Terminology guidelines to support WaterAid's equality, inclusion and rights framework

June 2022



WaterAid



▲ Cover image: Har Sah, 48 (middle) with her daughter in law Sushila Sah, 26 (left) and daughter Amitra Sah, 23, Itahari, Sunsari, Nepal, January 2018.

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#### Introduction

# Introduction



Language both reflects and shapes our understanding of reality and can also influence the thoughts and actions of those around us. **WaterAid's focus on** equity and inclusion means we need to carefully consider the language we use to talk about discrimination, marginalisation and exclusion, and how we talk to people who are disadvantaged or marginalised in any way.

**Language influences our actions.** If we refer to people who are disadvantaged as if there is a problem with that person, we are more likely to focus on the person as a problem. It is more constructive to use language that shows that the problems related to a person's disadvantage stem from the attitudes, systems or practices that create barriers. This is more likely to encourage approaches that aim to remove those barriers.

Language can sometimes be used in ways that emphasises some peoples power over others, maintain existing power imbalances or reinforces inequalities. So we must always check ourselves and ensure we are not using language that impinges on people's rights, dignity or negatively affects their identity. Using certain outdated language, particularly in international development, can mean that the very people we want to serve or work with are robbed of their agency and their context.

We 'inherit' language and often do not give it much thought, yet we do have a choice and we can make conscious decisions to use words and terms that say what we mean and give power, dignity and respect to all people. Most people want to be respectful of others yet may not realise how the language they use disempowers others.

We all need to re-examine the language we use and evaluate the meanings and connotations of our words, including their origins, in relation to, for example, persons living with disabilities, people who are HIV positive, or who belong to different ethnic groups. Some terms have different connotations in different contexts and cultures. The important thing is to recognise that terms do have connotations (or associated meanings) and find out what they are.

These guidelines were put together to help bring our attention to the way we talk about those people or groups that might be at risk of being marginalised or facing discrimination. These guidelines do not dictate which terms should or should not be used. Rather they provide some guiding principles, gathered from a range of sources, intended to help raise awareness among WaterAid staff and the partners we work with about the language we use and issues surrounding disability, gender, gender identity, sexual orientation, age, race, HIV and health status. While attempts have been made in this guide to reflect different contexts and geographies, it is very important that when using the guide you find out what the most appropriate terminology is in your location.

Please use this guide as a starting point and make the time and effort to work with rights identity based groups in your context to understand what empowering language they prefer to use and why.

Addressing people

# Addressing people in a way that communicates power, dignity and respect

At WaterAid, we believe that everyone has equal rights, regardless of gender, race, caste, disability or economic status, age, gender identity, sexual orientation, health status, or employment status. Treating all people with equal respect is the first step to overcoming barriers and creating a more just society.

How we address others is of utmost importance and should always be in a way that communicates power, dignity and respect for the other person. The language we use should be based on human rights principles, such as dignity, equality, nondiscrimination and participation. A **human rights-based approach** in WASH (water, sanitation and hygiene) seeks to change the relationship between WASH actors and people experiencing vulnerability, poverty or exclusion from WASH – previously this relationship has sometimes been treated as a relationship defined by charity, sympathy and powerlessness. But we believe it is a relationship of obligations (on the part of duty bearers) and the rights of all people. The use of this approach ensures everyone is fully recognised as being part of any WASH solution.

Underlying the human rights-based approach is the recognition that, beyond technical and financial factors, the power relations within a community or society are critical to whether basic rights are enjoyed by all. That is, people are excluded from WASH (or any other basic) services because of a lack of power rather than just a lack of resources. Therefore, when we talk about those who are at risk of being 'marginalised' or "discriminated against", we are referring to those people **experiencing unfulfilled rights to clean water and safe sanitation.**<sup>1</sup>

Some examples:<sup>2</sup>

- Giving is often about power; we don't want to "give to", we want to "stand with" or "work with" others. For example, we don't say "we are helping those living in poverty", but do say "we work with those addressing the root causes of poverty in their own communities" or "we are working with communities and governments on WASH solutions"
- Say "making sure the voices of those most affected are heard" not "giving people a voice"— they already have a voice.

<sup>2</sup> Ralph Underhill. (no date). A practical guide for communicating global justice and solidarity. An alternative to the language of development, aid and charity. Health Poverty Action (HPA). <u>Available here</u>



<sup>&</sup>lt;sup>1</sup> WaterAid (2017). *Guidelines on embedding and integrating a Human Rights-Based Approach in WaterAid Programmes*. <u>Available here</u>

Avoid sentences like "people still need our help", rather make sure we communicate that "people are trapped in a cycle of poverty often due to circumstances beyond their control or because of the multiple barriers they face in daily life".

The following five points<sup>3</sup> are also important to remember:

- 1. **Uphold dignity and respect.** Put the person first, don't label the person with her or his physiological condition or appearance or gender.
- 2. Acknowledge that all people have the same rights and the same basic **needs** as well as different needs. All people have different abilities and inabilities. It is often not helpful to refer to someone as having 'special needs'.
- 3. **Do not assume on behalf of people.** It is inappropriate to assume and address someone as a victim, a sufferer, as being challenged or vulnerable. Older people, or people with an impairment, might not feel frail or vulnerable. It is more relevant to talk about people in 'vulnerable situations' as this is something you can change easy access to a safe latrine can provide a solution for women who find themselves in a vulnerable or risky situation when they go out at night to defecate.
- 4. **Consider that what is normal to you may not be normal to others** because of our personal and cultural differences or other backgrounds. People may fall into the category of majority or average, but everyone is normal and abnormal in one way or another.
- 5. **Use simple and clear language.** Sometimes it may be clearer to address a person as having 'difficulty walking' (or hearing, seeing etc) rather than as a person with 'mobility impairment'. Sometimes language used within certain groups may not communicate well to people from different linguistic, geographical, educational, cultural or other social backgrounds.

### Useful terms in relation to our Equality, Inclusion and Rights Framework<sup>4</sup>

#### **Equality and equity**

**Equality** is when all people have the same economic, social, cultural, civil and political rights and entitlements. To achieve equality, different groups of people may require different treatment, as different groups of people have different situations according to privilege and disadvantage. While equality is an outcome, **equity** refers to the processes to achieve this outcome; this may require different approaches for different groups to respond to their different needs, interests, capacities, socioeconomic status and circumstances.

#### Discrimination

Any distinction, exclusion or restriction which has the purpose or the effect of stopping or reducing a person's ability to enjoy or exercise their human rights on an equal basis as others. Therefore, non-discrimination is the legal principle that prohibits any distinction, exclusion or restriction that results in either an individual or group of people not being able to enjoy or realise their human rights on an equal basis with others.<sup>5</sup>

<sup>&</sup>lt;sup>3</sup>World Vision (undated) World Vision international guidelines on inclusion of persons with disabilities. Available here

<sup>&</sup>lt;sup>4</sup>WaterAid (2021). Equality, inclusion and rights framework. <u>Available here</u>

<sup>&</sup>lt;sup>5</sup>Adapted from WaterAid (2018). *Equality, non-discrimination and inclusion in WASH: A toolkit.* <u>Available here</u>

#### Marginalisation

A term used to describe a process by which people's needs become less visible, their voice is absent from decision-making, and resources are not shared equitably, as a result of discrimination. Avoid using the term 'marginalised people' and instead adopt a people-first approach by saying 'people/persons who experience marginalisation'.<sup>6</sup> To be marginalised from mainstream society results in deliberate or inadvertent **exclusions** of various kinds, including power, opportunities and benefits of policies, programmes and services. This, in turn, leads to **vulnerabilities**, including risks to health, security and safety.

#### Intersectionality

Intersectionality refers to overlapping social identities and the related systems of oppression, domination and/or discrimination. The idea is that multiple identities intersect to create a whole that is different from the component identities, creating an intersectional disadvantage.

#### Participation

Participation means that people are involved in the social, economic, political and cultural processes that affect their lives. This is recognised as a right. To achieve equality, participation must be meaningful, appropriate and provide ownership.

#### Inclusion

Inclusion is both a process (who is included in decision-making, how, why and to what effect) and an outcome (how development outcomes – including prosperity, well-being, public goods and services – are distributed and shared). It means having intentional actions, including the identification and removal of barriers that hinder full and effective participation and inclusion in society, and seeking to redress disadvantages encountered by specific groups.

#### Exclusion

Exclusion is the process of obstructing or denying full access to individuals and/ or groups from rights, opportunities, resources, processes, activities and decisions that are fundamental to participation in economic, social or political life.<sup>7</sup>

#### Empowerment

A process of changing relations of power, achieved by individuals or groups of people becoming aware of the systematic nature of their lower status and power, and building their capacity to challenge and change this. It includes increased self-confidence and agency, having choice and control over resources. Ultimately, empowering outcomes can bring about **transformative change**, contributing to a world where the root causes of unequal WASH – including unequal power relations, unfair resourcing, inadequate involvement of certain groups or individuals and limited leadership opportunities – are actively being overturned.





# Age



Many older women and men in poor countries live in extreme poverty, do not have access to water and sanitation and are left out of important decision-making processes because of their age. However, WaterAid believes that older people make an invaluable contribution to the development and prosperity of their families and communities. Their experience and voices need to be heard in relation to water, sanitation and health initiatives. WaterAid believes that no person should be discriminated against because of their age.

Age also includes children. It is not necessarily important that you follow global official definitions, rather that you discuss and agree from the outset what you mean by the terms 'children', 'youth/adolescents' and 'older people' and that those align with national or regional definitions to some extent. You should make sure everyone involved in your programme knows the definitions you are using, including the communities and government officials you are working with.<sup>8</sup>

Growing older is not without its problems, which can prevent people from reaching their potential. Older people might also be more likely to deal with long-term, chronic illness or health issues. It is therefore important to use language that does not portray older people as helpless or victims; rather, it should be highlighted that they often face barriers in the physical environment, people's attitudes and institutions that prevent their rights from being realised.<sup>9</sup>

Appropriate	Not appropriate
Older people.	The aged, the elderly or elderly people.
Use the words that older people prefer in your region, such as 'elders' or 'seniors'.	
<ul> <li>Recipients, participants or older people.</li> </ul>	<ul> <li>Beneficiaries (this implies generosity on your part).</li> </ul>
Marital status is the personal status of each individual in relation to the marriage laws or customs of a country. The categories of marital status presented in World Marriage Data 2008 are: (1) single (never married); (2) married; (3) widowed and not remarried; (4) divorced and not remarried; and (5) married but separated.	<ul> <li>Spinster: a woman, especially an older one, who has not married. It is considered offensive and derogatory.<sup>10</sup></li> <li>Bachelor: unmarried man. Although it doesn't carry the same negative connotation as spinster, try to avoid it.</li> </ul>

<sup>8</sup>Adapted from WaterAid (2018). Equality, non-discrimination and inclusion in WASH: A toolkit. Available here

<sup>9</sup> Help Age International (2009). Ageways, practical issues in aging and development, Issue 73. <u>Available here</u>

<sup>10</sup>Spinster' in *The American Heritage Dictionary of the English Language*, Houghton Mifflin Harcourt Publishing Company.

## Caste

Caste denotes a **system of rigid social stratification into ranked groups defined by descent and occupation.** Caste is hereditary in the sense that is determined by one's birth into a particular family.<sup>11</sup> Some caste-based groups belong to the same larger ethnic, religious or linguistic community while others are a distinct ethnic group. Caste can be a key determinant of life opportunities as it privileges some groups while excluding and marginalising others, being a structural cause of poverty and inequality in at least 20 countries worldwide.

