced sexual intercourse within the past week, or obvious untreated physical injuries	In **past week**: threatened or pressured into sex; physically forced sexual intercourse or doing sexual things; suffered cuts, loss of consciousness; dislocated, sprained, fractured or broken bones; untreated injuries or severe injuries (requiring medical attention) reported as a result of physical or sexual violence; signs of acute malnutrition /neglect	With or without consent of participant: research team supervisor telephones <<named individual>> immediately from the field. Immediate transport to health centre is arranged by <organisation> in consultation with research team supervisor; concurrent arrangements made for other support as necessary by <organisation>, other adults notified at request of child. Transport arrangements may involve the research team, 3rd parties, or staff of <organisation> depending on	Participant taken to health centre immediately/same day/next day depending on the particulars of the case.	[INTERVIEWER]: “Because of what you’ve told me today, I am concerned about your health and safety. What this means is that I will to arrange to bring you to the health centre, to make sure that you are OK. What will happen next is that I will talk to my friend <<named individual>>, who works at <organisation> in child protection. She/he will arrange for you to visit the local health centre, and will want to speak with you. It part of <<named individual>>’s job to help make sure that young people in your community are safe and taken care of. She is very experienced and has helped many young people. You can ask me what is going on and what is going to happen next at any time.

				the time frame and particulars of the case.		Are there any other adults you would like me to help you get in touch with about the things you have told me? Would you like me to inform your parents/caregivers? It is your choice. What is the best way for <<named individual>> to get in touch with you about this, for example, at school, or at home, or some other way?”
Optional	Any age	All other disclosures causing concern	For example, other less severe forms of violence, mental health issues	Researcher offers to contact <organisation>; <<named individual>> will then provide list of agencies which may be able to provide support, and facilitates contact according to wishes of the participant	Discussion of each case and documentation of further action within three weeks of receipt of the case.	“Thank you for sharing those things with me. If you want, I can recommend somebody who might be able to help you. If you say yes, I would like to put you in touch with my friend <<named individual>>, who works at <organisation>. She/he may be able to help put you in touch with other organisations that can assist you. Do you think you would like me to contact <<named individual>> for you? <<if participant says yes>> “What is the best way for <<named individual>> to get in touch with you?”

PhotoVoice – guidance for researchers

Purpose of PhotoVoice

This exercise is designed to investigate the barriers to menstrual hygiene management that the primary participants face and how these barriers are prioritised (if at all) by the primary participants. This method aims to empower participants with photography skills so that they are able to share their personal perspectives and experiences of how these challenges affect the lives of individuals with disability. This method is particularly important for the exploration of this topic which tends to be difficult to talk about since it is very private.

Requirements

- Digital camera, SD card and spare battery
- Photo printing facilities
- Voice recorder
- Notebook and pen

Identifying participants

It may not be possible to do PhotoVoice with all individuals with disability. For this exercise it is important that participants are able to follow instructions and think critically about the task being given. Because of the nature of digital cameras motor skills are important. For individuals with severe intellectual impairments this task is likely to be difficult. However since it is also a very practical interactive exercise, it may be possible to undertake the activity with those who have mild intellectual impairments. Experience indicates that not only does this task work well with those who have physical disabilities, but it can also be used effectively with individuals who have sensory impairments (including those who are totally blind) and could work well with those who have hand/arm impairments.

Consent and explanation of the process

The consent process must be done very thoroughly to ensure that the primary participant understand the purpose of the activity and what they are agreeing to. Each primary participant will have been asked for their consent to be given through the in-depth interviews.

Consent to take part in the research must be signified in writing by the primary participant wherever possible. Where the participant is unable to give full consent or is 15 years old, a guardian/career must also provide written consent. Where primary participants or their caregivers are illiterate they should use a thumbprint to signify their consent.

A secondary process of obtaining permission should be done after the photos have been taken. This process relates to how the photos can be used and how they should be acknowledged. This is done after the process so that the participant can make a better judgement about how they wish them to be used.

PhotoVoice Process:

The PhotoVoice process used in this research was partly taken from the process developed by photovoice.org (http://www.photovoice.org/methodologyseries/inclusivemethodology/designing.htm)

1. **Understanding the camera** - A photographic camera (digital) will be provided to the participant. The field worker should explain simply how the camera works and allow the participant to observe (or feel if they are visually impaired) where the lens is and how the shutter works (a visually impaired person can listen to the shutter noise and feel the lens while closed, so not to leave marks on the lens). The field worker should take time to teach the participant the basic features of the device including how to switch the camera off and on, how to take a photo and how to view the photo. Allow the participant to have a go taking a photo to see what it feels like. It is important that while the participant is learning about the camera they are also holding it so that they begin to be familiar with how it feels. This is particularly important for people with sensory impairments so that they begin to learn how the buttons feel and how they are positioned. A useful starting point is to remind the individual to always use the wrist strap/head strap.

2. **Understanding photography** - Since many of your participants may never have seen a camera before and may have seen relatively few photos in their life, it is also important to explain the purpose of photography. We found that a simple way to explain this is to say that photography can serve several purposes. You can use photography to capture a moment you want to remember as if it was real again. Give an example of this by getting the participant to take a photo of the fieldworkers or their house, view the photo and point out that it looks exactly like it is in real life. Then explain that you can also use photography as if it was art by arranging things in a certain way that tells a story or creates a version of reality that can be explored or questioned. Give an example of this too – if you want to take a photo of the idea of 'hunger' it may be hard to show this literally. But you could use symbolism to show hunger. You might have a family seated in their living room, all looks normal except all of them have empty bowls in front of them. Explain that what we are going to do today is use photography to tell their story and creatively express their views.

3. **Understanding the elements of Photography** –
    a. **Landscape/Portrait -** Shooting can be done vertically (portrait) or horizontally (landscape). Show participants how this effects the image and explain that portraits can be better when you are focusing on a person and landscapes can be better when you want to capture more of the environment. For people who are visually impaired this can be demonstrated using a mount board window, which can be rotated and felt by the participants. A collection of tactile objects such as toys or fruit can be a good focus for this exercise – the window can be placed by the display in each position and the difference in what is contained in the 'photo' felt through the window.
    b. **Framing -** Explain that when taking a photograph it is not simply a matter of pointing towards the subject, but of deciding what is included in the photo – all or some of the subject, the subject and the background, the subject and what is above it etc. Tactile objects can be a useful reference for explaining this concept to someone who is visually impaired. Show the participant how to adjust the framing by using the zoom.
    c. **Foreground/background -** This must be explained in a verbal way as well as using their body as a reference. For example you can ask two participants to stand one in front of the other, and then explain who is in the foreground and who is in the background and what that would mean in a photograph (i.e. who would seem more important, more prominent, larger in the frame etc). Show the participant how to change the focus on the camera.

   d. **Distance (only for people with visual impairments) -** When taking a photograph, it is very important to identify the distance to the subject, in order to be sure that it is framed as desired. This can be done by reaching with or laying out a cane, measuring it with steps, or measuring with the joints, such as hands, wrists, arms and forearms. It can be very reassuring for a photographer to know how a photo of a person will be framed if taken from the distance of one cane's length, for example.
   e. **Focus/blur -** It is important to clearly identify the area that needs to be in focus. The photographer needs to remember that she can communicate different feelings or ideas depending on what is focused on in the photograph. Here is one way the concept can be explained in a way that makes sense to someone with no sight: When one touches a glass bottle, one identifies the material, its temperature, its dimensions and every detail that makes one recognize the object as a bottle. If this is done again with a thin cloth over the bottle, the details of the bottle won't be recognized so precisely. Nevertheless, one will still know it is a bottle, since some details, like its shape and size, are still recognised. This is what happens when one sees an image that's blurry or out of focus; one recognizes what it is but cannot make out the details clearly.
   f. **Light -** Light plays an important role in a photograph since it produces different effects, which lead to different feelings in the observer. A person in darkness, for example, may convey an experience of feeling hidden, where as a person in bright light may convey confidence or nothing to hide. These effects need to be explained fully to blind or visually impaired photographers who will not necessarily realise the impact of the light on their work. To explain this try invite the participant to think about the warmth they feel on their face if they are in the sun and use this sensation to determine where the light is coming from. Also teach the participant how to use the flash setting for dark environments.
   g. **Taking photos without showing a face** – explain how the participant can take portraits of herself and others without showing their faces. Techniques include:
      i. Taking photos with the light behind the subject so the figure will be in shadow.
      ii. Focusing on something behind or in front of the subject. This means that the subject will be in soft focus
      iii. Photographing a person's shadow
      iv. Taking a photo of someone from behind (the back of their head, their head / body etc)

