

The importance of water, sanitation and hygiene for lymphatic filariasis and leprosy care and inclusion



A group of leprosy affected individuals at a community self-care session, Mozambique.
Photo: Stephen Butler

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List of acronyms

AFL	Acute filarial lymphangitis
ADLA	Acute dermatolymphangiadenitis
DALY	Disability adjusted life year
GPELF	Global Program to Eliminate Lymphatic Filariasis
LF	Lymphatic filariasis
MMDP	Morbidity management and disability prevention
NTD	Neglected tropical disease
WASH	Water, sanitation and hygiene
WHO	World Health Organization

Definitions

Acute manifestation:

Clinical sign with a rapid onset and present over a short period of time

Chronic manifestation:

Clinical sign present over a long period

Disability:

Inability to adequately or independently perform routine daily activities such as walking, bathing and toileting; the negative aspects of the interaction between a person with a health condition and his or her context (environmental and personal factors)

Impairment:

Problem in body function or structure, often leading to disability

Opportunistic infection:

Infection that takes advantage of weaknesses in immune defensive

Introduction

About lymphatic filariasis and leprosy

Lymphatic filariasis (LF) and leprosy are neglected tropical diseases (NTDs) representing a significant global burden of disease morbidity. Like most NTDs, LF and leprosy are most prevalent in poor, rural and marginalised populations. NTD prevalence is becoming known as a ‘proxy for poverty and disadvantage’.¹

Although not commonly fatal, LF and leprosy both have devastating debilitating effects when left untreated. Both are treatable, yet millions of people around the world live with the consequences of permanent disability. Disability presents in impairments to mobility (LF and leprosy), vision and sensation (leprosy), and for both diseases is accompanied by physical deformities and pain (for more information on the pathology, presentation, epidemiology, and treatment of LF and leprosy please refer to Table 1).

In addition to functional limitations, the presentation of long-term disease has severe social and economic consequences. Where disease is visible, affected individuals experience significant stigma, resulting in social exclusion and discrimination.^{2, 3, 4} For example, in India there are currently numerous discriminatory anti-leprosy legislations. Political authority for divorce on the grounds of leprosy and lawful exclusion of infected individuals from public transportation are in effect. This stigma manifests in poor mental health and quality of life,⁵ as well as lost educational and employment opportunities,⁶ with the productivity loss to people suffering from LF potentially as high as 30%.⁷ On top of the consequences of providing physically demanding care, family members and care-givers of infected individuals experience similar stigma, further burdening productivity and finances.⁸ Ultimately, disease facilitates a vicious cycle of poverty.

Table 1: Pathology, presentation, epidemiology and treatment of LF and leprosy

	Lymphatic filariasis	Leprosy
Type of disease and pathogen	Chronic infectious disease caused by parasitic filarial nematodes (roundworms). There are three species of filarial worms – <i>Wuchereria bancrofti</i> (causative agent in 90% of cases of disease), <i>Brugi malayi</i> and <i>Brugia timori</i> .	Chronic infectious disease caused by the bacillus <i>Mycobacterium leprae</i> .
Vector / mode of transmission	Mosquito-to-human transmission. Larvae enter lymphatic system after bite from infective mosquito.	The exact mode of transmission is unknown. It is speculated that human-to-human transmission occurs via droplets from the nose and mouth of untreated patients with severe disease, or through cuts and abrasions in the skin.
Clinical manifestations of disease	<p>Acute clinical manifestations of disease, include acute dermatolymphangioadenitis (ADLA), usually caused by opportunistic infections, and acute filarial lymphangitis (AFL), caused by the death of worms. ADLA is the most common symptom of LF, and can be referred to as ‘acute attacks’, which result in the onset of fever with localised pain and warmth, with or without swelling or redness, in a limb or genital area. Acute attacks can leave individuals bedridden for three to five days and can occur up to eight times a year.⁹ AFL is characterised by tender nodules at the site of worms dying.</p> <p>Chronic clinical manifestations of disease include hydrocele (urogenital swelling), lymphoedema (swelling, typically of limbs), and in lymphoedema’s more advanced form, elephantiasis. All cause great pain and distress, increase risks of opportunistic infection, and result in severe life-long impairments and disfigurements.</p>	<p>Progressive, permanent damage to peripheral motor, sensory and autonomic nerves, causing various clinical manifestations of disease, including anaesthesia (loss of sensation) and muscle weakness.</p> <p>Anaesthesia is accompanied by an inability to sweat and therefore causes extreme dryness of skin. Dryness easily allows for skin lesions, increasing the risk of opportunistic infections.</p> <p>Muscle weakness typically presents in the hands, feet, and eyelids, and leads to motor impairments, deformity (e.g. claw hand, shortening of digits, and foot drop) and vision loss.</p>