The caste system is closely linked to notions of purity and pollution. As a result, people who belong to excluded castes share an inherited position in society in which they face discrimination, stigma, devaluation of their work (despite this being illegal in most cases) and restrictions on marriage that ensure their status is hereditary. Key characteristics of caste-based deprivation and discrimination are:

- Inability to alter inherited status.
- Socially enforced restrictions on marriage outside the community.
- Private and public segregation, including in housing and education, access to public spaces and public sources of food and water.
- Subjection to dehumanising discourses referring to pollution or untouchability.
- Limited freedom to renounce inherited occupations or degrading or hazardous work.
- Generalised lack of respect for human dignity and equality.<sup>12</sup>

In South Asia, the caste system determines and reinforces inequitable access to WASH for Dalits – the most excluded caste group – and especially Dalit women. Notions of caste-linked purity and pollution (and even untouchability) lead to the social exclusion of 'impure' groups, who are banned from communal water sources and excluded from decision-making. Due to the stigma attached to handling faeces, Dalits are designated sanitation and waste management work, an extremely undervalued and stigmatised job.<sup>13</sup>





<sup>11</sup> Human Rights Watch (2001). Caste Discrimination: A Global Concern. A Report by Human Rights Watch for the United Nations World Conference Against Racism, Racial Discrimination, Xenophobia and Related Intolerance. Durban, South Africa, September 2001. <u>Available here</u>

<sup>12</sup> Bond Caste and Development Group (2019). Caste and Development: Tackling work and descent-based discrimination to achieve the SDGs for all. London: Bond. <u>Available here</u>

13 Ibid.

WaterAid believes that no one should be excluded and exploited by caste hierarchies and social systems that discriminate on the basis of 'who you are and the work you do'. In the language we use, we must avoid reinforcing the ideas we challenge. Therefore:

Better to use	privileged or dominant caste	Dethersthere	upper caste
better to use	subordinated, excluded or oppressed caste	Rather than	low caste

Ideally, we should refer to communities using the names by which most members call themselves, recognising that caste identities are complex and context specific.

The table below presents some useful terminology.

Appropriate	To avoid
<b>Discrimination based on work and descent (DWD)</b> is the term used in international contexts to refer to caste and similar structures.	
In Africa, DWD is sometimes referred to as caste and can include systems of slavery.	
Caste-based systems have been found in several ethnic groups of West African countries such as the Wolof community in Senegal, the Igbo communities of south-eastern Nigeria, and the Haratine in Mauritania. Caste systems also exist in Kenya, Ethiopia, Somalia, Burkina Faso and Mali.	
Caste as a form of DWD is most conspicuous in South Asia (India, Nepal, Pakistan, Bangladesh and Sri Lanka) and its diaspora. Here, the term <b>caste</b> is widely used.	
<b>Dalits:</b> the most excluded and subordinated caste groups in South Asia, treated as 'untouchable' because of their occupations and history of subordination, economic dependency and enslavement. While Dalit organisations and social movements advocating for their rights are growing, Dalit has become a unifying political category for many people with various caste identities who are subordinated and ostracised from society. However, be aware that not all such people actively self-identify as Dalits. The Indian Government uses <b>'Scheduled Castes' ('SC')</b>	The term 'Untouchables' must always be avoided. Mahatma Gandhi termed the group as <b>'Harijans'</b> or people of God. <sup>14</sup> Politically, both the term SC and Harijans are generally strongly rejected by people of these communities, who prefer to call themselves Dalits, or the oppressed.
for people acutely affected by caste-based discrimination, although this is itself exclusionary because it does not include Muslims and Christians, many of whom are also affected.	N.B. Dalits are not a homogenous group. When possible, use the names of specific castes or social groups.

<sup>14</sup> Joshi, D., Fawcett, B (2001). Water, Hindu mythology and an unequal social order in India: paper presented at the Second Conference of the International Water History Association, Bergen, August 2001 Caste

Disability





WaterAid abides by the **'social model of disability'**<sup>15</sup>. Therefore, we acknowledge that the 'disability' is created by the impairment someone has plus the obstacles or barriers in the environment and in society's perception of their value, not their impairment alone.

A useful distinction in disability terminology is between **disability** and **impairments**. WaterAid separates 'disability' (social issue) from 'impairment' (medical or individual issue) in order to clearly see each of the two issues a person may be facing and taking specific actions and approaches towards focused solutions.

WaterAid believes that all those responsible for providing WASH have a key role in reducing attitudinal, institutional and environmental barriers and that no person should be discriminated against as a result of any impairment.

Disability	Impairments
Disability is a result of the limitations imposed on persons who have long-term physical, mental, intellectual or sensory impairments by <b>attitudinal, institutional, or environmental</b> <b>barriers</b> to their full and effective participation in society on an equal basis with others.	These include <b>physical, sensory, neurological,</b> <b>intellectual and/or mental health issues</b> that a person has been born with or has acquired through injury, accident or another cause.

WaterAid abides by this universal definition:



Source: OpenWASH (2018). Count me in! Inclusive WASH in Ethiopia, The Open University UK/WaterAid.

Other useful terms in relation to disability include:

#### **Function/functional limitation**

While impairments may affect the functioning of your body, they may not necessarily affect your ability to perform or function in certain activities.

<sup>15</sup> For more information see OpenWASH. 2018. Count me in! Inclusive WASH in Ethiopia, The Open University UK/WaterAid. <u>Available here</u>

## Mental illness or psychosocial disabilities and intellectual disabilities

Some people prefer to use the term 'mental illnesses' while others prefer 'psychosocial disabilities'. Both are used by WaterAid. However, it is important to avoid using 'mental illness' as an aggregated term. There are many different mental health issues – from depression to anxiety disorders, from schizophrenia to eating disorders – and people living with the same condition might experience it differently.<sup>16</sup> Try to be specific whenever possible and opt for a person-first language (i.e., people living with depression).

Worldwide, the term 'intellectual disability' has formally replaced 'mental retardation' which has become offensive to many people. Be aware that mental illness is not the same as intellectual disability, although they can occur together.

#### Organisations of Persons with Disabilities, Disabled People's Organisations and disability organisations

While general disability organisations can, and usually are, managed by people without disabilities working for people with disabilities, Disabled People's Organisations (DPOs) are organisations represented and managed by and for people with disabilities. But, increasingly, people are preferring to use the term Organisation of Persons with Disabilities (OPDs) as it is in line with person-first language – see below.

#### Universal design

Universal design is a method of designing interventions to be accessible and usable by the majority of people without the need for adaptation by the user. Application of the principles relies upon a process by which the full range of end-users are included in the design, implementation, and evaluation process. Universal design is a key mechanism for facilitating social participation for groups who experience marginalisation.<sup>17</sup>

An environment should be designed so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability. An environment (or any building, product, or service in that environment) should be designed to meet the needs of all people who wish to use it. This is not a special requirement, for the benefit of only a minority of the population. It is a fundamental condition of good design. If an environment is accessible, usable, convenient and a pleasure to use, everyone benefits. By considering the diverse needs and abilities of all people throughout the design process, universal design creates products, services and environments that meet everyone's needs, at all stages of their life. Simply put, universal design is good design.<sup>18</sup>

<sup>&</sup>lt;sup>16</sup> Health Partners. *Mental illnesses: Terms to use.* Terms to avoid. <u>Available here</u>

<sup>&</sup>lt;sup>17</sup> Funds Towards Transformation Strategy March, 2019. "Annex 2: Glossary". TTW Self-Assessment Facilitation Guide. Draft, p. 14.

<sup>&</sup>lt;sup>18</sup> https://universaldesign.ie/What-is-Universal-Design/

#### Terminology

When speaking to or about someone with disabilities, it is important to avoid harmful terminology, which reflects and perpetuates negative attitudes and stereotypes. We need to use **elevating terms with positive connotations that empower individuals.** However, the disability community is diverse. Therefore, **the language around disability is always evolving and varied**.

There are two main linguistic preferences to address disability: **person-first language** and **identity-first language**, explained in the table below. Both choices are appropriate since they have been designed to respect people with disabilities. However, what terms society considers elevating, or stigmatising, can vary across different countries and cultures. While some terms have become unacceptable almost everywhere (e.g., using 'Mongoloid' for a person with Down syndrome), there are still nuances and subtleties of language to refer to people with disabilities around the world. Some examples:

- A recent study has found 103 unique descriptive terms around disability from 24 countries, highlighting the importance of diversity and cross-cultural dialogue.<sup>19</sup> Some terms we should be aware of are:
  - 'diffable' (people who are differently able) and the corresponding 'diffability' are Indonesian terms created by grassroots movements to oppose the mainstream term 'disabilitas', adapted from the English "people with disabilities". When used in Indonesian, 'disabilitas' is deemed inappropriate since it focuses on physical deficits; conversely, 'diffability' seems to provide a more positive characterisation of people with disabilities, one which respects differences and recognises the abilities of people with impairments.<sup>20</sup>
  - Across Asia, the term 'differently abled' is sometimes used by disability rights advocates and DPOs/OPDs. However, in Western countries the same term is usually avoided because considered a euphemism (i.e. a 'nice' term that seems to deny reality and is perceived as false by people with disabilities).<sup>21</sup> In India, the government has recently started to refer to people with disabilities as 'Divyang' which is translated as 'one with divine body/abilities'. This is another example of a euphemism.
- The person-first language rooted in the human rights approach has become the international standard within government documents, scientific publications and the United Nations (UN).<sup>22</sup> Therefore, this sets the basis of WaterAid's preferred approach.
- However, organisations in the UK and Europe prefer identity-first language. From this point of view, 'person with disabilities' assumes that the person has the disability while 'disabled person' recognises the social oppression.<sup>23</sup> Therefore, WaterAid opts for identity-first language when collaborating with these organisations.

<sup>19</sup>Illes, J. and Lou, H (2019). A Cross-Cultural Neuroethics View on the Language of Disability. AJOB Neuroscience, 10(2), pp. 75-84

<sup>20</sup> Suharto, S. Kuipers, P and Dorsett, P (2016). *Disability terminology and the emergence of 'diffability' in Indonesia*, Disability & Society, 31(5), 693-712

- <sup>21</sup> Shikuku, O (2010). Disability-friendly language: human rights imperative or game of linguistic leap-frog?, unpublished discussion paper
- <sup>22</sup> See for example International Disability Alliance (2008). Position Paper on the Convention on the Rights of Persons with Disabilities (CRPD) and Other Instruments. Available here

- In Australia, People with Disability Australia (PWDA), other DPOs, the government and non-governmental institutions predominantly use person-first language.<sup>24</sup>
- Individuals in the United States and Canada tend to go back and forth between the two depending on the specific disability being represented. So, while The American Psychological Association promotes a person-first language, the National Federation of the Blind, the National Association of the Deaf and the autistic rights community use identity-first language when speaking of disabilities.

#### **Guidance note**

- Both identity-first language and person-first language are acceptable. In some countries, a third option ('differently abled') could also be acceptable or even the commonly used language.
- WaterAid prefers person-first language ('people with disabilities') since we promote a human rights-based language. 'People with disabilities' is also preferred internationally.
- Always contact national networks, movements, rights bodies and OPDs/DPOs operating in the context in which you work and ask for their preferred usage. You can also check the National disabilities strategy and action plans of your country, aimed at guiding the implementation of the Convention on the Rights of Persons with Disabilities.





Mengheang Heng, 24, was injured in a car crash and uses the disability-friendly toilets at the Mong Riev Health Centre. Mong Riev Health Centre, Mong Riev Commune, Tboung Khmum District, Tboung Khmum Province, Cambodia, November 2018.