4. **The photographic task** - Once the participant is comfortable with all this, set them their task. Explain that you would like them to take a total of 10 pictures. These pictures should represent their feelings about menstruation and how they manage it. Ask the participant if anything springs to mind. Help the participant make a list of these issues so that these things can be remembered. For each one, the participant should think about how she could represent the experience or feeling. If the participant needs more guidance, work through one example with her, but make sure she leads the process.
5. **Self-Directed portraits** - It is likely that in settings where participants are unfamiliar with cameras and photography that they will be keen to be in the photos rather than just taking them. If the participant wanted to be in the picture then they still had to direct the field researcher as to how they wanted the photo to look, providing direction on whether it was to be a portrait or landscape shot, what was in the foreground or background, how much of their body should be in shot etc.

6. Arrange a suitable time to return to the individual's house to give them their photos and have a short discussion.

Printing and interview

When you return with the printed images ask the participant to caption each of the images. To explain what a caption is ask the participant to imagine that there is a person looking at the photo who doesn't know them or anything about how they live – their task is to explain to them the experience they were trying to convey. Ask the participant to explain what story she was trying to tell when taking the photo.

Once they have done this get the photos and ask them to rank these from most important to least important. Document the order by taking a photo of them in order. Ask questions to explore why the participant has ordered the photographs in that way. Explore why the most important are particularly significant.

PhotoVoice images

Result: The barriers to MHM differ depending on the person's impairment

Fig. 1 "It is difficult to go to the toilet." PhotoVoice image taken by Sharmila Tamang. Ranked 1 out of 4.

Fig. 2 "Water issue is also there, I would have to carry water which is difficult." PhotoVoice image taken by Sharmila Tamang. Ranked 2 out of 4.

Fig 3. “It is not only easier to use this type of toilet for those with spinal cord injury but it is a necessity. So even in villages, these types of toilets should be built for people as not everyone can live in the cities. During period also it is difficult to stand to change pads so these kind is easier to use.” PhotoVoice image taken by Babita Thapa. Ranked 1 out of 5.

Fig 4. “During period one should be careful using bathroom. Our legs might already feel weak (lulo) so we might fall down and meet an accident. Here the toilets are made for everyone to use but if it was to built at home for crutches user, it is to be made in a way that it is not slippery. Marble should not be used as it is slippery.” PhotoVoice image taken by Babita Thapa. Ranked 3 out of 5

Fig 5. “For us to be able to wash our own clothes, bathroom should be made in such a way that we can wash our clothes ourselves while sitting on wheelchair. It will be much easier.

“I can’t wash clothes while standing or sitting. At home, I sit in a small stool but there is none here. If the washing space could be reached while sitting on a wheelchair, it would be good.” PhotoVoice image taken by Babita Thapa. Ranked 5 out of 5.

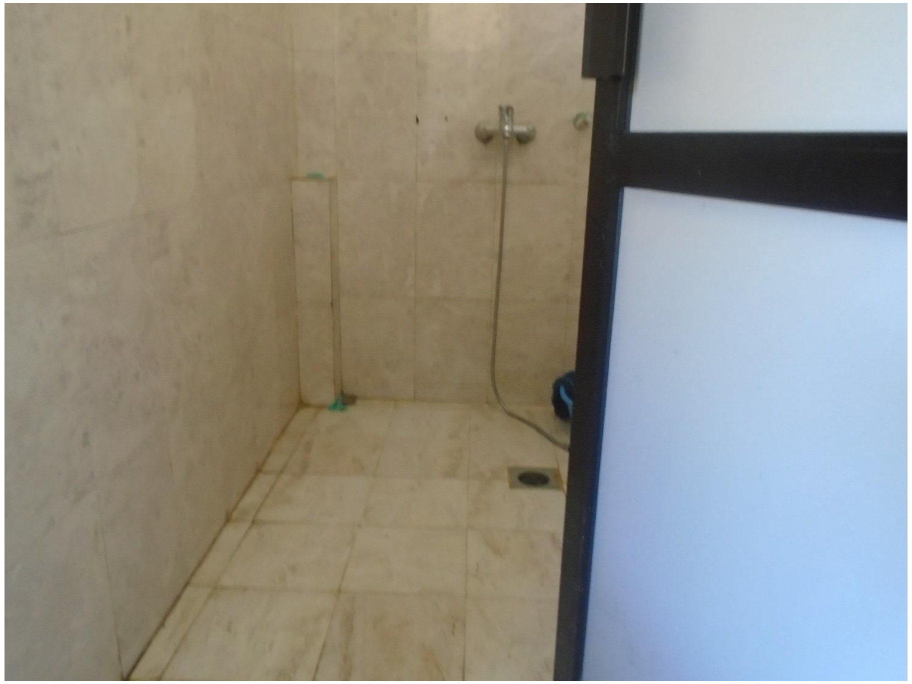


Fig. 6 "When I have to use the toilet, I need someone else to help with the latch otherwise I can't do it myself." PhotoVoice image taken by Tulasa Karki. Ranked 3 out of 4.

Result: Disposable menstrual pads are preferable, but disposal practices and services are inadequate

Fig. 7 “Pad is easy to use compared to cloth.” PhotoVoice image taken by Sharmila Tamang. Ranked 3 out of 4.

Result: Impacts of menstrual restrictions

Fig. 8 "During menstruation we are not allowed to enter the house." The image is of the hut Tulasa sleeps in when menstruating. PhotoVoice image taken by Tulasa Karki. Ranked 2 out of 4.

Fig. 9 "There is a belief that if you touch plants during period, it will rot." PhotoVoice image taken by Tulasa Karki. Ranked 4 out of 4.

Fig. 10 “Cannot touch during period as per our tradition.” The image is of worshiping area inside Bishnu’s home. PhotoVoice image taken by Bishnu Maya Sapkota. Ranked 1 out of 4.

Fig. 11 “We have to follow our tradition, so should not touch kitchen during period. If one touches kitchen, worshipping area is also touched. If touched, I feel discomfort and fear that something might happen. However, in case of my daughter if she touches, god will forgive her.” PhotoVoice image taken by Bishnu Maya Sapkota. Ranked 2 of 4.