Functional limitations	Permanent, long-term disability (difficulties in walking, balancing and bending affected limb) and deformity.	Permanent long-term disability (inability to feel heat or pain, impaired motor activity, difficulties in walking and gripping, and impaired sight) and deformity. Secondary effects, such as wound infections, can lead to amputation.
Incubation period	Larvae take 6-12 months to develop into the adult worms that cause damage to lymphatic vessels. The majority of cases of disease are asymptomatic. Clinical manifestations of disease can take years to present.	The incubation period and clinical manifestations vary greatly depending on an individual's immunological response to <i>Mycobacterium leprae</i> . Disease presentation can take three months or as long as 30 years to appear.
Non-health consequences	Severe stigma and discrimination resulting in social exclusion, and typically an impact on the socioeconomic status of the affected persons and their families.	Severe stigma and discrimination resulting in social exclusion, and typically an impact on the socioeconomic status of the affected person and their families.
At-risk population	An estimated 1.4 billion people at risk living in 73 endemic countries. ¹⁰ The poorest most vulnerable are most at risk.	The poorest most vulnerable are most at risk in the 102 countries reporting cases of leprosy in 2014. ¹¹
No. infected people	An estimated 120 million people are infected worldwide. ¹²	Total estimates of people infected worldwide are unknown. However, at the beginning of 2014, the number of cases registered globally was 180,618. In 2013 alone, 215,656 new cases were reported. ¹³
No. people with disease-related disabilities	An estimated 40 million people are living with clinical chronic manifestations (hydrocele, lymphoedema, and elephantiasis). ¹⁴	In 2013, 13,289 new leprosy cases with grade-2 disabilities (visible deformity or damage, severe visual impairments) were reported. ¹⁵ Although exact figures are unknown, experts estimate up to three million people to be disabled by leprosy globally.
DALYs lost due to disease	2.78 million per year ¹⁶	6,045 per year ¹⁷
Treatment	Multi-drug treatment with albendazole and ivermectin or with diethylcarbamazine citrate . Between 2000-12, more than 4.4 billion treatments were delivered to 984 million individuals in 56 countries. In 2012, 13 of 73 endemic countries entered a post-intervention phase of disease control. ¹⁸	Multi-drug treatment with Rifampicin, Clofazimine and Dapsone. Approximately 16 million people have been cured through multi-drug treatment over the past 20 years. ¹⁹

Purpose of this briefing note

The similarities in disease presentation between LF and leprosy provide a case for a combined exploration of approaches to mitigating disease.

LF and leprosy are targeted for elimination by the World Health Organization (WHO)²⁰. Global efforts to reduce the burden of disease have been guided by WHO targets for disease elimination.²¹ Roadmaps for eliminating LF and leprosy include strategies that identify guidelines for disease prevention, treatment, and morbidity management and disability prevention (MMDP).^{22, 23, 24, 25}

For the purpose of this paper we are primarily interested in MMDP²⁶. A significant portion of disease burden associated with LF and leprosy are related to disability and deformity caused by disease. Therefore, to reach elimination targets and meet the needs of those affected by disease, strategies and programmes must have a strong focus on MMDP.

The Global Program to Eliminate Lymphatic Filariasis (GPELF) strategy for MMDP focuses on alleviating suffering and disability of disease through the introduction of basic measures, such as improved hygiene and skin care, providing surgery for men with hydrocele, and providing psychological and socioeconomic support. Operational guidelines on MMDP supporting the Enhanced Global Strategy for Eliminating Leprosy focus on home-based self-care, simple interventions organised by local clinics, and referral services to specialists in complex cases.