<sup>23</sup>Leonard Cheshire. (no date). *The language of respect quiz.* <u>Available here</u>

<sup>24</sup> People with Disability Australia (2019). What do I say? A guide to language about disability. Available here

The table below provides some guidelines on respectful language around disability<sup>25</sup>:

Person-first language	Identity-first language	To avoid
<ul> <li>It emphasises the value and worth of the person, by putting them before their impairments.</li> <li>It takes a right-based approach by reducing the dehumanisation of disability.</li> </ul>	<ul> <li>It focuses on the disability, allowing people to claim their disability with pride. It is used by those individuals who see their disabilities as inseparable parts of who they are and want to celebrate them.</li> <li>It is based on the social model of disability with the recognition that people who have impairments are disabled by social barriers.</li> </ul>	<ul> <li>'Special needs/talents' or 'special abilities': disabled people's needs are no more 'special' than anyone else's. These terms seem infantilising and patronising.</li> <li>Expressions such as 'suffer from/victim of/stricken with/ afflicted with' which appear to connotate pity. So, 'they have muscular dystrophy' is preferred to 'they suffer from muscular dystrophy'.</li> </ul>
General		
<ul> <li>Person with a disability/ Impairment.</li> <li>Person living with a disability.</li> <li>Person who has a disability.</li> <li>Person without a disability.</li> <li>Organisations of Persons with Disabilities.</li> </ul>	<ul> <li>Disabled person.</li> <li>Not disabled or non-disabled.</li> <li>Disabled People Organisations.</li> </ul>	<ul> <li>The disabled, the impaired, impaired person: To call any group of people 'the [anything]' is to dehumanise them.</li> <li>Handicap, the handicapped.</li> <li>Defective, abnormal.</li> <li>Normal, healthy, able-bodied.</li> </ul>
People wit	h intellectual or mental in	npairments
<ul> <li>Person with an intellectual disability.</li> <li>Person with a mental health disorder/a mental illness (usually preferred).</li> <li>Person with/living with 'medically diagnosed term'.</li> <li>Person living with depression; person with difficulty learning; people with Down's syndrome.</li> </ul>	<ul> <li>Intellectually disabled person.</li> <li>Mentally disabled person.</li> <li>Down's syndrome person.</li> </ul>	<ul> <li>Mentally challenged, mentally retarded, mentally ill.</li> <li>Mad, crazy, schizo, schizophrenic, insane, nuts, psycho, psychotic, demented, senile, loony or lunatic.</li> <li>The depressed/depressed people.</li> <li>Down's (as a noun).</li> </ul>

<sup>25</sup> American Psychological Association (2019). *Disability*. <u>Available here</u> National Center on Disability and Journalism. 2018. *NCDJ Style Guide*. Available here Centre for Disability Rights. 2018. *Disability Writing and Journalism Guidance*. <u>Available here</u>

People with neurological impairments		
<ul> <li>Person with autism.</li> <li>Person who has cerebral palsy.</li> <li>Person who has difficulty moving (or speaking).</li> <li>Person who has epilepsy (or an epileptic seizure or spasm).</li> </ul>	Autistic person	<ul><li>Spastic.</li><li>Epileptic/the epileptic.</li></ul>
Рео	ple with physical impairm	ents
<ul> <li>Person who uses a wheelchair/in a wheelchair.</li> <li>Person who has a physical impairment.</li> <li>Person with/who has difficulty walking (or moving).</li> <li>Children with a congenital disability.</li> </ul>	Wheelchair user.	<ul> <li>'Wheelchair-bound' or 'confined to a wheelchair'.</li> <li>Cripple, invalid, physically challenged, physically impaired.</li> <li>Polio victim.</li> </ul>
Рео	ple with sensory impairm	ents
<ul> <li>Person with hearing impairments.</li> <li>Person who is hard-of- hearing/deaf, person with hearing loss.</li> <li>Person who is blind/visually impaired.</li> <li>Person who is partially sighted, person with low vision.</li> <li>Person with/who has difficulty seeing (or hearing or speaking).</li> <li>Person who has communication difficulties.</li> </ul>	<ul> <li>Deaf person, hard-of-hearing person, deaf-blind person (usually preferred).</li> <li>Blind person, visually impaired person, vision impaired person (these last two are contested).</li> </ul>	<ul> <li>Hearing impaired, person with deafness, deaf and dumb.</li> <li>Visually challenged person, sight challenged person, person with blindness.</li> <li>Mute, dumb.</li> </ul>

# Gender



# WaterAid believes that no person should be discriminated on the basis of gender.

Gender refers to the socially constructed roles and positioning of men and women rather than the biologically determined differences of sex in a given society at a specific time and place. These roles, and the relationships between them, are not fixed but can and do change over time, within and across cultures. They are usually unequal in terms of power, freedom, agency and status as well as access to and control over entitlements, resources and assets.<sup>26</sup>

The differences between sex and gender are outlined in the table below<sup>27</sup>.

Sex	Gender
Sex refers to the physical and biological characteristics, such as external and internal reproductive sex organs, a person is born with. Male or female sex characteristics determine the gender assigned at birth, typically using the gender-binary framework of 'boy/man' or 'girl/ woman'. However, other non-binary genders are increasingly acknowledged (see next chapter).	Gender refers to the socially constructed roles of men and women, and the relationships between them. Gender norms, roles and relations are hierarchical, leading to power inequalities. The cultural, behavioural and psychosocial characteristics of gender are learned, time and context specific and changeable.

A number of terms are used in relation to gender. They include:

#### **Gender equality**

This means the different behaviours, aspirations and needs of women and men are considered and valued equally.

#### Gender mainstreaming

This term was defined by the UN in 1997 as "a strategy for making women's as well as men's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres so that women and men benefit equally, and inequality is not perpetuated".

<sup>26</sup> Adapted from Global Water Partnership (2006) Mainstreaming gender in integrated water resources management strategies and plans: Practical steps for practitioners, Technical Brief 5. Available at <u>https://www.gwp.org/en/learn/KNOWLEDGE\_RESOURCES/Global\_Resources/Technical-Briefs/</u>

<sup>27</sup>Adapted from World Health Organisation – Gender And Health. <u>Available here</u>

#### **Targeted approach**

This is an approach to development interventions through targeted activities, projects and components that address women's priorities, needs and capacities, provide opportunities for women's advancement and empowerment, for women to learn, create collection action, and exercise agency and solidarity in a safe space. Targeted activities might include advocacy, policy development, research or projects at community level. Such activities remain important as a way to reduce existing disparities, catalyse promotion of gender equality and build momentum for change. Gender equality initiatives targeting men support promotion of allyship in support of women and girls.<sup>28</sup>

#### Gender parity (or balance)

This is a numerical concept. It requires that equal proportions of girls and boys or men and women are involved in a given activity.

#### Gender disaggregated data

This is a form of measurement where data is reported and broken down into gender components. Increasingly, gender disaggregated data is being challenged to look beyond just binary gender and include third gender/transgender or gender non-confirming statistics.

#### **Gender lens**

A "gender lens" means working to make gender and the powers associated with it, visible; asking if, how, and why social processes, standards, and opportunities differ systematically for women and men. It also means recognizing that gender inequality is interlinked with other systems of inequality. Applying a gender lens is necessary to untangle the gender bias that informs social, political and economic practice in development.<sup>29</sup>

#### **Triple burden**

According to Caroline Moser's Gender Planning Framework,<sup>30</sup> women have the burden of simultaneously balance their triple role in society, which severely constrains their opportunities and empowerment. Women's work includes reproductive work (e.g., domestic chores, childcaring and rearing, adult care, caring for the sick, water and fuel related work, health related work), productive work (e.g., work for income and subsistence, work in informal sector enterprises either at home or the neighbourhood, formal employment) and community managing work (i.e., activities primarily undertaken by women at the community level around the provision of items of collective consumption).

#### Patriarchy

Where the 'male' and the 'masculine' are privileged over the 'female' and the 'feminine'. Cultural, political, economic and social structures and ideas that directly or indirectly favour men and lead to women or anyone not identified as male/ masculine having lower status and being denied equality.<sup>31</sup>

<sup>&</sup>lt;sup>28</sup> Adapted from Funds Towards Transformation Strategy (March, 2019). "Annex 2: Glossary." TTW Self-Assessment Facilitation Guide. Draft.

<sup>&</sup>lt;sup>29</sup>Adapted from Wendy Harcourt (2019) What a gender lens brings to development studies in "Building Development Studies for the New Millennium". Palgrave MacMillan, UK

<sup>&</sup>lt;sup>30</sup> Original source Moser, C (1989). *Gender planning in the third World: Meeting Practical and Strategic Gender Needs*. World Development. 17(2), pp. 1799-1825. This framework is still widely used. See for example: McLaren, H.J.; Wong, K.R.; Nguyen, K.N.; Mahamadachchi, K.N.D (2020). Covid-19 and Women's Triple Burden: Vignettes from Sri Lanka, Malaysia, Vietnam and Australia. Soc. Sci. 9(5). 87

<sup>&</sup>lt;sup>31</sup>WaterAid (2021). Equality, inclusion and rights framework. Available here

# Gender identity and sexual orientation



Sexual orientation and gender identity – and language – provide individuals with opportunities to describe, explore and develop themselves. However, people around the world face violence and inequality – sometimes torture and even execution – because of who they love, how they look or who they are.

**Heterosexism** is a term used to describe a structural system of attitudes, bias and discrimination favouring heterosexuality and marginalising persons whose sexual orientation is not exclusively heterosexual, or whose gender identity is not cisgender, by excluding them from participating fully in society. It is a result of **heteronormativity**, the assumption that all people are (or should be) heterosexual and gender is binary, consequently implying that other sex or gender constructs are deviant and inferior.<sup>32</sup> Hence, people around the world still experience social, political and legal discrimination, stigma and violence based on their sexual orientation and gender identity. Many of these people develop mental health disorders as a result of abuse and social isolation. They may also be at risk of HIV infection and tend to have less access to critical prevention and care services, on top of being discriminated in the workplace. **WaterAid believes that all such forms of discrimination and violence are unacceptable**.

We must always maintain a person's dignity and be respectful of all sexual orientations and gender identities in our choice of language. Two important recommendations:<sup>33</sup>

- Recognise the diversity of people's experiences, identities, aspirations and requirements. Do not presume one individual or group can speak for all transgender and gay people and be aware of likely differences in perspective between generations.
- Acknowledge that the language of gender identity and sexual orientation is not fixed, varying across cultures and between generations.

Therefore, it is paramount to use the terminology each individual uses to identify themselves, recognising the diversity of sexual orientations and gender identities.

Acknowledging that the language of sexual orientation and gender identity is evolving and dynamic, the tables below try to give guidance on appropriate and inappropriate use of language.<sup>34</sup> We focus first on Global North lexicon only because it represents the language used for global activism and advocacy. After that, the final table seeks to provide a comprehensive (although not exhaustive) account of context-specific terminology.