Table 1. **Most preferred product according to the person's impairment**

Impairment	**Product**	**n=**
Hearing	Reusable pad with wings	1
Cognition	Disposable pad with wings	1
Visual	Reusable pad with wings	1
	Disposable pad with wings	1
	Cloth	1
Self-care	Disposable pad without wings	1
Mobility	Disposable pad with wings	3
	Cloth	1
	Disposable pad without wings	1
Mobility and self-care	Disposable pad with wings	1
	Reusable pad with wings	1
	Cloth	1
Mobility and communicating	Disposable pad with wings	1
Mobility, cognition	Disposable pad with wings	1
Totals		16

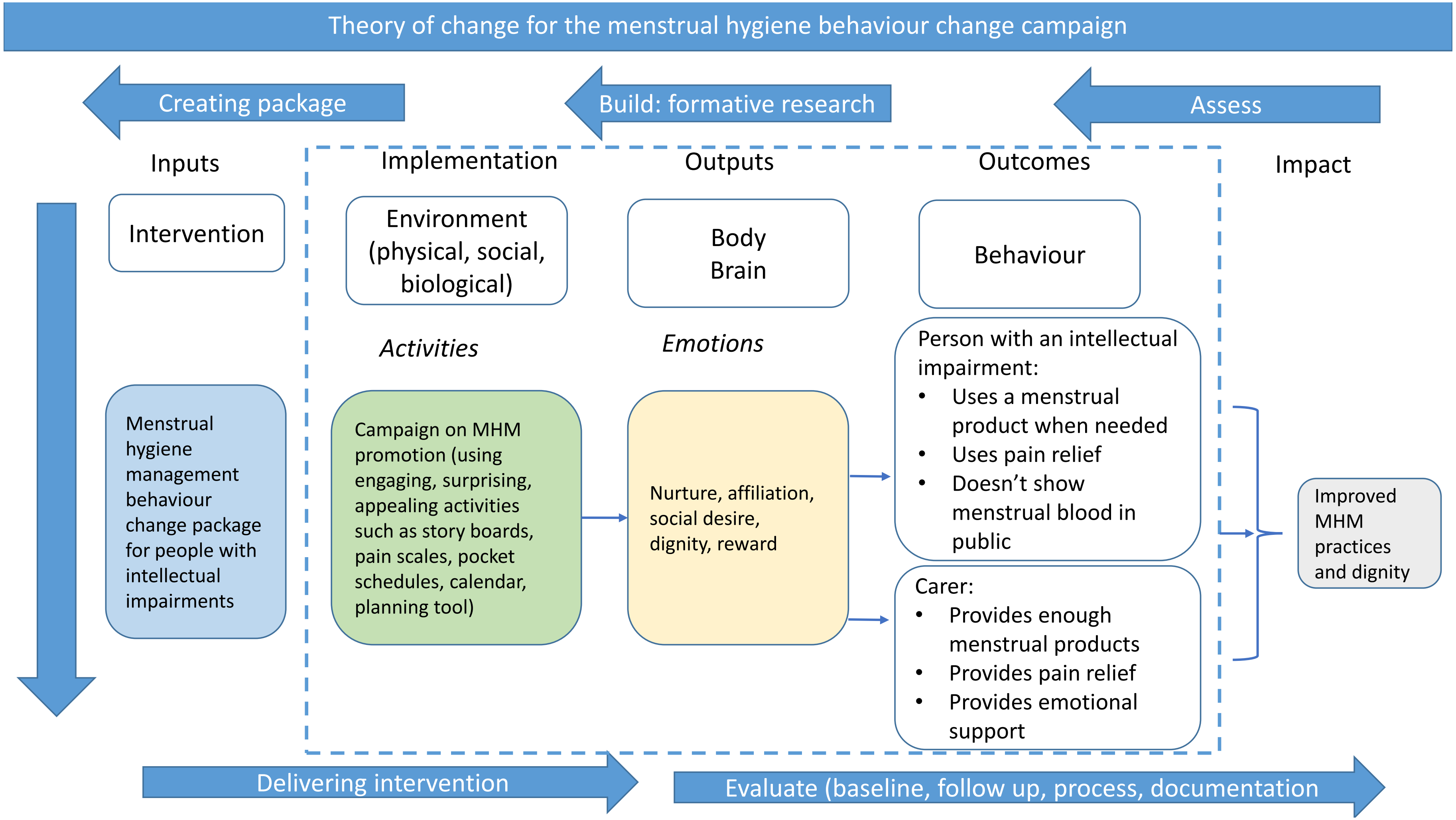
Table 2. Least preferred product according to the person's impairment*

Impairment	**Product**	**n=**
Visual	Cloth	1
	Disposable pad without wings	1
	Reusable pad with wings	1
Self-care	Cloth	1
Mobility	Nappy	1
	Cloth	1
	Disposable pad without wings	2
	Reusable pad with wings	1
Mobility and self-care	Reusable pad with wings	2
	Cloth	1
Mobility and communicating	Cloth	1
Totals		13

*No data not available for three participants.

Appendix 5. Supporting information for Paper Four

Figure S2. Theory of Change for the menstrual hygiene behaviour change campaign



Theory of change for the menstrual hygiene behaviour change campaign

Creating package

Build: formative research

Assess

Inputs

Intervention

Menstrual hygiene management behaviour change package for people with intellectual impairments

Implementation

Environment (physical, social, biological)

Activities

Campaign on MHM promotion (using engaging, surprising, appealing activities such as story boards, pain scales, pocket schedules, calendar, planning tool)

Outputs

Body
Brain

Emotions

Nurture, affiliation, social desire, dignity, reward

Outcomes

Behaviour

Person with an intellectual impairment:
- Uses a menstrual product when needed
- Uses pain relief
- Doesn't show menstrual blood in public

Carer:
- Provides enough menstrual products
- Provides pain relief
- Provides emotional support

Impact

Improved MHM practices and dignity

Delivering intervention

Evaluate (baseline, follow up, process, documentation

Table S2: Example: Insight development for the 'comfort and confidence' theme.

Findings	**Theme**	**Target behaviours**	**Statement connecting the theme with relevant behaviour/s**	**Insight**	**Motives**
Persons with disabilities: want to feel more comfortable; may not understand the purpose of a menstrual product; may be sent home from school if unable to manage menstruation; may go out with blood stained clothes. Carers: want to be a good carer; need to earn an income, so might leave the person they care for at home all day with a very thick menstrual cloth on; they have many tasks and may be too tired to change the menstrual product at the end of the day; might not always provide pain relief. General: there is a belief that pain relief tablets can damage health, so many people do not take them; some people use natural remedies to manage menstrual cramps, such as a hot water bottle or tying a piece of cloth tightly around the abdomen.	Comfort and confidence: pads, pain relief, understanding and communicating pain.	Disabled person: uses a menstrual product when needed, uses pain relief; does not show menstrual blood in public. Carer: provides enough menstrual products, provides pain relief and provides emotional support and love.	Managing menstrual blood and cramps can be made easier and more comfortable for disabled persons by using effective products and pain relief. Carers need to be able to provide these and give emotional support.	A good carer supports a person with an intellectual disability to be as independent as possible during menstruation. A person with an intellectual disability can feel more comfortable and confident to manage bleeding, pain and stress if they use effective menstrual products and pain relief and their carer provides emotional support, advice, pain relief and menstrual products.	Comfort, dignity, reward, affiliation

Appendix 6. Supporting information for Paper Five

Supplementary material 1: Visuals of key behaviours and handwashing


महिनावारीको समय दुखाई कम
गर्ने उपाय अपनाउनु पर्छ ।


प्रेरणादायी स्याहार
विशेषताको आधार
विशेषतासँग सफा र पर्याप्त मात्रामा महिनावारी सामग्री भएको सुनिश्चित गर्नुहोस् ।


विशेषतालाई दुखाई कम गर्न
उचित विकल्प दिनुहोस् ।


विशेषतालाई माया गर्नुहोस् र
भावनात्मक सहयोग दिनुहोस् ।

Supplementary material 2: I Change My Pad Visual story

प्रेरणादायी स्याहार
विशेषताको आधार

I change my pad

Jane Wilbur, Thérèse Mahon and Shila Thapa
Illustrations by Raju Shakya (Sarab)