Limitations to realising the success of MMDP guidelines are evident in both programming and the strategies themselves. Progress reports on disease elimination indicate poor uptake of MMDP in comparison to disease prevention and treatment.^{27, 28} Only about a third of national LF programmes report on MMDP activities,²⁹ while little is known about the extent of MMDP activities for leprosy programming. A lack of information and monitoring of MMDP suggests that alleviating the suffering of individuals affected by chronic disease is of a lower priority in programming than disease prevention and treatment.

Along a similar vein, while strategies indicate MMDP to be an important element of achieving elimination, there are clear gaps in putting into operation successful self-care. MMDP relies heavily on access to safe water and sanitation, and ability to practise hygiene (WASH); however, global LF and leprosy strategy guidelines reflect this to varying degrees. For example, while guidelines should ideally include WASH for MMDP self-care and facility-based treatments, WHO MMDP guidelines for LF recognise the importance of clean water and hygiene in self-care in only a brief statement, while those for leprosy fail to mention the importance of WASH entirely. For the purpose of this briefing note, we will focus on WASH for MMDP self-care only. Discussions on ensuring a greater focus on WASH for the provision of safe quality healthcare are currently taking place elsewhere.³⁰

Poor uptake of MMDP coupled with a lack of WASH consideration in MMDP strategy guidelines represents a significant barrier to improving the quality of life and health of infected individuals. Therefore, this paper aims to clearly identify the role of WASH for MMDP self-care, the WASH needs required for practising and optimising self-care, and the potential barriers to an individual's access to WASH services. We then offer recommendations for moving forward and urge improved uptake of an integrated approach to MMDP self-care.

The role of WASH for self-care

Here we explore WHO elimination strategy guidelines and literature in order to identify practices for LF and leprosy MMDP self-care. Self-care for LF and leprosy are simple, affordable interventions that affected individuals can maintain within their homes or communities. With a clear understanding of self-care in practice for both LF and leprosy, we then illustrate the role of WASH for adequately practising and optimising self-care.

Self-care practices

LF

The GPELF strategy focuses on improved hygiene and skin care for self-care. In individuals with LF, even if asymptomatic and at early stages of disease, adult filarial worms cause inflammation of the lymphatic system, leading to lymphatic vessel damage. This puts individuals with LF at risk of opportunistic infection as their immunological response is weakened³¹. Bacterial and fungal pathogens find entry points to damaged lymphatic vessels through lesions in the skin, which are common for individuals with LF.

Opportunistic infections provoke acute attacks. Acute attacks are known to play a role in the development and progression of disease to chronic clinical manifestations of lymphoedema and elephantiasis³². Considering lymphoedema increases the risk of tissue damage and presentation of skin lesions, as lymphoedema progresses, risks of opportunistic infections and acute attacks also increase.

Good skin hygiene of the affected limb, with particular attention to skin lesions, is vital to decreasing the risk of opportunistic infections and acute attacks. A skin hygiene-based 'washing' programme for LF with 1,089 participants showed a 38.9% reduction in incidence of acute attacks in 4.5 months of implementation.³³ When acute attacks do occur, to manage the episode WHO recommends that the affected leg is soaked in cold water or a cold compress is applied, and the individual drinks plenty of water, rests, and takes antibiotics for the infection and antipyretics/analgesics for managing pain.³⁴

Where disease has progressed, the WHO LF MMDP guidelines³⁵ indicate managing chronic clinical manifestations of disease (lymphoedema and elephantiasis) through the following self-care activities:

- **Washing:** The affected limb should be washed twice daily with soap and clean water at room temperature and the skin dried carefully with a clean cotton cloth or gauze.
- **Wound and skin care:** Skin should be kept clean, hydrated and dry. Medicated creams or antibiotics (e.g. antiseptics, antifungal and antibiotic creams) should be used to treat small wounds or abrasions. For patients with

elephantiasis, antifungal creams can help prevent fungal infections in deep folds and in interdigital spaces.

- **Elevation and exercise:** The affected limb should be elevated at night and during the day where possible, and exercised regularly with low intensity movements of joints.
- **Foot care:** The nails and spaces between the toes must be kept clean, and comfortable shoes should be worn to protect the skin.
- **Managing acute attacks:** As per previously described above.