<sup>&</sup>lt;sup>32</sup>Adapted from LGBT Resource Center, UCSF. General Definitions. <u>Available here</u> Haymer, M. et al (2020). Language and History of the LGBTQ Community. In: Lehman, J.R., Diaz, K., Ng, H., Petty, E., Thatikunta, M., Eckstrand, K. (Eds.). The Equal Curriculum: *The Student and Educator Guide to LGBTQ Health*. Springer

<sup>&</sup>lt;sup>33</sup>Boyce, P. Brown, S. Cavill, S. et al (2018). Transgender-Inclusive Sanitation: Insights from South Asia. Waterlines, 37(2), pp.102-117. <u>Available here</u>

<sup>&</sup>lt;sup>34</sup> Craven, C. 2019. Terminology Politics and practice. In: *Reproductive Losses: Challenges to LGBTQ Family-Making*, New York: Routledge, p.ix- xxiv

Gen	eral
Usually appropriate	To avoid
<ul> <li>There is no universally accepted English language word, phrase or acronym for people whose biological sex, sexuality, gender identity and/or gender expression depart from majority norms.<sup>35</sup> Here some general terms:</li> <li>Gay and transgender people, or lesbian, gay, bisexual and transgender people if needed for clarity.</li> <li>LGBT: Umbrella term used to describe people who self-identify their sexual orientation as lesbian, gay or bisexual, and/or their gender identity as transgender. Some people use LGBTQ where Q represents Queer (see below). Others extend the acronym to LGBTQIA where I stands for intersex and A for asexual.</li> <li>LGBT+/LGBT*: Adding an + or a * is a way to including an even broader range of identities.</li> <li>LGBT(+) community: To describe a group whose sexual orientation is not exclusively heterosexual or whose gender identity is not cisgender.</li> <li>Gender and sexual minorities: Gender minorities refers to people whose gender identity or expression does not fit into the cis-normative categories of female or male. Sexual minorities refers to people whose sexual orientation is outside the heterosexual norm.</li> </ul>	<ul> <li>Avoid using narrow terms to describe a broad and diverse community, e.g., avoid calling an LGBT community a 'gay community'. Clustering people into one single category carries the risk of oversimplifying and is not inclusive.</li> <li>Always remember that these umbrella terms include considerable diversity as well as a multiplicity of identities and behaviours. Avoid considering and representing sexual and gender minorities as a homogeneous group.</li> </ul>
Queer: An adjective used by some people, particularly younger people, who identify with any, all or none of the parts of the acronym LGBT. As a noun, it refers to non-heterosexual and non-gender binary, all individuals who fall outside of the gender and sexuality norms. Sometimes, it is a shorthand term for LGBT. "a queer person", "queer woman"	'Queer' is not a universally accepted term, even within the LGBT community. Historically, it has been used as a derogatory term, but it is increasingly seen as an expression of self-empowerment; a celebration of not fitting into social norms. Therefore, it is highly important to consult those in the community about which terms they identify with and want to be referred to as.
<ul> <li>Homo/transphobic: People, policies and actions that are hostile to or discriminatory against sexual and gender minorities.</li> </ul>	

<sup>35</sup>O'Malley, J. et al (2018). Sexual and gender minorities and the Sustainable Development Goals, United Nations Development Programme. <u>Available here</u>

## Gender identity and gender expression

Gender identity is a person's internal, deeply held sense of their gender. For transgender people, their own internal gender identity does not match the sex they were assigned at birth. Commonly, people have a gender identity of man or woman (or boy or girl). However, for some people across the world, their gender identity does not fit neatly into one of those two choices and non-binary genders are increasingly recognised.<sup>36</sup>

Gender expression is the external manifestation of one's self-identified gender, expressed through a person's name, pronouns, clothing, haircut, behaviour, voice and/or body characteristics. Society identifies these cues as masculine and feminine, although what is considered masculine or feminine changes over time and across cultures.

WaterAid believes that a person's non-binary or diverse gender identity should never lead to discrimination or abuse. We recognise that gender identities, along with their particular histories and levels of social acceptance, could vary significantly depending on context (see table below). Nevertheless, discrimination based on gender identity in relation to access to WASH is not acceptable, in accordance with our work on equity and inclusion. Discrimination in the workplace is also unacceptable.

Terms used in relation to WASH activities:

#### Sex-segregated toilets

Public bathrooms separated according to sex. In most cases the segregation is by male and female which, for some members of the transgender communities, is associated with exclusion, denial of access, verbal harassment, and sometimes even physical abuse and violence.

#### **Gender-neutral toilets**

Public bathrooms that are not separated by sex and gender, usually deemed more inclusive, as long as safety considerations are fully integrated. However, there is a diversity of preferences within the transgender community in South Asia, with some considering gender-segregated toilets (male/female/third gender) a more gender-inclusive solution.<sup>37</sup> The choice therefore must be made after consultation with different groups.



<sup>36</sup>Adapted from GLAAD. *Glossary of Terms – Transgender*. <u>Available here</u>

<sup>37</sup>Examples and case studies of transgender-inclusive sanitation can be found in Boyce, P. et al (2018).

#### Gender identity and gender expression To avoid Usually appropriate Avoid using narrow terms to describe a broad Transgender: Refers to those people who identify themselves as a different gender and diverse community, e.g., avoid calling to that assigned to them at birth. They may an LGBT community a 'gay community'. express their identity differently to that Clustering people into one single category expected of the gender role assigned to their carries the risk of oversimplifying and is sex. At some point in their lives, transgender not inclusive. people decide they must live their lives as the Always remember that these umbrella terms gender they have always known themselves include considerable diversity as well as a to be, and often transition to living as that multiplicity of identities and behaviours. Avoid gender. Transgender individuals may identify considering and representing sexual and as a man, a woman, third gender, non-binary, gender minorities as a homogeneous group. or in other terms. • **Transition:** It is the process of altering one's birth sex. It is a complex process that occurs over a long period of time and varies from person to person. It includes many steps, from changing names, pronouns, dressing differently to undergoing surgery. Use a transgender person's chosen name and refer to that person using the pronoun of that gender. Third gender: This term is used almost 'Third gender' is almost term used exclusively in South Asia, where countries predominantly in South Asian – it is not a such as India, Pakistan, Nepal and static cultural or rights-based label, but a Bangladesh all recognising a third gender. contextually particular and variable term with 'Third gender' does not mean that there are a complex history and complex contemporary politics that should not be taken as a (only) three genders; it is rather a way of signifying gender variance outside the maleregionally equivalent term for transgender. female binary.<sup>38</sup> Third gender categories have Note that some activists are against this term. taken shape differently in different contexts throughout history.<sup>39</sup> Country-specific terms used for third gender people are given in the following table. Gender non-conforming: A term used The term is not a replacement for 'transgender' and should only be used if someone selfto describe some people whose gender expression is different from conventional identifies as gender non-conforming. Simply expectations of masculinity and femininity. being transgender does not make someone gender non-conforming.

<sup>38</sup> Lugones, M (2016). The coloniality of gender. In *The Palgrave handbook of gender and development* (pp. 13-33). Palgrave Macmillan, London.

<sup>39</sup> Bochenek, M. and Knight, K (2012). Establishing a third gender category in Nepal: Process and prognosis. Emory Int'l L. Rev., 26, p.11.

Gender identity and gender expression		
Usually appropriate	To avoid	
Non-binary and/or gender queer: A term used by people who experience their gender identity and/or gender expression as falling outside the categories of man and woman. They may define their gender as falling somewhere in between man and woman, or they may define it as wholly different from these terms.	The term is not a replacement for 'transgender' and should only be used if someone self-identifies as non-binary and/or gender queer.	
Intersex: A term used to describe a person who may have the biological attributes of both sexes or whose biological attributes do not fit with societal assumptions about what constitutes male or female. Intersex people may identify as male, female or non-binary.		
• <b>Cisgender:</b> A term used to describe those people whose gender identity aligns with the sex assigned at birth. Simply speaking, it refers to people who do not self-identify as transgender.		
Non-transgender people: A more widely understood way to describe people who are not transgender.		
<ul> <li>Transphobia: Fear or hatred of transgender people or people who do not meet society's gender role expectations.</li> </ul>		

## **Sexual orientation**

**Sexual orientation** is a way to describe a person's feelings for another person. Sexual orientation isn't a choice but a part of who we are. Since feelings are personal and everyone is different, there is a variety of different terms that are used to describe sexual orientation. For some people, these words enable them to properly describe their feelings, while others prefer to avoid using a label.

WaterAid believes that sexual orientation should never lead to discrimination

**or abuse.** We recognise that being a lesbian or gay person is criminalised in several countries where WaterAid works and that some people have strong objections based on their culture or religious beliefs. Nevertheless, discrimination based on sexual orientation in relation to access to WASH is not acceptable, in accordance with our work on equity and inclusion. Discrimination in the workplace is also unacceptable.

Sexual orientation <sup>40</sup>		
Usually appropriate	To avoid	
<ul> <li>Orientation/Sexual orientation: A person's physical, romantic, and/or emotional attraction to another person of the same gender, opposite gender or multiple genders. It is self-identified.</li> </ul>	<ul> <li>Sexual preference: This term is used by anti-gay activists to suggest that being gay is a choice, and therefore can be changed or "cured".</li> <li>Gay lifestyle, homosexual lifestyle: it is used to stigmatise gay people and suggests that their lives should be viewed only through a sexual lens. There is no single LGBT+ lifestyle and people are diverse in the ways they lead their lives.</li> </ul>	
<ul> <li>Gay: The adjective used to describe people whose enduring physical, romantic, and/or emotional attractions are to people of the same gender. The term can be used to describe both gay men and lesbians.</li> <li>Lesbian: A woman whose enduring physical, romantic, and/or emotional attraction is to other women. Some women prefer this term, over gay. It can be used as an adjective and a noun.</li> <li>Gay people; gay man/men; lesbian couple; he is gay; she is a lesbian; she talked about being gay.</li> </ul>	<ul> <li>Using gay as a noun, as in 'He is a gay'.</li> <li>Same-sex attractions.</li> <li>Homosexual/homosexuality: Often used in a negative and dehumanizing way.</li> <li>Lesbianism: Often pejorative.</li> <li>'That's so gay' (a negative insult).</li> </ul>	
<ul> <li>Bisexual/Bi: a person who has physical, romantic, and/or emotional attractions to those of the same gender or to those of another gender.</li> <li>He is bi; bi/bisexual people; bi men and women.</li> </ul>	<ul> <li>Using a hyphen in the word bisexual.</li> <li>Using 'bisexual/bi' as a noun.</li> </ul>	
Pan: A person whose emotional, romantic and/or sexual attraction towards others is not limited by sex or gender.		
<ul> <li>Heterosexual: refers to someone who experiences romantic feelings, sexual attraction and/or intimate attractions towards people of the opposite sex or gender.</li> </ul>		
Homophobia: Hatred and fear of people attracted to the same sex. Homophobia occurs on personal, institutional, and societal levels and includes prejudice, discrimination, harassment, and acts of violence.		

<sup>40</sup> Adapted from GLAAD (2020). An Ally's Guide to Terminology: Talking About LGBTQ People & Equality. Available here Stonewall, The Kite Trust and The Proud Trust. no date. 11 Key signposting and Glossary. Available here

#### The importance of context and subjectivity

Gender identity terminology is not static; it shifts across culture and between generations. Sex/ gender configurations vary internationally, and some have been observed across different cultures for millennia, while LGBTQI terms have originated only recently in the Global North. Hence, using these terms in a universalising fashion is problematic. A universalist approach can be a powerful tool for activism to trigger social and political change, but it might overlook the specificities of individual or group experiences and reinforce South/North inequalities. It can be challenging to think outside of available gender identity stereotypes in one's own culture and time. Yet, it is important to recognise culturally specific identities, although they can themselves be contested and under debate. Ultimately, it is good practice to mirror the terminology each individual utilises to describe themselves.<sup>41</sup>

In the Global South, a wide range of forms of identity are apparent, some of which do not separate gender and sexual identities in the way that is taken for granted in the Global North. Some culturally specific terms have very long histories and are best understood within their evolving cultural context. Be aware that some indigenous terms are labels imposed upon transgender people, and some are insulting.