WaterAid

LONDON
SCHOOL *of*
HYGIENE
&TROPICAL
MEDICINE

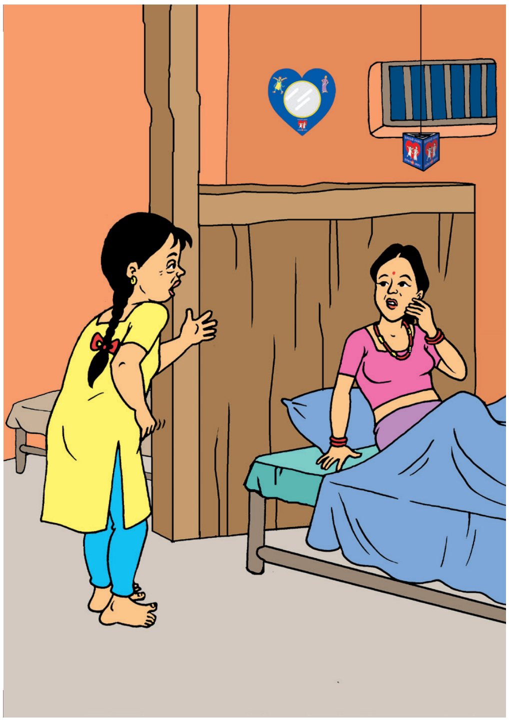
DOWN SYNDROME SOCIETY, NEPAL

1

2

3

4



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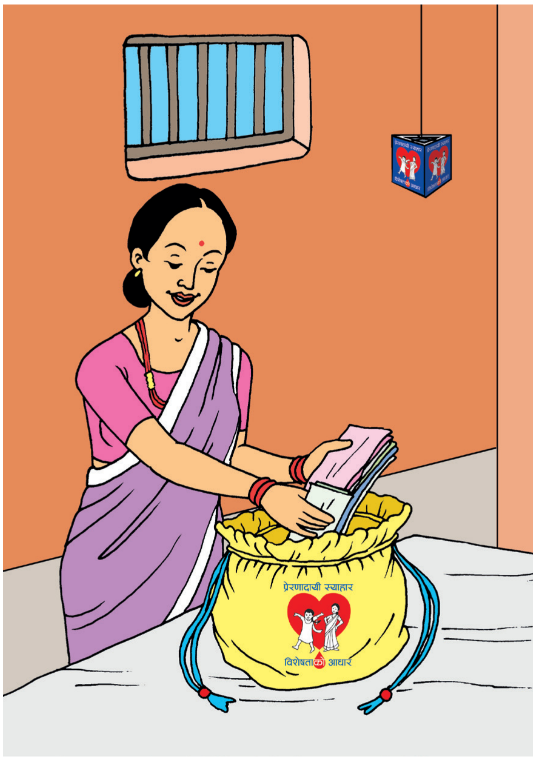

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21

The following words are for carers who want a ready-made story rather than making up your own.

Page 1: Bishesta helps with the household chores.

Page 2: Bishesta refuses to eat because she has menstrual cramps.

Page 3: Bishesta has menstrual cramps.

Page 4: Bishesta goes to Perana for help.

Page 5: Perana comforts Bishesta.

Page 6: Perana gives Bishesta a hot water bag to put on her stomach. Perana comforts Bishesta.

Page 7: Bishesta gets up in the morning and sees blood on her bed.

Page 8: Bishesta goes to see Perana.

Page 9: Bishesta shows Perana the blood in her bed.

Page 10: Perana gives a clean menstrual cloth to Bishesta.

Page 11: Perana puts more menstrual cloths in the menstrual storage bag.

Page 12: Perana shows Bishesta how to put the menstrual cloth in her underwear.

Page 13: Perana explains to Bishesta that girls menstruate when they reach puberty. It is normal and there is nothing to be scared about.

Page 14: Perana shows Bishesta her menstrual storage bag and the menstrual shoulder bag.

Page 15: Perana shows Bishesta the menstrual bin.

Page 16: Bishesta puts her used menstrual cloth in the bin.

Page 17: Bishesta washes her hands with soap and water.

Page 18: Bishseta washes her used menstrual cloth. Perana guides her to do this.

Page 19: Bishesta hangs the washed menstrual pad in direct sunlight to dry. Perana guides her to do this.

Page 20: The Bishesta family sit and eat together.

Page 21: A group of people greet Bishesta and Perana.

Page 22: Bishesta is happy and comfortable. Perana is proud of Bishesta.

Appendix 7. Supporting information for Paper Six

Table S1. Feasibility study indicators and results

No.	**Indicator**	**Achieved (Y/N)**	**Comments**
1	50% of young people and carers recognised as Bishesta households	N	To achieve Bishesta household status, households had to meet the household monitoring indicators. 100% of young people met the indicators, but only 10% (*n* = 1) of carers used the menstrual calendar, meaning 90% (*n* = 9) of households did not achieve Bishesta household status.
2	Carers reporting that they and / or the young person positively benefited from the involvement in the Bishesta programme	Y	
3	50% of participants practicing target behaviours	Y	
4	85% of participants attended three group training sessions	Y	
5	All group training delivered as planned	N	One of the three group training sessions were not delivered by the intended number of facilitators.
6	Facilitators reporting effective delivery of the group training sessions	Y	
7	Cost per young person is in line with similar pilot studies	?	No 'similar pilot studies' exist, so benchmarking the costs per young person is impossible
8	Intervention could be delivered alongside general menstrual hygiene management interventions or existing disability programmes	Y	
9	Desire to expand the programme into other areas of Nepal	Y	

Table S2. Structured questionnaire results and analyses of the findings against the qualitative data.

Question		Baseline		Endpoint		Analysis
	Answer	Number of participants	Percentage of participants	Number of participants	Percentage of participants	
The person I care for uses a menstrual product	Always	8	80%	8	80%	Two more young people using a menstrual product. Qualitative data indicates a greater improvement.
	Sometimes	0	0%	1	10%	
	Never	2	20%	1	10%	
The person I care for is able to understand when she needs to change her menstrual product	Yes	8	80%	5	50%	Reduction in 3 young people's understanding of when to change a menstrual product. Not supported by the qualitative findings.
	No	1	10%	4	40%	
	N/A	1	10%	1	10%	
The person I care for is able to change her menstrual product independently	Yes	5	50%	6	60%	One more young person able to change her menstrual product independently. This supports the qualitative findings.
	No	4	40%	3	30%	
	N/A	1	10%	1	10%	
The person I care for needs support to change her menstrual product	Yes	4	40%	6	60%	Two more young people need support to change her menstrual product. These are the two young people that are now using a menstrual product (see question 1).
	No	5	50%	3	30%	
	N/A	1	10%	1	10%	
The person I care for has shown her menstrual pad/blood to other people	The last time she menstruated	0	0%	0	0%	Two young people who showed their menstrual blood in public, have not since the intervention. Qualitative data indicates a greater improvement.
	In the last two months	0	0%	0	0%	
	In the last three months	2	20%	0	0%	
	Never	8	80%	10	100%	
The person I care for takes pain relief	Always	0	0%	4	40%	40% ($n = 4$) young people always taking pain relief; 10% ($n = 1$) decrease in young people never using pain relief. This supports the qualitative findings.
	Sometimes	5	50%	4	40%	
	Never	3	30%	2	20%	
	N/A	2	20%	0	0%	