Leprosy

The WHO Leprosy Elimination Strategy Operational Guidelines identify key MMDP self-care practices for eyes, hands and feet of leprosy affected individuals. Muscle weakness caused by nerve damage leads to deformity and motor impairments of eyelids, limbs of individuals with leprosy. Problems with closing eyelids lead to dryness of the eyes and an increased risk of ocular damage and injury. Individuals with leprosy can end up with loss of vision or even blindness.

The effects of nerve damage on hands and feet put individuals with leprosy at risk of injury and acquiring opportunistic infections. Nerve damage causes lost sensation, making individuals with leprosy more prone to, and unaware of, injury. Compounding this, nerves that control perspiration are affected, causing the skin to dry out. Dryness of skin results in skin cracking and can lead to lesions if not attended to. Open wounds from injury and/or dryness of skin increases the risk of opportunistic infections by providing entry points for pathogens. Infection then exacerbates skin lesions and prevents natural healing. This, in turn, can cause chronic ulceration, and can trigger severe, life threatening infections such as necrosis, gangrene, tetanus or septicaemia, sometimes requiring amputation. A cycle of injury and infection contributes to advancing disease and disability, leading to further impairment.

The WHO Leprosy Elimination Strategy Operational Guidelines list the following activities for self-care.

For problems with eye closure:

- Inspect the eye in a mirror every day to check for redness.
- Learn to blink frequently to keep the eyes moist and exercise the lids.
- Wear a hat or sunglasses to prevent dust from getting into the eyes.
- Use a sheet or mosquito net to cover the head at night.

For problems with the hand:

- Inspect daily for signs of injury.
- Loss of feeling is associated with dryness of the skin, so the insensitive hand must be soaked in water for about 30 minutes every day, to maintain skin elasticity. Use a rough stone to smoothen the callus, and then apply oil or petroleum jelly when the skin is still wet to prevent the skin from drying out.
- Use a clean cloth to cover any open wound.

- If there is weakness of the muscle in the hand, passive stretching and active exercises will help prevent contractures and may lead to some strengthening.

For problems with the foot:

- Inspect daily for signs of injury.
- Soak and oil the feet. As for the hands use a rough stone to rub away the callus.
- Walk as little as possible and walk slowly. Rest frequently.
- If ulcers are present, rest is essential.
- Use a clean cloth to cover open wounds.
- If there is a foot-drop, passive stretching will help prevent a contracture of the Achilles tendon.

In addition to the above practices, good skin hygiene is vital to managing skin cracks and decreasing risks of infection. While the WHO Leprosy Elimination Strategy Operational Guidelines indicate the need to cover open wounds, washing wounds out daily, managing pain and infections with medicines (analgesics and antipyretics to reduce pain and fever, and antibiotics to treat infection), and remaining hydrated are also good practices of self-care.³⁶

Both LF and leprosy

In addition to activities identified for directly practising self-care for both LF and leprosy, it should be noted that there are indirect factors for consideration that optimise self-care practices. It is well known that infections are intimately linked to the environmental conditions in which we live. In the case of LF and leprosy, having a clean, hygienic environment decreases the risks of opportunistic infection by limiting the risk of exposure to pathogens. Numerous steps can be taken to improve the hygiene conditions of environments (e.g. eliminating open defecation and ensuring human waste doesn't enter the environment, washing and disinfecting surfaces, laundry, etc.).

WASH requirements for practising and optimising self-care

Based on identified practices for LF and leprosy self-care, as well as known indirect considerations in support of self-care, such as preventing infection, Table 2 illustrates the WASH requirements for adequately fulfilling and optimising self-care for MMDP.