#### Asia

- Sex and gender variance in India is rich and complex and has ancient roots. There is a strong faith element to Indian conceptualisations of gender, sex and sexuality, which are also influenced by socio-economic factors. The category of kothi encompasses aspects of both gender and sexual variance: Kothis are born as male, their gender expression is feminine, and they are attracted to masculine partners. Similarly, hijras currently form a third sex/gender community. Most Hijras and Kothi in India belong to the poorest classes, and heavily experience economic marginalisation, while LGBTQ identification tends to be associated with being urban and middle- or upper-class. In some instances, terms such as gay are used to refer to what, in the Global North, would be called transgender.<sup>42</sup>
- Research in Bangladesh shows that hijras, who claim to be neither female nor male, are socially excluded and subject to harassments and abuses,<sup>43</sup> while the majority of kothis (men with nonstereotypical gender expression and male sexual partners) face discrimination in workplaces,<sup>44</sup>
- In Nepal, there are a variety of indigenous terms used to describe transgender individuals assigned male at birth, who identify either as a woman or as a third gender individual. These include meti, kothi, fulumulu, hijara and nachaniya. Meti is the most familiar transgender identity in Nepal, but even this term includes a range of identities "that span a spectrum of masculinity and femininity, which may be represented in the variety of words used to refer to Meti individuals such as third gender, transvestite, hijra, Tg, meta and Pinky meta".<sup>45</sup>
- <sup>41</sup> Monro, S (2020). Sexual and Gender Diversities: Implications for LGBTQ Studies, Journal of Homosexuality, 67(3), pp. 315-324
- <sup>42</sup> Chakrapani, V., et al (2007). Structural violence against Kothi-identified men who have sex with men in Chennai, India: a qualitative investigation. AIDS education and prevention : official publication of the International Society for AIDS Education, 19(4), pp. 346-64.
- <sup>43</sup>Khan, S.I., Hussain, M.I., Parveen, S., Bhuiyan, M.I., Gourab, G., Sarker, G.F., Arafat, S.M., and Sikder, J (2009). Living on the Extreme Margin: Social Exclusion of the Transgender Population (Hijra) in Bangladesh. Journal of Health, Population, and Nutrition, 27, pp. 441 – 451.
- <sup>44</sup>O'Malley, J. et al (2018). Sexual and gender minorities and the Sustainable Development Goals, United Nations Development Programme. Available here
- <sup>45</sup> Boyce, P. Brown, S. Cavill, S. et al (2018). *Transgender-Inclusive Sanitation: Insights from South Asia*. Waterlines, 37(2), pp.102-117. Available here





- Regional terms used for people assigned female at birth who identify as male include the following: bandhu (Bangladesh), transpinoy (the Philippines), thirutambi and kua xing nan (Malaysia) in Asia; and fa'afatama (Samoa), tangata ira tane (New Zealand) and Brotherboy (Australia) in the Pacific.
- Regional terms used for people assigned male at birth who identify as female or as a third gender include the following: khwaja sira (Pakistan), kathoey (Thailand), waria (Indonesia), mak nyah (Malaysia), transpinay (the Philippines) and bin-sing-jan and kwaa-sing-bit (Hong Kong) in Asia; and fakafifine (Niue), fa'afafine (Samoa and Tokelau), leiti (Tonga), palopa (Papua New Guinea), akava'ine (Cook Islands), whakawahine (New Zealand) and Sistergirl (Australia) in the Pacific.<sup>46</sup>

#### Africa

- Local identities in African countries may also contrast with the categories included in the LGBTQ acronym. African-centred understandings of gender and sexual categories ascribe different meanings and connotations to Western terms, informed by colonialism, tradition, nationality, faith and patriarchy. Therefore, African non-heterosexual sexualities and gender identities are dynamic and changing, blurred, varied and very context-specific.
- In Senegal, for example, identity categories such as gay and lesbian often do not resonate. In the sub-Saharan region, due to the nearly universal expectation of marriage and procreation to continue kinship lines, same-sex sexual activity often occurs alongside but without challenging the norms of heterosexual marriage. Some activists and scholars in sub-Saharan Africa, particularly in the public health field, refer to men who have sex with men (MSM) rather than using the category of gay, as it seems a more fluid and more inclusive understanding of sexuality.<sup>47</sup>
- Queer identity in Africa is seen by many as excess and promiscuity and perceived as 'un-Africanness'. This results in attempts to minimize citizenship and even the withdrawal of rights by the state, leading to violence and abuse against African queers.<sup>48</sup>





- <sup>46</sup> Health Policy Project, Asia Pacific Transgender Network, United Nations Development Programme (2015). Blueprint for the Provision of Comprehensive Care for Trans People and Trans Communities. Washington, DC: Futures Group, Health Policy Project.
- <sup>47</sup> Bond, J (2016). Gender and Non-Normative Sex in Sub-Saharan Africa. Michigan Journal of Gender & Law, 23(1), pp. 65-145
- <sup>48</sup> Matebeni, Z., Monro, S., & Reddy, V (2018). Queer in Africa: LGBTQI identities, citizenship, and activism. London and New York: Routledge.

# Health

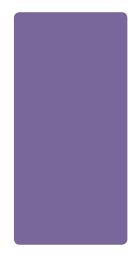


WaterAid believes that the need for WASH goes beyond infection prevention and control- it's also about dignity. Therefore the language we use must uphold dignity, respect and the human rights of all users and staff in relation to healthcare. It's about pride. It's about giving frontline health workers the basic resources they need to do their jobs.

## Albinism<sup>49</sup>

People living with albinism face health-related challenges such as abnormal skin pigmentation, visual impairments and increased susceptibility to skin cancer. Alongside health issues, people living with albinism face social stigma and, in some cases, is the biggest danger they live with. In sub-Saharan Africa, where more people live with albinism compared with the rest of the world, they are sometimes referred to as 'white ghosts' and 'devils' within their communities. Prominent myths include the belief that albinos have supernatural powers and bring misfortunes to a family as well as superstitions that albino body parts bring wealth, power or sexual conquest and that having sex with a person living with albinism cures HIV and AIDS.<sup>50</sup> These social taboos and misconceptions result in threats of killings, attacks and abductions.Women and girls with albinism are particularly vulnerable as they are exposed to intersecting and multiple forms of discrimination.

WaterAid believes that no person should be discriminated against because they are living with albinism. It is therefore important to consider the language we use, both written and verbally, to avoid terms that cause offence and align with any social stigmas that are present.



<sup>49</sup>Adapted from UN-library, (December 2017 – March, 2018). "Ending albino persection in Africa: Governments, UN and human rights groups step up advocacy to enlighten communities." *Africa Renewal.*; The National Organisation for Albinism and Hypopigmentation (NOAH), "Information Bulletin – What Do You Call Me?" accessed on 27/03/19 via <u>https://www.albinism.org/information-bulletin-what-do-you-call-me/</u>

<sup>50</sup> UN-library, (December 2017 – March, 2018). "Ending albino persection in Africa: Governments, UN and human rights groups step up advocacy to enlighten communities." *Africa Renewal*, p. 26. Following is some useful terminology to use when referring to the albinism community and people living with albinism:

Usually appropriate	To avoid
<ul> <li>Use person-centred language – the term 'person/people with albinism' is commonly preferred instead of 'an albino' (noun) or 'albino person'</li> <li>Activities, projects and components targeted specifically for the albinism community can be referred to as 'service to support people living with albinism (e.g. eye testing and skin screening, provision of glasses and sun lotions, as well as psycho-social support services); and 'community response' and 'protection services' (e.g. providing bicycles, security whistles, reflective jackets, torches, hats, umbrellas).<sup>51</sup></li> </ul>	Opinions vary on the use of the word 'albino.' Some people find it extraordinarily offensive; others feel the label carries neutral or even empowering connotations. It is therefore important to consult local organisations and people living with albinism in the community to understand contextual preferences. Until this consultation sheds light on which terms to use, it is best to avoid 'albino' and instead use the people-centred term 'people/person living with albinism.' This will avoid causing offence more generally.

## HIV / AIDS

Globally, approximately 33 million women and men are living with HIV (human immunodeficiency virus) or AIDS (acquired immune deficiency syndrome). Unfortunately, these people are often marginalised as a result of stigma, discrimination and fear by those around them. WaterAid believes that no person should be denied access to WASH because they have HIV or AIDS.

As a result of the interaction between race-, gender- and health-based discrimination, some groups of people experience the least power and control over their health outcomes or experience the biggest barriers or burdens in society. This is sometimes referred to as the Triple Burden of health, race and gender.<sup>52</sup>



<sup>51</sup>Information Bulletin – What Do You Call Me?, Available at <u>https://www.albinism.org/information-bulletin-what-do-you-call-me/</u>. Accessed on 18.05.22

<sup>52</sup> Health Education Quarterly, Volume: 20 issue: 3, page(s): 305-320 Issue published: October 1, 1993

The following table shows the preferred terminology to use in relation to HIV or AIDS.  $^{\rm 53}$ 

Appropriate	Not appropriate
<ul> <li>HIV is the virus which causes AIDS. HIV stands for human immunodeficiency virus, so there is no need to repeat 'virus'.</li> <li>AIDS stands for acquired immunodeficiency syndrome. Since it is a clinical syndrome, it is incorrect to refer to an AIDS virus.</li> <li>Use the term that is most appropriate in the context, for example:</li> <li>People living with HIV.</li> <li>HIV prevalence.</li> <li>HIV prevention.</li> <li>HIV testing.</li> <li>HIV-related disease.</li> </ul>	<ul> <li>AIDS virus.</li> <li>HIV/AIDS, HIV or AIDS: avoid confusion between HIV (a virus) and AIDS (a clinical syndrome). Most people with HIV do not have AIDS.</li> <li>Use the term that is most specific and appropriate in the context.</li> </ul>
<ul> <li>AIDS diagnosis</li> <li>People living with AIDS.</li> <li>Children made vulnerable by AIDS, children orphaned by AIDS.</li> <li>The AIDS response.</li> <li>National AIDS programme.</li> <li>AIDS service organisation.</li> <li>Both HIV epidemic and AIDS epidemic are acceptable.</li> </ul>	
<ul><li>Person living with HIV.</li><li>HIV-positive person.</li></ul>	<ul> <li>Labelling people as 'AIDS infected' or 'HIV infected' avoid the term infected.</li> <li>Transmitters.</li> <li>'AIDS victim': the word 'victim' is disempowering. Use the term AIDS only when referring to a person with a clinical AIDS diagnosis.</li> <li>'AIDS carrier': it is incorrect, stigmatising and offensive to many people living with HIV.</li> </ul>

<sup>53</sup>Adapted from UNAIDS (2015). UNAIDS Terminology Guidelines. Available here

	neatti		
Appropriate	Not appropriate		
<ul> <li>Patient with advanced HIV-related illness (or disease) or AIDS-related illness (or disease).</li> </ul>	<ul> <li>AIDS patient.</li> <li>Use the term 'patient' only when referring to a clinical setting.</li> </ul>		
HIV test or HIV antibody test.	<ul> <li>'AIDS test': There is no test for AIDS. The test is for HIV.</li> </ul>		
Risk of acquiring HIV, risk of exposure to HIV.	Risk of AIDS.		
End the AIDS epidemic as a public health threat (preferred).	End AIDS; end HIV; eliminate HIV; eliminate AIDS; eradicate HIV; eradicate AIDS.		
End the epidemic, end the AIDS epidemic.	Eliminating HIV is still not an achievable goal at the moment. However, proven strategies for the prevention and treatment of HIV are available and can be made to work together to end the AIDS epidemic as a public health threat.		
<ul> <li>Sex work or commercial sex, or the sale of sexual services.</li> <li>Sex worker: intended to be non-judgemental. Sex workers include consenting female, male and transgender adults who regularly or occasionally receive money or goods in exchange for sexual services. As sex work is defined as the consensual sale of sex between adults, children (people under 18</li> </ul>	<ul> <li>'Commercial sex work': no need to use both commercial and work.</li> <li>Prostitute.</li> </ul>		
years) involved in sex work are victims of sexual exploitation.			