Question		Baseline		Endpoint		Analysis
	Answer	Number of participants	Percentage of participants	Number of participants	Percentage of participants	
During the first day of the person I care for menstruation, I change her pad	Less than 1 times a day	0	0%	0	0%	Carers changing young person's menstrual pad more often during the first day of menstruation. This supports the qualitative findings.
	1 times a day	2	20%	2	20%	
	2 times a day	4	40%	3	30%	
	3 times a day	1	10%	4	40%	
	4 times a day	2	20%	1	10%	
	More	0	0%	0	0%	
	N/A	1	10%	0	0%	
The person I care for knows where to get clean menstrual pads	Yes	3	30%	10	100%	70% ($n = 7$) more young people know where to get clean menstrual pads. This supports the qualitative findings.
	No	6	60%	0	0%	
	N/A	1	10%	0	0%	
When the person I care for has menstrual cramps, I:	Give her a hot water bottle	0	0%	1	10%	Increase in carers intervening when young person has menstrual cramps and providing different pain relief options. This supports the qualitative findings.
	Give her hot water to drink	0	0%	9	90%	
	Give her pain killer tablets	3	30%	2	20%	
	Let her rest	7	70%	6	60%	
	Do nothing	0	0%	0	0%	
	N/A	0	0%	1	10%	
When the person I care for is angry, sad, upset because of her menstruation, I:	Leave her alone	3	30%	0	0%	Increase in carers supporting young person when they feel angry, sad, upset because of her menstruation. This supports the qualitative findings. a) 30% ($n = 3$) less leaving the young person alone; b) 60% ($n = 6$) increase in reassurance;
	Keep her at home	0	0%	0	0%	
	Give her a hug	0	0%	0	0%	
	Reassure her	3	30%	9	90%	
	Do nothing	0	0%	0	0%	
	N/A	4	40%	0	0%	

c) 40% (*n* = 4) reduction in carers saying this is not applicable

Appendix 8. Feasibility study data collection tools

Topic guide: self-advocate

Information sheet

My name is .... I work for a University in England. We want to talk to you about the Bishesta menstrual hygiene campaign. Your carer will be here all the time.

If we talk, I'd like to record what you say. That way, I won't miss anything. Your words might be used in a report. I won't use your name. No one will know you have spoken to me.

You don't have to talk to me or do the activities. That's ok.

If you do want to, we can stop whenever you want. You don't have to say why.

Do you want to ask me anything?

Consent form

Participant: (First & Last Name)____

Participant code: ____

- I have been told about this study. I understand what I am being asked to do.
- I have been able to ask questions. These have all been answered.
- I know I don't have to take part. I can stop talking at any time. I don't have to say why.
- What I say can be recorded. What I say can be put in a report. My name will not go in the report.

Assent from the self-advocate to participate

Name	Date	Signature/Thumbprint

Consent from carer of the self-advocate to participate.

Relationship to the person for whom you are giving consent**:**

____

Name	Date	Signature/Thumbprint

Witness of the above

Name	Date	Signature/Thumbprint

In Depth Interview Question Guide

Objective: to explore what the self-advocate thought about being part of the Bishesta programme. In particular to investigate her thoughts of, and feelings about each campaign component.

Inclusion criteria: self-advocates who participated in the Bishesta programme.

Materials needed: information and consent sheet, voice recorder, spare batteries, notebook and pen, all programme components (yellow menstrual storage bag, blue menstrual shoulder bag, menstrual calendar, I change my pad visual story, I manage visual story, pain bangle), emoji heads and refreshments.

Introduction

Remind them that are free to decline to answer any of the questions or stop the interview at any time.

Code	
Interview Date and time	
Interview venue and location	
Interviewer	
Carer's name	
Name of the self-advocate	
Age of the self-advocate	
General observations (anything which might impact how the interview is conducted)	

INSTRUCTIONS: INTERVIEWER TURN ON THE TAPE RECORDER AND SAY CLEARLY THE DATE, TIME, LOCATION, AND THE INTERVIEWER'S NAME

Activities

EMOJI BALLS AND DRAMA

Participant: a person who can recognise visual cues and emotions

Materials needed: emoji balls – happy, laughing, sad, confused, angry, scared, large Bishesta doll, 'I change my pad' visual story, 'I manage' visual story, the yellow menstrual storage bag, the blue menstrual shoulder bag, the menstrual bin, bag to carry the campaign components

Process:

1. Show the self-advocate the emoji balls
2. Encourage her to hold them and look at each expression
3. When she picks one up, ask her how she thinks the ball is feeling. Have fun. Enact out the expressions / emotions with her. You don't need to go through every one.
4. Line the emoji balls up in a horizontal line
5. Give her the large Bishesta doll
6. Observe her reaction to it. If she smiles when she sees the doll or picks it up and hugs it, you know that she may like the doll
7. **Observer**: record her reaction
8. Ask her to pick up the emoji ball that represents her feelings about the Bishesta doll
9. If she is unsure, you can go through the emoji balls together. Ask her if the doll makes her happy (show the ball)? Sad (show the ball), angry (show the ball etc)? If she says yes to all the emotions, you know that she is just assenting to what you say
10. **Observer**: record the options given to the self-advocate
11. Ask her questions related to the chosen emoji. For instance, what do you like about it; what don't you like; what makes you angry, confused etc?
12. **Observer**: record her responses
13. Ask her to put the emoji ball back on the table
14. Repeat the exercise for the following campaign components in this order (work through as many as you can, but don't worry if you don't get through them all):

   a. ‘I change my pad’ visual story
   b. ‘I manage’ visual story
   c. The yellow menstrual storage bag
   d. The blue menstrual shoulder bag
   e. Pain bangle
   f. Menstrual bin

15. Ask if she wants to tell you anything else?
16. Close the session

Interview pack - carers

Information sheet

You are being invited to take part in a research study. My name is .... I am one of the interviewers for a study on behalf of researchers at WaterAid and the London School of Hygiene and Tropical Medicine (LSHTM). Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

You have just completed the Bishesta programme on menstrual hygiene management. This included attending group training sessions with your self-advocate, allowing facilitators to monitor your progress at home / institution and using menstrual hygiene management resources. We want to understand what you thought about these so we can improve the programme.

What does the study involve?

We are talking everyone who took part in the Bishesta programme.

Today's interview

I would like to ask you what you thought about the group training sessions, the monitoring visits and the menstrual hygiene management resources that were given out. I will ask your thoughts. Then I will ask you to tell me what your self-advocate thought. We will talk to you in your home / institution. It will take about 1 hour.

Confidentiality and sharing data

All information which is collected in the research will be kept strictly confidential. We will combine information from everyone we speak to. We will not use your name, contact details or the name of your village in any reports. What you say to me will be anonymous.

If you agree I would like to record the conversation. This recording will then be written up. Your name will not be used in this write up or any report we write on the research.

Quotes

We would like your permission to use quotes from your interview in the research report, other reports, campaigns and publications by LSHTM and WaterAid, on the LSHTM and WaterAid website and in the promotion of the research. We will not use your name against any of the quotes. No one will be able to know who you are from your quote.

Risks and discomfort

Some of the questions we will ask you are very personal. If there are any questions that you don't want to answer then you don't have to. If you do answer, we assure you that all your responses will be kept confidential.

Do I have to take part?

No. It is up to you to decide whether or not to take part. You can stop at any time during the interview. You can carry on after a break, or you can withdraw from the interview completely whenever you want. All our notes and recordings from our discussion will be destroyed. This will not affect any future care that you receive.

What are the benefits?

The information collected in this study will help us and others to plan and improve menstrual hygiene management services that are available for people with intellectual disabilities and their carers in Nepal. However, there is no direct compensation to you or your family by agreeing to talk to me.