Table 2: WASH needs for practising and optimising LF and leprosy self-care

Disease	WASH need and purpose	Size of need
LF	Water	
	To wash affected limb(s) and maintain skin and foot care	Significant quantities: each portion of water must only be used once, washing should continue until water runs clear, and washing process must be repeated 2-4 times every day ^{37,38}
	To take medication (analgesics and antipyretics to reduce pain and fever, and antibiotics to treat infection)	Small quantities of safe (uncontaminated) drinking water
	To soak the affected limb(s) (pain management) in cold water or apply clean cloth soaked in cold water	Medium quantities: water must be replaced once cooling effect lost
	To remain hydrated, especially during fever from acute attacks	Medium quantities
Leprosy	Water	
	To soak affected limb	Significant quantities: soaking must be performed for about 30 mins once or twice a day, on a daily basis to maintain benefits ³⁹
	To wash out open wounds	Medium quantities on an occasional basis: irrigation must be conducted on a daily basis until ulcer or blister fully healed
	To take medications (analgesics and antipyretics to reduce pain and fever, and antibiotics to treat infection)	Small quantities of safe (uncontaminated) drinking water
	To remain hydrated, especially during fever from infection	Medium quantities
Both	Water, sanitation and hygiene	
	Water and bleach solution to clean bathing and latrine areas and drains, in order to remove pathogens which are a key source of opportunistic infection and could compromise health and self-care practices ⁴⁰	Large quantities to achieve a thorough clean on a regular basis
	Water for additional laundry needs due to open wounds soiling clothing and bedding, to eliminate infection risk, and maintain dignity	Large quantities on a regular basis
	Sanitary bathing and latrine arrangements which allow individual to practise good hygiene and maintain dignity	Accessible, clean and functional bathing facilities and toilets in households, healthcare facilities and schools

WASH access needs and barriers

WASH access needs

In order to fulfil WASH needs for MMDP self-care, individuals affected by disease need to have adequate access to WASH services. This means that services must be designed and located to promote ease of access and use. Table 3 illustrates the specific WASH needs in terms of access for individuals affected by LF and leprosy.

Table 3: WASH access considerations for LF and leprosy affected individuals

Need	Description of need
Ease of access	Nearby water and toilet facility (preferably within household/compound) within 'safe limits' of walking, due to difficulties in walking, and tissue damage caused by walking. Walking long distances causes pain and repetitive trauma and stress on affected tissues, which can aggravate ulcers and cracks, triggering skin breakdown, and increasing susceptibility to infections and worsening impairments. Facilities being located within safe limits of walking can also decrease the risk of sexual violence for particularly vulnerable disabled women and girls.
	Smooth, well-surfaced path to facility that is clearly delineated. Good paths reduce the risk of falls for people with limited mobility or reduced sensitivity (trauma aggravates lesions and introduces dirt and infection, worsening impairment). Well-surfaced paths also enable wheelchair users to access the facility. Clearly marked paths enable people with leprosy-related sight loss to safely access the facility.
	Appropriate water carrying and storage solutions , which are easy to maintain and clean, and enable people to carry enough water to meet both self-care needs and basic daily needs, and easily use that water once within the household. Appropriate solutions minimise the number of visits to the water source, which reduces strain and trauma on affected body parts and meets the needs of individuals for whom rest is indicated, or who cannot carry water in their hands (due to hand deformities or use of crutches/walking sticks to rest affected foot).
Ease of use	Accessible water and toilet facility that can be used comfortably, sanitarily and with dignity by people with physical and sensory impairments. A suitable facility does not force the individual to put unnecessary strain on the affected body part and keeps the risk of infection to a minimum. It does not put the individual at risk of falling in (open latrine or open water source), and prevents individuals from using alternative dangerous and unsanitary solutions.
	Water source is improved, ⁴¹ to reduce water treatment workload for disabled individual or caregiver, and decrease risks of infection. Alternatively, adequate water purification solutions are readily available, whether water purification tablets (affordable) or fuel to boil water (nearby, affordable, transportable). If using water purification solutions, the tools to do so with compromised mobility, functionality and sensitivity are present (due to nerve damage or bulky dressings), and risks of burns and trauma, which might cause further disability and increase risk of infection, are mitigated (appropriate low-cost, low-tech solutions).

Barriers to accessing WASH services

When working to make access to WASH services accessible to individuals with LF or leprosy it is important to consider potential barriers to access. While very little is known about the experiences of accessing WASH services among individuals living with LF and leprosy, much can be learned from the broader area of intersection between WASH and disability. As with disability, individuals living with LF and leprosy can experience poverty, social exclusion and a continual deterioration in health status and disability (further explained in Box 1).