## **Neglected tropical diseases**

Neglected tropical diseases (NTDs) are a diverse set of infectious conditions that affect more than one billion people worldwide, predominantly in tropical and subtropical areas among the most vulnerable and marginalised communities.<sup>54</sup> They are called neglected because they are reported late as well as diagnosed and treated late; hence, they are widespread, painful and debilitating, yet treatable and preventable. WASH is a crucial but all too often underplayed part of the prevention and control of NTDs.<sup>55</sup>

<sup>&</sup>lt;sup>54</sup> For a summary of all diseases see WHO (2020). Ending the neglect to attain the Sustainable Development Goals. A road map for neglected tropical diseases 2021–2030. <u>Available here</u>

<sup>&</sup>lt;sup>55</sup> For more information on the link between WASH and NTDs see WaterAid (No date). WASH: The silent weapon against NTDs. <u>Available here</u>

Many NTDs have long-term consequences, such as visual and physical impairments. Additionally, NTDs can have a detrimental impact on a person's mental health as a result of stigma and discrimination. Very often, people with NTDs face stigmatising behaviour and social exclusion from community and family members, leading to depression, anxiety and shame as well as difficulties in employment and marriage.<sup>56</sup> There are many different causes for stigma, including fear, unattractiveness, cultural beliefs and religious values.

The use of inappropriate language and images is one of the key sources of stigma in relation to NTDs. Over time, these diseases have become a metaphor to convey messages of despair, disaster, infectiousness or social exclusion, used by journalists and politicians alike.<sup>57</sup>

WaterAid believes that no one should be stigmatised and excluded because of their disease. Therefore, we must be vigilant to challenge dehumanising language and portray people affected by NTDs in a dignified manner.

Among all NTDs, leprosy represents the clearest example of disease-related stigma. Being generally associated with anything that is considered shameful or that should be kept apart, the word 'leper' alone has become an insult in many languages, and the expression of feeling 'like a leper' is a synonym for social exclusion. The table below presents some guidelines to preferred terminology according to organisations of persons affected by leprosy.<sup>58</sup>

<sup>56</sup> Kuper, H (2019). Neglected tropical diseases and disability – what is the link?. Transactions of The Royal Society of Tropical Medicine and Hygiene, 113 (12), pp. 839–844.

Appropriate

Use people-first language: 'a person affected

whose lives have been challenged by

The term 'leprosy patient' or 'Hansen's

individuals once they are cured.

Disease patient' should only be used in

clinical settings and not used to describe

leprosy' etc.

by leprosy'; 'people with leprosy; individuals

<sup>57</sup> International Federation of Anti-Leprosy Associations (ILEP) and the Neglected Tropical Disease NGO Network. 2019. Guide 1 on Stigma and Mental Wellbeing. <u>Available here</u>

<sup>58</sup> International Leprosy Association (ILA). Terminology: The Importance of Language in Promoting Dignity. <u>Available here</u> and ILEP.



To avoid

other languages are considered derogatory

disease, avoid calling them 'former patient'

The term 'leper' and comparable terms in

and dehumanising so must be avoided.

Avoid labels such as 'victim' and 'sufferer'

that promote images of helplessness.

Once people are medically cured of the

or 'ex-patient'.

## Sexual and reproductive health and rights

Sexual and reproductive health (SRH) is a state of physical, emotional, mental, and social wellbeing in relation to all aspects of sexuality and reproduction, not merely the absence of disease, dysfunction or infirmity. WaterAid believes that all individuals have a right to make decisions governing their bodies, free of stigma, discrimination, and coercion. These decisions include those related to sexuality, reproduction and the use of sexual and reproductive health services<sup>59</sup>.

WASH is increasingly recognised as a foundation of health, including SRH. The realisation of the human right to water and sanitation is interconnected with the fulfilment of sexual and reproductive health and rights (SRHR). The multiple intersections between WASH and SRHR have been explored across key areas,<sup>60</sup> presented in the glossary below.

#### **Menstrual Health**<sup>61</sup>

Research and practice have developed a nuanced understanding of menstrual experiences and their intersections with physical, mental, and social health.

Varied terminologies have evolved, but increasingly actors are using 'menstrual health' to refer to a holistic framework relevant to the varied objectives of policy and programming.

This definition of menstrual health was developed through a multi-stage process, led by the Terminology Action Group of the Global Menstrual Collective (www.globalmenstrualcollective.org).

Menstrual health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in relation to the menstrual cycle.

Achieving menstrual health implies that women, girls, and all other people who experience a menstrual cycle, throughout their life-course, are able to:

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

<sup>59</sup> Starrs, A. et al (2018). Accelerate progress – sexual and reproductive health and rights for all: report of the Guttmacher–Lancet Commission. The Lancet, 391(10140), pp. 2642-2692

<sup>60</sup> For more information see WaterAid, MSI, IWHC and Simavi (2019). A shared agenda. Exploring links between water, sanitation, hygiene, and sexual and reproductive health and rights in sustainable development. Available here

<sup>61</sup> Julie Hennegan, Inga T. Winkler, Chris Bobel, Danielle Keiser, Janie Hampton, Gerda Larsson, Venkatraman Chandra-Mouli, Marina Plesons & Thérèse Mahon (2021). *Menstrual health: a definition for policy, practice,* and *research, Sexual and Reproductive Health Matters,* 29:1, DOI: 10.1080/26410397.2021.1911618

#### Other definitions of menstrual health and hygiene<sup>62</sup>

**Menstrual health and hygiene (MHH)** encompass both menstrual hygiene management and the broader systemic factors that link menstruation with health, well-being, gender equality, education, equity, empowerment, and rights. These factors include informed and comfortable professionals, referral and access to health services, sanitation and washing facilities, positive social norms, safe and hygienic disposal and advocacy and policy.<sup>63</sup>

**Menstrual hygiene management (MHM)** refers to the management of hygiene associated with the menstrual process. It encompasses the knowledge, materials, facilities and services required for good menstrual hygiene to be practised at a personal level (safe use and disposal of menstrual materials, changing and washing) and a public level (end disposal of menstrual materials).

**Menstrual hygiene materials** are products used to catch the menstrual flow, such as sanitary pads, tampons or cups. In resource-poor settings, women often resort to using old cloths, tissue paper, cotton or wool pieces.

**MHM facilities** are basic separated sanitation facilities for females that provide privacy; soap, water and space for washing hands, private parts and clothes; and places for changing and disposing of materials used for managing menstruation.

**Perimenopause:** Often known as 'the change', is the phase of transition in a woman's life between the reproductive years and menopause. It is a natural biological process, marked by various symptoms (e.g., hot flushes and sweating, irregular menstruation, loss of sleep).<sup>64</sup>

**Menopause:** The period beginning one year since the permanent cessation of periods. Women going through menopause and perimenopause (or perimenopausal women) have special WASH needs.

**Incontinence:** A complex health and social issue, which involves the involuntary loss of urine or faeces or both. It can affect menopausal women, women and adolescent girls who have given birth or suffered fistula. It can also affect older people, people with disabilities or illnesses and even those who have experienced highly stressful situations, such as conflict or disasters.<sup>65</sup>



<sup>62</sup>WaterAid (2012). Menstrual hygiene matters. Training guide for practitioners. <u>Available here</u>

<sup>63</sup>UNICEF. 2019. Guidance on Menstrual Health and Hygiene. <u>Available here</u>

<sup>64</sup> Bhakta, A., Fisher, J and Reed, B. 2014. WASH for the perimenopause in low-income countries: changing women, concealed knowledge?. *Sustainable Water and Sanitation services for all in a fast-changing world*. Briefing paper 1909. For more information see Amita Bhakta's blog for WaterAid <<floating refs?>>

<sup>65</sup> Elrha (2019). Exploring the barriers to inclusion faced by people living with incontinence. Available here

#### Maternal and newborn health

**Maternal health** refers to the health of women during pregnancy, childbirth and the postpartum period.

**Perinatal health** refers to the health of women and babies from 22 completed weeks of gestation until 7 completed days after birth.

Newborn health refers to babies' first month of life.66

**Fistula and other reproductive tract injuries:** Fistula is an abnormal opening between the vagina and the bladder or rectum, and can be caused by prolonged obstructed labour and poor obstetric care (obstetric fistula), or by trauma to the genital area through violence or cultural practices including female genital cutting (traumatic fistula).<sup>67</sup>

**Family planning:** Voluntary and available methods of contraception (previously referred to as birth control). It can be customised to individual needs with a range of methods that are acceptable to all and effective if used correctly.<sup>68</sup>

#### Infections and illnesses<sup>69</sup>

**Sexually transmitted infections** (STIs) include gonorrhoea, chlamydia, trichomoniasis and Human papillomavirus (HPV). WASH is critical in addressing STIs. Hygiene — including clean, dry underwear and the ability to wash and wipe properly — is also important in preventing reproductive tract infections (RTIs) such as bacterial vaginosis, yeast infections, and urinary tract infections (UTIs).

Reproductive cancers include cervical and breast cancer.

#### Violence

**Gender Based Violence (GBV)**<sup>70</sup> is any form of violence used to establish, enforce or perpetuate gender inequality. Also called male violence, GBV is predominately perpetrated by men in the name of gender and the gender order, and its targets are selected because of their gender. It includes violence against women and girls (VAWG) – in particular intimate partner violence (IPV) and sexual violence by a non-partner – but also violence against children and other men who do not conform to gender norms.<sup>71</sup>

A **victim** is a person who is, or has been, sexually exploited or abused. This term is often used in the legal and medical sectors, while the term **survivor** is generally preferred in the psychological and social support sectors to a person who has experienced sexual or gender-based violence because it implies resilience.<sup>72</sup>

<sup>66</sup>WHO Regional Office for Europe (2021). Maternal and Newborn Health. Available here

- <sup>67</sup>WaterAid, MSI, IWHC and Simavi (2019). A shared agenda. Exploring links between water, sanitation, hygiene, and sexual and reproductive health and rights in sustainable development. <u>Available here</u>
- <sup>68</sup> Shaw, D (2010). The ABC's of Family Planning. Partnership for Maternal Newborn Health. Online. Available here

<sup>69</sup>WaterAid, MSI, IWHC and Simavi (2019). A shared agenda. Exploring links between water, sanitation, hygiene, and sexual and reproductive health and rights in sustainable development. <u>Available here</u>

<sup>70</sup> Ferguson, H., et al (2003). Ending gender-based violence: A call for global action to involve men. Stockholm: Sida

<sup>71</sup>World Health Organization (2013). Global and regional estimates of violence against women. Prevalence and health effects of intimate partner violence and non-partner sexual violence. <u>Available here</u>

<sup>72</sup> UN (2017). Glossary on Sexual Exploitation and Abuse. <u>Available here</u>

## Race



Campaigners (and scientists) understand that the biological notion of 'race' is an invented and false way to differentiate and categorise people. Even though people may have observable physical differences, such as skin colour and hair type, these are superficial and provide no insight into who people are, their characteristics or behaviours. And certainly 'race' provides no reason for unjust treatment.<sup>73</sup> **Race** is the "social categorisation of people based on perceived shared physical traits that result in the maintenance of a socio-political hierarchy". Similarly, **ethnicity** is defined as "a characterisation of people based on having a shared culture (e.g., language, food, music, dress, values, and beliefs) related to common ancestry and shared history".<sup>74</sup> 'Race' is strongly linked to skin colour. Yet white populations across the world were not 'racialised' in the same way non-white populations were.

According to The International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), **racial discrimination** is: "any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms."<sup>75</sup>

WaterAid believes that no person should be discriminated against because of their race. Language plays a key role in both maintaining and challenging discrimination and racism. As a result, we need to be careful about the language we use, both spoken and written, using a language that is free from racist bias while avoiding terms rooted in negative stereotypes which could cause offence. Even more so, discriminatory and racist use of language can pave the way for violent actions.<sup>76</sup>

Respectful use of language can sometimes be difficult because language changes with time and some terms that were formerly appropriate are now more likely to cause offence. In addition, different terms are acceptable in different countries. As a general rule, the more precise language that can be used, the better. When describing racial and ethnic groups, try to be clear and specific, and use the terms that people use for themselves whenever possible.