WaterAid Safeguarding Standard

We will keep the information discussed today confidential but if there is a concern raised about the safety of the person you care for, then that information will be shared with WaterAid Nepal. Also at the end of the interview, if you would like to talk further about any of the issues with someone from the WaterAid Nepal office then we can pass on your contact details to the local office. If you have any further questions please contact:

Sandhya Chaulagain (SandhyaChaulagain@wateraid.org), WaterAid Nepal,
Kupondole, Lalitpur, GPO Box No. 20214, Kathmandu, NEPAL

The researcher is from the London School of Hygiene and Tropical Medicine in the UK is Jane Wilbur. Email jane.wilbur@lshtm.co.uk

Consent sheet

In Depth Interview Question Guide

Objective: to explore what carer's and the self-advocate thought about being part of the Bishesta programme. In particular to investigate:

- The organisation and content of the group training sessions
- The acceptability of the menstrual calendar for carers
- The acceptability of the contents of the menstrual hygiene packs for self-advocates (yellow menstrual storage bag, blue shoulder bag, menstrual products, I change my pad visual story, I manage visual story)
- If any of the training content or resources have led to any changes in the way carers support self-advocates during menstruation
- If any of the training content or resources have led to any changes in the self-advocates manage their own menstruation

Inclusion criteria: carers who participated in the Bishesta programme.

Materials needed: information and consent sheet, voice recorder, spare batteries, notebook and pen, all programme components (yellow menstrual storage bag, blue menstrual shoulder bag, menstrual calendar, I change my pad visual story, I manage visual story) and refreshments.

Introduction

Good morning and thank you for your time. I am (Interviewer's name) from........... Remind them of the issue of confidentiality and anonymity which is fully explained in the information and consent form that they completed. Check if they have any questions from the information and consent form about the research. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

Code	
Interview Date and time	
Interview venue and location	
Interviewer	
Carer's name	
Name of the self-advocate	
Age of the self-advocate	
General observations (anything which might impact how the interview is conducted)	

INSTRUCTIONS: INTERVIEWER TURN ON THE TAPE RECORDER AND SAY CLEARLY THE DATE, TIME, LOCATION, AND THE INTERVIEWER'S NAME

Opening questions

1 **What is your relationship to the person you look after?**

2 **Could you tell me a bit about [female's name]?**

- How old is she?
- What you enjoy doing together?

3 **How long have you been caring for [female's name]?**

Now I'm going to ask you some short questions about how [female's name's] manages her menstruation. You may have answered these before.

Table 2. BASELINE DATA COLLECTION QUESTIONS		
No.	**Question**	**Circle one answer only**

1	**The person I care for uses a menstrual product:**	1. Always 2. Sometimes 3. Never
2	**The person I care for is able to understand when she needs to change her menstrual product**	1. Yes 2. No 3. N/A
3	**The person I care for is able to change her menstrual product independently**	1. Yes 2. No 3. N/A
4	**[Female's name] needs support to change her menstrual product**	1. Yes 2. No 3. N/A
5	**The person I care for has shown her menstrual pad / blood to other people:**	1. The last time she menstruated 2. In the last two months 3. In the last three months 4. Never
6	**The person I care for takes pain relief menstrual cramps:**	1. Always 2. Sometimes 3. Never 4. N/A
7	**During the <u>*first day*</u> of [female's name's] menstruation, I change her pad**	1. Less than once a day 2. Once a day 3. Two times a day 4. Three times a day 5. Four times a day 6. More
8	**[Female's name] knows where to get clean menstrual pads**	1. Yes 2. No 3. N/A
Circle more than one option if required		
9	**If [female's name] has menstrual cramps, I:**	1. Give her a hot water bag 2. Give her hot water to drink 3. Give her pain killer tablets

		4. Let her rest 5. Do nothing 6. N/A
10	**If [female's name] is angry, sad, upset because of her menstruation, I:**	1. Leave her alone 2. Keep her at home 3. Give her a hug 4. Reassure her 5. Do nothing 6. N/A

Now I'm going to talk to you about the Bishesta programme. This includes the group training sessions you went to, the menstrual hygiene packs the self-advocate and you received and when the facilitators visited your institution / home. Is that clear?

We are reviewing this programme to understand what has and has not worked so that we can make it better. As you have been part of it, we are interested to hear what you think. Please be as open as possible. There are no right or wrong answers. What you say will help us improve the programme.

Group training sessions

1. **Were you and [female's name] able to attend all three group training sessions?**

- If no, why?

2. **What did you think about how the group training sessions were organised?**

- Transport?
- Venue?
- Location?
- Facilities?
- Start time?
- Length of training?
- Number of group training sessions (one per month for three months)?
- *Summarise points discussed and ask:* ***How could these be improved?***

First, I'm going to ask what you thought about the group training session. I'll move onto [name] after that.

3. **How did you think / feel about the sessions?**
- What did you find most useful?
- What did you find least useful?

4. **Did you feel anything was missing?**
- Did we cover everything you had hoped to learn and practice?
- How could the group training sessions be improved?

5. **What did [female's name] think about the group training sessions?**
- What did she like most?
- What did she not like?
- What did she think about the large Bishesta doll that we used in the group training?
- What did she like about the doll?
- What did she not like about the doll?

6. **When [female's name] is menstruating, have you done anything differently since the start of the Bishesta programme? Please explain**
- In terms of:
    - Her menstrual products?
    - Pain relief?

7. **What happened as a result of these changes?**

8. **Did you remind [female's name] how to use the menstrual hygiene packs between the group training sessions?**
- If yes, please explain what you covered and how often you covered it?
- Do you feel this helped [female's name] remember how to manage her menstruation?
- If no, please explain

9. **Did you face any difficulties in using the menstrual hygiene packs or putting the learning into practice? Please explain**
- Using the menstrual calendar to track [female's name's] menstruation?
- Keeping the menstrual storage bags stocked up?
- Providing pain relief for menstrual cramps?
- Understanding changes in the self-advocate's behaviour before and during menstruation?

- Looking at the visual stories with [female's name]?

10. **When [female's name] is menstruating, has she done anything differently start of the Bishesta programme? Please explain**

- Does she use a menstrual product when she didn't before?
- Does she use pain relief for menstrual cramps more often?
- Has she shown her menstrual blood to others less often?
- What do you think caused these changes?
- How do you feel about these changes / what have they meant for you?

11. **What do you think led to these changes?**

12. **Did [female's name] face any difficulties in using the menstrual hygiene packs or putting the learning into practice? Please explain**

- In terms of:
    - The menstrual product?
    - Pain relief
    - Showing her menstrual blood in public?

Monitoring visits

13. **Please can you tell me about the times the facilitators visited your home / rehabilitation centre after the group training sessions?**

- What things did you talk about?
- What did you think about these visits?
- *Probe into length of time, visit time, if people found them useful, intrusive or unhelpful*

14. **Apart from what you have already said, how to you think we can improve the Bishesta programme?**

Resource assessment

Now I'm going to ask you about the content in the menstrual hygiene packs. Please give as much detail as you can as this will help us improve them. I have them all here, so you can pick them up and look at them as you talk. First I will ask your thoughts on them. And then I will ask you to tell me what [female's name] thought about them.

Notes for researchers:

- *Lay out all the resources in front of the carer*

- *When the carer identifies the resource, verbally repeat the selection so it is captured on audio. Do this subtly so you don't disrupt the flow of the conversation.*
- *If a number of resources have been used, ask these questions on all of them separately*

15. **Please can you order the resources into those that you used least often to most often?** (Left being least often, right being most often)
- Why have you ordered them that way?

16. **Why did you use this resource most often** (refer to the resource on the right)**?**
- What did you like about it?
- How could it be improved?

17. **Why did you use this resource least often** (refer to the resource on the left)**?**
- Why did you use it least often?
- How could any be improved?

Take a photo of the ranked resources. Tightly crop the photo. ***OR****: write a note of how the resources have been ranked. Put the resources together in front of the carer.*

Take a photo of the ranked resources. Tightly crop the photo. ***OR****: write a note of how the resources have been ranked. Put the resources together in front of the carer.*

18. **Now, please can you order the resources according to which [female's name] used least to most often? Please explain** (Left being the least used and right being the most used).
- Why have you ordered them that way?

19. **Can you tell me why [female's name] used this resource most often?**
- What did she like about it?
- How did she use it?
- How could it be improved?

20. **Do you think [female's name] will continue to the resource she used most in the future? Please explain the reasons**
- If no, what can be done to encourage her to use it in the future?

21. **Please can you tell me why you think [female's name] used this resource least often? Please explain** *(refer to the resource on the far left)*

- Why did she use it least often?
- What did she not like about it?
- What can be done to improve it?

Take a photo of the ranked resources. Crop the photo tight so that you do not include any identifying objects from the carers home. ***OR****: write a note of how the resources have been ranked.*

Lay all the resources out in front of the carer.

22. **Please can you order them in terms of what you think led to the biggest change in [female's name's] menstrual practices? Please explain why** (Left being least useful, right being most useful).

- Do you think female's name will continue using this resource in the future? Why?
- If not, why?
- How can we improve the resource?

Take a photo of the ranked resources. Tightly crop the photo. ***OR****: write a note of how the resources have been ranked.*

23. **As you know, we have been testing the Bishesta programme. In your opinion, are there any resources that carers could provide themselves? E.g:**

- Menstrual pads?
- Menstrual bin?
- Menstrual storage bag?
- Menstrual shoulder bag?

24. **Beyond what you have already said, how do you feel we can improve any of these resources?**

Thank you very much for your thoughts on the Bishesta programme and for answering all my questions. Before we finish is there anything else you want to tell me? Is there anything you would like to ask me?

Topic guide – facilitators

Preparation: Print out this interview guide

Materials: information and consent sheets, campaign components, camera, voice recorder, spare batteries

Overall aims:
1. To explore how the programme ran
2. To explore how the programme may be integrated into existing MHM programmes

Present the information sheet and consent form.

Turn on the tape recorder, say the date, time, location and your name

Ask rapport building questions.

Facilitator's training

First I'm going to ask you about what you thought about the preparation (e.g. training, manual, content, your readiness), and later I will ask about how the group training sessions went. Then I will go into the monitoring visits and the campaign resources. Is that clear? OK, first the preparation.

1. **What did you think of the <u>content</u> of the facilitator's training?**

- What did you find useful / less useful?
- How could the training be improved?

2. **How prepared did you feel before the first group training session?**

- How confident / ready did you feel?
- Why did you feel that way?
- What could have been done to help you feel [more] confident? *Delete text in brackets if they didn't feel confident.*
- *Probe into levels of understanding of the campaign and how to deliver it*

Campaign manual

3. **What do you think of the campaign manual?**

- Strengths / weaknesses?
- Was there anything missing?
- Did it give enough / too much guidance?
- Did you have to adapt it during the training?
- What was the reason for the changes?

- How did you change it?
- Did the changes help?
- How could the manual be improved?

Group training sessions

Now I'm going to ask you about how the group training sessions went.

4. **What did you feel about the organization of the group training sessions?**

- Transport for participants?
- Venue?
- Location?
- Facilities?
- Start time?
- Length of training?
- Number of group training sessions (one per month for three months)?
- Number of participants at each group training session?
- How could these be improved?

5. **Overall, how do you feel the group training sessions have gone?**

- What were the strengths? Why?
- What were the weaknesses? Why?
- Probing questions:
    - How relevant was the training content for the needs of group?
    - How confident did you feel facilitating the sessions?
    - How did you feel about the way the facilitator's roles and responsibilities were split out?
    - Were there any questions you found difficult to answer?
    - How did you feel about buddying up with another facilitator?

6. **Which were the best sessions of the group training sessions? What made them good?**

- Did anything surprise you during the sessions? What / why?

7. **Were there any sessions that did not go so well? Why?**

- If you were to run them again, how would you do that?
- Are there topics that you feel were missing in the group training sessions?
- Were there topics that you feel were not needed?
- Do you have any recommendations about the group training sessions?
- *Probe: thoughts on content, campaign components, timing, attendance, ability of participants to understand, absorb and apply the learning; staff*

time to plan, deliver and monitor the process, participant's levels of engagement

8. **How do you feel the carers responded to the programme?**

- How do you feel they interacted with each other?
- Prompts: did you see anyone chatting during the breaks, or helping each other (probing into peer to peer support)?

9. **Did you notice any changes in the way the carer and the self-advocate interacted with each other within each group training session? Please explain**

10. **How do you feel the self-advocates responded to the group training sessions?**

Monitoring visits

Now I'm going to ask you about the monitoring visits.

11. **How did you feel the monitoring visits went?**

- What do you think went well / less well? Why?
- How would you improve these?
- Did participants ask you to repeat anything covered in the group training sessions? Please explain

Personal satisfaction

12. **Now thinking about your personal involvement in the programme: what did you like / not like about being a facilitator for the Bishesta programme?**

- *Probe: daily rate, amount of days allocated / work load, roles and responsibilities*
- *Probe into recommendations for this going forward*

Demand

13. **As you know, this has been a pilot programme, so we are unable to say what will happen after it. We may or may not scale it up. If we do scale it up we don't know what that would look like, or who would implement it.**

Bearing that in mind, do you feel that the Bishesta programme would be useful for other people with intellectual impairments and their carers in Nepal? Please explain

14. **If we do scale this up, who do you think is best placed to run the programme? E.g.**

- Government (which ministry? Level?)?
- CBR workers?
- Organisations working in disability service provision?
- Organisations working in WASH service provision / health etc?

15. **As you know, this has been a pilot programme. Do you have any recommendations about how we can improve the Bishesta programme if we are able to scale it up?**

- *Probe into concerns already raised and how to build on strengths*

Resource assessment

Now I'm going to ask you about the campaign resources. Please give as much detail as you can as this will help us improve the materials. I have them all here, so you can pick them up and look at them as you talk.

Notes for researcher: lay out the resources in front of the participant; when the participant identifies the resource, verbally repeat the selection so it is captured on audio.

16. **Please order the resources into those you felt were <u>most useful</u> during the group training sessions? Left – least; right - most**

- Why have you ordered them that way?
- Why do you feel the left one is of least use? How could it be improved?
- Why do you feel the one on the right is of most use?
- Can you think how any of the resources could be improved?
- *Probe: ability to explain its use in an understandable way, how the participant interacted with it and participants.*

Take a photo of the order. Crop it tightly.

First I'm going to ask you about the resources used by people in their homes. And then I will ask you about the resources used in the rehab centre.

17. **Please order them according to which you felt were the <u>most used by participants</u> <u>at home</u>. Please draw on your conversations with participants and the monitoring visits**

- Why have you ordered them that way?
- Why do you feel the left one was used least? How could it be improved?
- Beyond what you have already said, is there any way you can think of to improve the resources?
- *Probe: ability to explain its use in an understandable way, how the facilitator interacted with it and participants.*

Take a photo of the order. Crop it tightly.

18. **Now please order them according to which you felt were the <u>most used in the rehab centre</u>. Please draw on your conversations with participants and the monitoring visits**

- Why have you ordered them that way?
- Why do you feel the left one was used least? How could it be improved?
- Beyond what you have already said, is there any way you can think of to improve the resources?
- *Probe: ability to explain its use in an understandable way, how the facilitator interacted with it and participants.*

Take a photo of the order. Crop it tightly.

Thank you very much for delivering the Bishesta programme. Thank you for all your thoughts on this and for answering all my questions. Those are all my questions. Is there anything else you want to tell me? Any other recommendations? Is there anything you would like to ask me?

Topic guide – key informant interviews

Preparation: Print out this interview guide, provide an overview of the programme in advance

Materials: information and consent sheets

Overall aims: to ask key informants about the need for the programme and possible integration into existing MHM and / or disability programmes

Present the information sheet and consent form.