The following table – alongside the Annex – is a guide to talk about race and ethnic identity with respect, dignity and inclusivity<sup>77</sup>. As language is ever-evolving, this is not meant to be comprehensive.

<sup>&</sup>lt;sup>73</sup> Sanjiv Lingayah, Elena Blackmore and Bec Sanderson (2020). Common ground and contested spaces: Public and campaigner thinking about racism and what this means for building public support for racial justice. Runnymede Trust and Voice4Change, <u>Available here</u>

<sup>&</sup>lt;sup>74</sup> American Psychological Association, APA Task Force on Race and Ethnicity Guidelines in Psychology (2019). Race and Ethnicity Guidelines in Psychology: Promoting Responsiveness and Equity. <u>Available here</u>

<sup>&</sup>lt;sup>75</sup> UNHCR (2020). Guidance on Racism and Xenophobia. <u>Available here</u>

<sup>&</sup>lt;sup>76</sup> Samy Alim, H (2018). Introducing Raciolinguistics. In: Samy Alim, H., Rickford, J. and Ball, A. (eds.), Raciolinguistics: *How language shapes our ideas about race*. New York: Oxford, pp.1-30

<sup>&</sup>lt;sup>77</sup> Adapted from: American Psychological Association (2019). *Racial and ethnic identity*. <u>Available here</u>; Christiansen, S. L. 2020. Inclusive Language: Race and Ethnicity. *ANNUAL MEETING REPORTS*. 43(3), p. 95-96

Race

BOND – a UK network for organisations working in international development – have produced <u>Taking British politics and colonialism out of our language: Bond's</u> <u>language guide</u>. This short guide is very useful in helping to ensure that our language is not reinforcing colonial or outdated thinking but rather supports the principles of progressive, considered, respectful and inclusive development.

Appropriate	To avoid			
General				
<ul> <li>Racial and ethnic groups are capitalised.</li> <li>Capitalise 'Indigenous People' or 'Aboriginal People' when referring to a specific group (e.g., the Indigenous Peoples of Canada), but use lowercase for 'people' when describing persons who are Indigenous or Aboriginal (e.g., 'the authors were all Indigenous people but belonged to different nations').</li> <li>Use racial and ethnic terms as adjectives in the interests of person-centred language. These terms should describe (instead of defining) people by race.</li> </ul>	<ul> <li>'Black' and 'white': do not use colours to refer to other human groups; this can be taken offensively in some places while in others places or for other people this might feel ok.</li> <li>Using 'Blacks' and 'Whites' as nouns.</li> <li>Using hyphens in multiword names, even if the names act as unit modifiers (e.g., write 'Asian American participants' not 'Asian- American participants').</li> </ul>			
<ul> <li>'Of diverse heritage'; 'multiracial'; 'biracial'; 'multi-ethnic': Terms used when people belong to multiple racial or ethnic groups.</li> </ul>	Half-caste; mixed-race.			
<ul> <li>'People of colour', 'underrepresented groups/people': Terms used to describe non-White racial and ethnic groups collectively (usually used in the 'Global North').</li> <li>If a distinction is needed between a population group and subgroup, use a modifier (e.g., 'ethnic'; 'racial') when using the word 'minority' (e.g., 'ethnic minority'; 'racial minority'; 'racial-ethnic minority'; 'emerging minority'; 'religious minority'; 'linguistic minority'). When possible, use the specific name of the group(s) to which you are referring.</li> <li>When referring to an Indigenous group, use people or nation. Use the names that they call themselves.</li> </ul>	Minority/minorities: using such a broad term to describe often very diverse groups is lazy or inaccurate and it is usually equated with being less than, oppressed, or deficient in comparison with the majority.			
<ul> <li>When referring to people of African, Asian, European or Hispanic origin, it is always preferable to be more specific and use a precise nationality or region of origin.</li> <li>If that is not possible, and you are confronted with a choice (Black vs. African American, Hispanic vs. Latinx etc.), always follow a person's preference. For more details, see the Annex.</li> </ul>				

# Sanitation workers



In low- and middle- income countries sanitation workers are usually marginalised, poor and vulnerable. Although providing an essential public service, sanitation work is invariably precarious, with poor pay, no social security and no legal protection. Sanitation workers across Africa and Asia often take on low-grade, labour intensive, and dangerous work, which violates both their dignity and human rights.<sup>78</sup>

Useful terms in relation to sanitation workers<sup>79</sup> include:

### **Sanitation workers**

This term refers to all people – employed or otherwise – responsible for cleaning, maintaining, operating, or emptying a sanitation facility at any step of the sanitation chain. They include:

- Toilet/latrine cleaners and caretakers in domestic, public, and institutional settings.
- Workers who empty pits and septic tanks once full and other faecal sludge handlers.
- Workers who clean sewers and manholes.
- Workers at sewage and faecal waste treatment and disposal sites.

'Sanitation workers' can be used more broadly, including not just those dealing with faecal waste, but also with solid waste (waste collectors, recyclers etc).

In developing countries, many sanitation workers are often informal workers, unprotected by laws or labour rights and at risk of exposure to hazardous waste material. In South Asian countries, they predominantly belong to oppressed castes and/or religious minorities.

#### Sewer work

The job of sewer workers (or sewer and manhole cleaners) involves maintaining and unblocking sewers, drains and manholes when they are flooded by rainwater and clogged by waste. When technology is lacking, this work is done manually.

<sup>79</sup>WaterAid (2019). *The hidden work of sanitation workers*. <u>Available here</u>

<sup>&</sup>lt;sup>78</sup>World Bank, ILO, WaterAid, and WHO (2019). Health, Safety and Dignity of Sanitation Workers: An Initial Assessment. World Bank, Washington, DC

### Pit and septic tank emptying

The work of pit emptiers and septic tank cleaners involves emptying and cleaning pits and septic tanks, and then transporting the faecal waste for treatment or disposal. If there are no public services, this work can be done by hand with rudimentary tools, and often involves entering into the pit or tank. In Tanzania, manual emptiers are commonly called 'frogmen'. In Bangladesh, informal emptiers are called 'sweepers' and live in segregated 'sweeper colonies' which are unhygienic slum-like areas offering poor and overcrowded living conditions. It is advisable to check with the groups representing these workers to understand their preferred terminology (it may not be the one that governments use).

#### Faecal Sludge Management (FSM)

FSM is understood as the process by which faecal sludge is contained, collected, transported, treated and then safely disposed of or reused. Those who work at Faecal Sludge Treatment Plants are called FSTP plant workers, desludgers or desludging operator<sup>80</sup>.

#### Manual scavenging/scavenger

In South Asian countries, 'manual scavenging/scavenger' describes any type of sanitation work carried out without adequate protection – leading to direct contact with human waste. Traditionally, manual scavenging denoted the manual emptying of dry latrines (bucket latrines, or shallow/open pits) and carrying the waste away (a job still existing and predominantly one by women and girls). Nowadays, it is also used to refer to those cleaning railway tracks and other areas where people practise open defecation, or emptying pits and cleaning sewers and open drains without adequate protection. The work is predominantly undertaken by people considered low caste, belonging to religious minorities or other vulnerable groups. In addition to health and safety risks, manual scavenging is highly stigmatising and is a serious violation of human rights due to the unsafe working environment and health risks, and the associated discrimination.

<sup>80</sup>WaterAid (2019). *Faecal Sludge Management Landscape in South Asia*. <u>Available here</u>

#### Urban poor

### **Urban poor**



Today, more than one billion people in the world live in informal settlements and slums. This means that about one in four people in urban communities lives in conditions that harm their health, safety, prosperity and opportunities. Mega-slums (e.g., Dharavi in Mumbai, Kibera in Nairobi) are often well known and tend to attract interest and funding when in fact, the majority of the urban poor live in other, lesser-known settlements. A common constraint in informal settlements is inadequate access to WASH and other basic infrastructures or services.<sup>81</sup> WaterAid believes that people living in these urban areas should not be discriminated against and denied their rights and access to WASH.

Informal settlements are concentrations of poverty, however, low-income urban dwellers may be living in all areas of the city. WaterAid takes the broader view that poor urban communities include not only residents of informal settlements but also other groups of urban poor people – small vendors in marketplaces, pavement-dwellers/street children – without access to public facilities.<sup>82</sup> At the same time, we recognise that not everybody living in informal settlements/slums is poor.

When talking about urban poor communities it is important to choose the term appropriate for that country, as some terms might be derogatory in one context but appropriate in another. For example, 'slum'/'slum dweller' is mostly used across Asia and is still one of the official terms of UN-Habitat, but most African countries prefer the term 'urban poor'; 'shack dweller' is relevant in South Africa but not in most other countries. Therefore:

- When unsure, use 'informal settlement' as a global term.
- Whenever possible, use the name residents have chosen for themselves. For instance, there is the National Slum Dweller Federation in India as well as the Federation of the Urban Poor in Tanzania. Slum/Shack Dwellers International (SDI) is a network of community-based organisations of the urban poor across Africa, Asia, and Latin America. Check its <u>website</u> for a list of its 33 country affiliates.

The following table provides an overview of the most common terms related to the urban poor.

<sup>&</sup>lt;sup>81</sup> United Nations Human Settlements Programme (UN-Habitat). Goal 11/ Target 11.1/Indicator 11.1.1. Last updated: October 2020. <u>Available here</u>

<sup>&</sup>lt;sup>82</sup>WaterAid (2019), Urban Framework. <u>Available here</u>

Appropriate	To avoid
<ul> <li>The word 'slum' is often used to describe informal settlements within cities and towns that have inadequate housing and services, and miserable living conditions. Slums are often not recognised or addressed by public authorities as an equal part of the city.</li> <li>The UN Program on Human Settlements (UN-Habitat)<sup>83</sup> defines a 'slum household' as one in which the inhabitants suffer one or more of the following 'household deprivations':         <ol> <li>Lack of access to improved water sources.</li> <li>Lack of sufficient living area.</li> <li>Lack of security of tenure (i.e. the right of protection by the State against forced evictions).</li> </ol> </li> <li>The term 'slum dweller' refers to a person living in a household that lacks any of the attributes above.</li> </ul>	<ul> <li>'Slum community'; 'slum people'.</li> <li>These settlements acquire different names in different countries, such us 'basti' and 'Zopadpatti' in India, 'katchi abadis' in Pakistan, and 'squatter camp' in South Africa. Slums in cities may be also called 'shanty towns', 'shanties' or 'shacks'. Some of these terms may be perceived as derogatory, therefore it is always preferable to check which terms are appropriate in a particular context.</li> <li>Slum dwellers represent a diverse group of people with different interests, means and backgrounds. Likewise, slums are not homogeneous entities, and some provide better living conditions than others.</li> </ul>
'Informal settlement' is a more general term describing those settlements which have been built illegally, without the consent of the planning authorities, usually without infrastructures and services, and often without fully secure tenure. <sup>84</sup> Since the criteria used by the UN to identify an informal settlement are already covered in the definition of slums, the two are often seen as synonymous or used in combination.	
<ul> <li>'Squatter settlement' is another form of informal settlement. While slums are areas where people with land ownership live in poor environmental and socioeconomic conditions, in squatter settlements people build houses without any legal title to land. What squatter settlements and slums have in common is being residential areas of low-income group dwellings in cities and towns.<sup>85</sup></li> <li>Being illegal settlements, most at risk of 'slum clearance' programmes, they require 'temporary' WASH solutions.<sup>86</sup></li> </ul>	

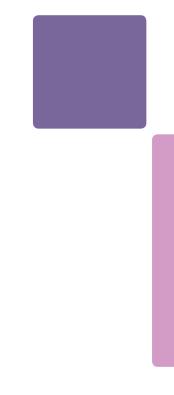
<sup>&</sup>lt;sup>83</sup> Definitions used by UN Habitat to measure indicator 11.1.1 Proportion of urban population living in slums, informal settlements or inadequate housing of the SDG 11: Make cities and human settlements inclusive, safe, resilient and sustainable.

<sup>&</sup>lt;sup>84</sup>UN Habitat (No date). UN-Habitat Global Housing Strategy: Framework Document. <u>Available here</u>

<sup>&</sup>lt;sup>85</sup> Mohanty M (2020), Squatter Settlements and Slums and Sustainable Development. In: Leal Filho W., Azul A., Brandli L., Özuyar P., Wall T. (eds) Sustainable Cities and Communities. Encyclopedia of the UN Sustainable Development Goals

<sup>&</sup>lt;sup>86</sup>WaterAid (2011). *Urban framework.* WaterAid, London. <u>Available here</u>

Appropriate	To avoid
<b>'Small towns'</b> : Settlements with a sufficiently high density of people that would justify collectively managed water services and excreta management systems. In turn, these systems would not be of interest to large cities' utilities to manage due to their size, and the fact of not being financially viable. <sup>87</sup>	
'Slum upgrading' is the process of improving physical and environmental conditions, as well as providing infrastructure and services, in the areas considered slums, and incorporating them into the mainstream city. To be successful the process must be community-driven and fully participatory. <sup>88</sup>	
'Slum organisations' or 'slum-based groups' aim to improve living conditions in their settlements by catalysing community efforts. They focus on those issues which are specific to their settlements. <sup>89</sup>	
Community-based organizations of the urban poor are non-governmental organizations whose mission is to empower urban poor communities to improve their social, economic, and environmental conditions through a community-driven approach. <sup>90</sup>	
Federations of the urban poor are networks of community-based organisations, organised groups, and urban poor people. They can be at the national or citywide scale. <sup>91</sup>	



<sup>87</sup> WaterAid (2019). *Urban framework*. WaterAid, London. <u>Available here</u>

<sup>88</sup>UN Habitat (No date). UN-Habitat Global Housing Strategy: Framework Document. Available here

<sup>89</sup>E.g., <u>https://www.muungano.net/about</u>

<sup>90</sup>E.g., <u>https://www.justempower.org/about-jei</u> or <u>https://codohsapa.org/about-us/</u>

<sup>91</sup>E.g., <u>https://sdinet.org/affiliates/</u>

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Be mindful that each country has different parameters to define an urban context, a town or city. Similarly, the definition of what constitutes a slum/informal settlement varies by country, state and even city. For example, applying the UN's definition to Ugandan cities would result in 93% of the urban population living in slums; therefore, the Ugandan Ministry of Land uses its own definition in governmental documents and plans.<sup>92</sup> In India alone, four different definitions of what constitutes a slum have been identified, which often differ in designating which households are slum dwellers.<sup>93</sup> In South Africa, an informal settlement is defined as "an unplanned settlement on land which has not been surveyed or proclaimed as residential, consisting mainly of informal dwellings (shacks)". An informal dwelling is described as "a makeshift structure not erected according to approved architectural plans".<sup>94</sup> This mismatch complicates efforts to upgrade slums and ensure access for all to adequate, safe and affordable housing and basic services.



An overview of the informal settlements of Somgande, where Issaka SINARE and Adelise SOULGA are working, in Ouagadougou, Burkina Faso.

- <sup>92</sup> A slum has one or more of the following attributes: 1) Attracting a high density of low income earners and/or unemployed persons with low levels of literacy, 2) An area with high rates/levels of noise, crime, drug abuse, immorality (pornography and prostitution) and alcoholism and high HIV/AIDS prevalence, or 3) An area where houses are in environmentally fragile lands, e.g. wetlands. See: Ministry of Lands, Housing and Urban Development (2008). National Slum Upgrading Strategy and Action.
- <sup>93</sup> Nolan L. B (2015). Slum Definitions in Urban India: Implications for the Measurement of Health Inequalities. Population and development review, 41(1), 59–84.
- <sup>94</sup> Hendler, Y. and Fieuw, W (2018). Exploring partnerships with local government: A people's led approach to informal settlement upgrading. CORC, Cape Town. <u>Available here</u>



Suggested exercise

### Suggested exercise



Explore what terminology is appropriate and inappropriate in a national or local context.

This group exercise provides an opportunity for participants to question the different terms that are used locally to describe people who are disabled, older, sick or belonging to a minority.

It is a simple exercise and it is ideal if there are participants who are disabled or from a disability organisation in the group to provide their perspectives on different terms. The following steps could be completed:

- 1. Ask participants to discuss in small groups what words are used locally to describe people who are disabled, older, sick or belong to a disadvantaged minority. Each group then writes the words on post-its or cards (one word per card).
- 2. The facilitator should write the criteria for words that are empowering and respectful on a flip chart or print out the page and distribute as handouts. The criteria are:
  - Uphold dignity and respect.
  - Acknowledge that all people have the same rights and the same basic needs.
  - Do not assume on behalf of people.
  - Consider that what is normal to you may not be normal to others and use simple and clear language.

Details are on page 5 of this guide. Go through each of the criteria above and discuss them briefly in plenary so that everyone understands what they mean.

- 3. Put up flip chart papers or a sticky cloth divided into three sections with three headings: Always appropriate; Sometimes appropriate; Never appropriate.
- 4. Now ask the participants to stick the cards with the different terms up under the relevant heading. The group can discuss in plenary the different words, how they are used by different people, and what they imply. The views of people who often experience discrimination, such as disabled people, older people, or people from marginalised groups are very helpful at this stage. If nobody in the group is sure about a particular word it can be put to one side to find out about later. There may be some words that can be used in different ways, some of which are appropriate and some that are not. These can go into the middle category.

It is useful to discuss how some words may seem to be neutral but can be expressed in a way that is either empowering or disempowering. If they want to, people can share their own experiences about the use of language and how it makes them feel.

- 5. Finish the meeting by referring back to the criteria for language. Emphasise that language also changes over time and in different contexts. Some words can be unacceptable in one context but acceptable in another. Words are also generational and meaning can change over time. For example, older people may use terms that have become unacceptable in the current context without meaning to be insulting.
- 6. It may be useful to type up the lists of words under the different categories and distribute them as a local terminology guide.



▲ Nazia Naureem, a teacher at Ghazali School also works as a social mobilizer conducts an awareness session for women in her community about WASH techniques with the help of a training she attended by Wateraid in Muzaffargarh District, Pakistan, March 29, 2022.



Adama G Sheriff, pump mechanic in Blama, Small-Bo Chiefdom, Kenema District, Sierra Leone, May 2017.

# Annex

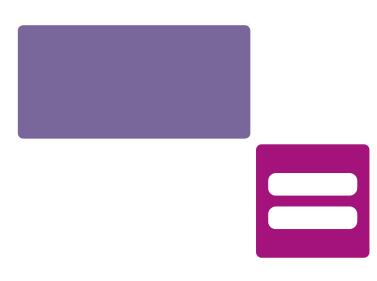


Guidelines<sup>95</sup> on how to use inclusive and respectful language when referring to people of different origin.

Appropriate	To avoid	
People of African origin		
<ul> <li>People of African descent have widely varied cultural backgrounds, family histories, and family experiences. Some will be from Caribbean islands, Latin America, various regions in the United States, countries in Africa, or elsewhere. Always follow a person's preference.</li> <li>'Black' used in some places such as the UK</li> </ul>	<ul> <li>Non-white.</li> <li>Coloured.</li> <li>Negro.</li> <li>Negress.</li> </ul>	
'African American': Acceptable for American people of African ancestry.	<ul> <li>'Afro American' is outdated and inappropriate.</li> </ul>	
• 'Black British': This term started to be used in the 1980s to stress the political unity between African, Caribbean and South Asian people in Britain. Now mainly used to refer to British descendants of first-generation Caribbean migrants, or more broadly to all people of African or Caribbean descent living in Britain.		
People of Asian origin		
<ul> <li>'Asian' (see below for people of Asian origin living outside of Asia).</li> <li>If you can, be more specific by providing nation and region of origin: 'South Asian' (including most of India and countries such as Afghanistan, Pakistan, Bangladesh, and Nepal), 'Southeast Asian' (including the eastern parts of India and countries such as Vietnam, Myanmar, Cambodia, Thailand, Indonesia, Timor-Leste and the Philippines), and 'East Asian' (including countries such as China, Vietnam, Japan, South Korea and North Korea, and Taiwan).</li> <li>In WaterAid, we often use Southeast Asia and the Pacific to include our offices in Papua New Guinea.</li> </ul>	<ul> <li>Oriental.</li> </ul>	
'Asian' (see below for people of Asian origin living outside of Asia).	It is problematic to refer to as 'Asian' people of Asian origin living in North America. It reinforces the idea that Asian Americans are perpetual foreigners.	

<sup>95</sup> Adapted from: American Psychological Association (2019). *Racial and ethnic identity*. <u>Available here</u>; Christiansen, S. L. 2020. *Inclusive Language: Race and Ethnicity*. ANNUAL MEETING REPORTS. 43(3), p. 95-96; Equality Act. 2010. Chapter 15. <u>Available here</u>

	Annex	
Appropriate	To avoid	
People of Hispanic or Latinx ethnicity		
When writing about people who identify as Hispanic or Latino ask participants to determine the appropriate choice. In general, using a nation or region of origin is preferred (e.g., Bolivian, Salvadoran, or Costa Rican).		
'Hispanic': Usually refers to those who speak Spanish. Be aware that not every group in Latin America speaks Spanish (e.g., in Brazil, the official language is Portuguese).		
'Latinx', 'Latin@': For people of Latin American ethnicity, the most common term 'Latino' is gendered (Latino/s is masculine, and Latina/s is feminine). Therefore, some groups advocate for the use of Latinx, others for Latin@. Latinx is widely used as a gender-neutral or nonbinary term inclusive of all genders.		
People of European origin		
<ul> <li>Once again, it is preferable to use a precise nationality when possible (e.g. Spanish, Irish, German, French) or region of origin (e.g. Scandinavian).</li> <li>White American, White British etc. These are evolving and less used as often people don't refer to colour when talking about 'white' people from particular places due to histories of power and control by so called white).</li> </ul>	'Caucasian': It was a way to describe White people as a superior race.	
Indigenous Peoples		
When referring to an Indigenous group, use <b>people</b> or <b>nation</b> . Use the names that they call themselves.	Tribe.	
<ul> <li>The Americas:</li> <li>Collective terms to use are 'Native American' or 'Native North American'. If possible, specify the nation or people: e.g., Cherokee, Navajo, Sioux.</li> <li>'Alaska Natives': Indigenous Peoples in Alaska, Canada, Siberia, and Greenland may identify as a specific nation (e.g., Inuit, Iñupiat).</li> <li>In Canada, collective terms to use are 'Indigenous Peoples' or 'Aboriginal Peoples'. If possible, specify the nation or people: People of the First Nations of Canada, People of the First Nations, or First Nations People; Métis; Inuit etc.</li> </ul>	<ul> <li>'Indian': This term only refers to people from India.</li> <li>'Eskimo': It might be considered pejorative by Alaska Natives.</li> </ul>	
<ul> <li>Latin America and the Caribbean:</li> <li>'Indigenous People'. If possible, specify the nation or people: e.g., Quechua, Aymara, Taíno, Nahuatl.</li> </ul>		



<sup>96</sup> Slimane, S (2003). *Recognizing Minorities in Africa.* Minority Rights Group International. <u>Available here</u>



Srinivasulu, 45, washes utensils at his house in Narayanapuram village, Sri City, Andhra Pradesh, India, August, 2018.





Silt can be removed using a grabbing contraption through mechanised sewer servicing in Delhi, India, 2019.

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