Turn on the tape recorder, say the date, time, location and your name

Implementation

1. Based on your understanding, what do you feel were the key strengths of the programme?
2. How could these be built upon?
3. What do you feel were some of the weaknesses? How could these be addressed?

Demand

4. Based on what you have seen in your role, do you feel a programme such as this is needed for people with intellectual impairments and their carers in Nepal? Why?

Integration of the programme

5. Having looked at the programme, to what extent do you feel that this could be integrated into the work of your organisation? How would this best be undertaken?
6. Do you feel that it should be taken forward by another organisation or integrated into their work? By whom, why and how would this work?

Expansion of the programme (if applicable)

7. To what degree do you feel a programme like this could be expanded to other areas of the country? How would this be done?
8. How would it be resourced?

Other

Thank you for your time and for sharing your thoughts on the programme. Is there anything else important which I haven't asked you which you want to share with me? Do you have any further recommendations?

Appendix 9. PhotoVoice Initial and Secondary Informed Consent Sheet

INITIAL INFORMED CONSENT

You are being invited to take part in a research study. My name is .... I am one of the interviewers for a study on behalf of researchers at WaterAid and the London School of Hygiene and Tropical Medicine. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study? We are going to different parts of the Kavre district to talk to adolescents and young females with disabilities about their experiences of having their periods. We are talking to their parents / carers about how they assist their daughters / the person they care for when they have their periods. We are speaking to policy makers and people involved in implementing menstrual hygiene programmes in Nepal to understand the wider context. These experiences will help us understand if these groups of people have specific requirements related to their periods, what these are, and how these could be met. This research is being carried out by WaterAid and the London School of Hygiene and Tropical Medicine (LSHTM).

What will I be asked to do? If you decide to participate, we will spend 2-4 hours with you. You will be lend a photographic camera and taught how to use it. We will ask you to take several photos of what you do when you have their period and how that makes you feel. We can work through some examples with you. We will also show you how to take photos without showing your faces if you'd like that. At the end of those 2-4 hours the researchers will leave the cameras with you. The next day (or at another preferred date) the researchers will collect the camera and develop the photos. On the same day the researchers will return with the printed photos and they will discuss the photos with you. This activity is called photo voice because it is designed to give you an opportunity to express your perspective.

You will be shown all the photos taken and can keep copies of the photos you take. With your permission, the photos you take may be used in the report from this study, on the website or an exhibition to help others understand the perspectives of women and girls with a disability. This is completely voluntary. If there are any photos that you don't want us to use, you don't need to explain why and we won't use them. This will not affect any future support or care that you might get. You will own the copyright on the digital images. This means that you have the right to say how they will be used. It also means that when they are used you will be always acknowledged as the photographer.

Do I have to take part? No. Your participation is voluntary, if you feel uncomfortable with the process at any time please tell us. You can also decide to end your involvement with the study at any time. Learning about photography may be something new to you and at times may seem frustrating or too difficult. Let us know if you are feeling like this so that we can try a different approach.

Risks and discomfort: Some of the questions we will ask you about your photographs are very personal. You may choose not to answer any questions that you do not want to. If you choose to answer, we assure you that all your responses will be kept confidential. If you decide after we start that you don't want to participate, you can withdraw at any time and all our notes and recordings will be destroyed. If there is a concern that you do not understand what informed consent entails, we will ask for your parent / carers consent. We will then interview your parent / carer. We will not use any photos that show full or partial nudity, or that compromise your dignity (e.g. a photos showing a person who has experienced a menstrual hygiene 'accident').

What are the benefits? The information collected in this study will help us and others to plan and improve menstrual hygiene services that are available for women and girls with disabilities. You can keep the photos, but there is no direct compensation to you or your family by agreeing to talk to me.

Do you have any questions?

PARTICIPANT TO COMPLETE:
I have read/been read the information provided above and I have understood it. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

Assent from Adolescent or Young Person (15-17 years old) to participate

Name	__	Date	__	Signature/Thumbprint

Consent from carer of the Adolescent or Young Person (15-17 years old) to participate.

Relationship to adolescent or young person giving consent:____

Name	__	Date	__	Signature/Thumbprint

Consent from Adolescent or Young Person (18-24 years old) to participate

Name	Date	Signature/Thumbprint

Witness of the above

Name	Date	Signature/Thumbprint

SECONDARY INFORMED CONSENT

You have agreed to take part in a research study. My name is .... I am one of the interviewers for a study on behalf of researchers at WaterAid and the London School of Hygiene and Tropical Medicine. Please ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study? We are going to different parts of the Kavre district to talk to adolescents and young females with disabilities about their experiences of having their periods. We are talking to their parents / carers about how they assist their daughters / the person they care for when they have their periods. We are speaking to policy makers and people involved in implementing menstrual hygiene programmes in Nepal to understand the wider context. These experiences will help us understand if these groups of people have specific requirements related to their periods, what these are, and how these could be met. This research is being carried out by WaterAid and the London School of Hygiene and Tropical Medicine (LSHTM).

What I will be asked to do? If you decide to participate a researcher will show you the printed photos you have taken. We will discuss the photos, carry out a short interview with you and ask you to rank the photos according to their importance. This interview will be recorded. This activity is called photo voice because it is designed to give you an opportunity to express your own perspective.

You will be shown all the photos taken and can keep copies of the photos you take. With your permission, the photos you take may be used in the report from this study, on the website or an exhibition to help others understand the perspectives of women and girls with a disability. This is completely voluntary. If there are any photos that you don’t want us to use, you don’t need to explain why and we won’t use them. This will not affect any future support or care that you might get. You will own the copyright on the digital images. This means that you have the right to say how they will be used. It also means that when they are used you will be always acknowledged as the photographer.

Do I have to take part? No. Your participation is voluntary, if you feel uncomfortable with the process at any time please tell us. You can also decide to end your involvement with the study at any time. Learning about photography may be something new to you and at times may seem frustrating or too difficult. Let us know if you are feeling like this so that we can try a different approach.

Risks and discomfort: Some of the questions we will ask you about your photographs are very personal. You may choose not to answer any questions that you do not want to. If you choose to answer, we assure you that all your responses will be kept confidential. If you decide after we start that you don’t want to participate, you can withdraw at any time and all our notes and recordings will be destroyed. If there is a concern that you do not understand what informed consent entails, we will ask for your parent / carers consent. We will then interview your parent / carer. We will not use any photos that show full or partial nudity, or that compromise your dignity (e.g. a photos showing a person who has experienced a menstrual hygiene 'accident').

What are the benefits? The information collected in this study will help us and others to plan and improve menstrual hygiene services that are available for women and girls with disabilities. You can keep the photos, but there is no direct compensation to you or your family by agreeing to talk to me.

Do you have any questions?

PARTICIPANT TO COMPLETE:

I ………………………………………………….. understand that I retain copyright of my photographs but give permission for WaterAid and the LSHTM to retain copies of the images for use as consented to in the list below:

CONSENT CHECKLIST

I am happy for LSHTM to use my photographs in the following ways:	**YES** ☑	**NO** ☒
As part of this study report		
In other reports, campaigns and publications by LSHTM, WaterAid or affiliated partners and donors		
At public exhibitions related to this study		
On the LSHTM website		
On the WaterAid website		
In media about this study		

Do you want these photographs to be credited with your real name? **YES / NO**

If no please specify alternative name to be used……………………………………………..

PLEASE FILL IN YOUR FULL CONTACT DETAILS BELOW:

Photographer's full name:

Photographer’s Address:

Mobile (if applicable):

Email (if applicable):

Signed:

Name

Date

Signature/Thumbprint

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