Box 1: Potential experiences and causes of poverty, social exclusion and continual deterioration in health status and disability for individuals affected by LF and leprosy

Poverty:

- **Medical costs** – treatment fees (e.g. surgery for men with hydrocele, surgery for leprosy affected eyes or necrosis), travel to medical facility, managing complications of disease, lost income while receiving treatment (for both patient and caregiver)
- **Loss of income** – short-term inability to work during acute episodes (LF), long-term inability to work (often physically-demanding work) due to chronic physical impairments, caregiver's inability to work while providing care, loss of custom due to stigma and discrimination
- **Financial insecurity** – stigma-related rejection by family and breakdown of marriages (particularly affects women in cultures in which men are typically decision-makers and bread-winners)

Social exclusion:

- **Forced exclusion** – from everyday social interactions (e.g. sharing meals, utensils, washing lines, toilet facilities), from social activities (e.g. friendship groups), differential treatment or exclusion from formal services (e.g. schools, health centres, religious institutions). Also due to inaccessibility of buildings or inability to adhere to expected behaviours (e.g. dress codes)
- **Self-exclusion as a protective measure** – to avoid actual or expected teasing, public rejection, or abuse
- **Self-exclusion due to feelings of worthlessness** – internalisation of stigma, leading to feelings of shame, self-loathing and resigning self to own fate. Loss of employment and of physical and financial independence lead to loss of sense of purpose and self-worth, feelings of no longer belonging in society and acceptance of 'sick-role'. Withdrawal, avoidance and self-isolation

Deteriorating health status and disability:

- **Deterioration in physical health and progression of disability** – delays in seeking diagnosis and treatment due to poverty and stigma, poor treatment adherence due to resignation to fate, and living and working conditions that make hygiene and self-care compliance difficult.
- **Deterioration in mental health** – internalisation of stigma, loss of self-worth and sense of purpose can lead to mental health co-morbidities and a general low quality of life

The socioeconomic impact of poverty, social exclusion and a continual deterioration in health status and disability can be just as disabling as the physical impairment itself. For this reason, it is important to consider an individual's impairment in combination with a variety of other potential barriers when developing and implementing MMDP self-care interventions.

The 'social model' of disability shows that experiences of disability are largely the result of how society is organised – that it is really society that disables people, not their impairment. This model looks at identifying and removing barriers that restrict disabled individuals from accessing services and being equal in society.

Using the social model of disability, potential barriers to accessing WASH services for people living with LF and leprosy are mapped below into environmental, attitudinal and institutional barriers (Table 4). Barriers are ultimately driven by poverty and social exclusion.

Table 4: Applying a social model of disability to identify barriers to LF and leprosy affected individuals’ access to WASH⁴²

Environmental barriers	Attitudinal barriers	Institutional barriers
<p>‘Physical barriers that make it difficult or impossible to reach and use WASH resources.’</p>	<p>‘Lack of information or misinformation on the cause and nature of a disability or illness, which leads to negative beliefs, stigma or discrimination towards the affected individuals.’</p>	<p>‘Established practices or structures that marginalise or block the ability of vulnerable individuals to have a voice in issues that affect them.’</p>
<p>Location of WASH facilities</p> <ul style="list-style-type: none"> • Steep, slippery, uneven path(s) • Long distance • Obstacles (trees/bushes) • Unsafe location • Lack of security/privacy/dignity • Accessibility and usability of hardware and infrastructure • Steps (toilets/water pump) • Raised platform (toilets/water pump) • High sides (well) • Narrow doorway (toilets) • No platform, no steps • High pump handle/exhausting to operate • Narrow cubicle (toilets) • Wide drop hole • Danger of falling into well/river • Nothing to hold onto/support oneself • No lifting mechanism (well) • Heavy water containers • Inaccessible information about WASH services and possibilities 	<ul style="list-style-type: none"> • Community-level decision-making dominated by ‘healthy’ men • False beliefs about causes and transmission pathways of diseases and impairments • Stigma and prejudice surrounding difference • Traditional beliefs around family honour and shame 	<ul style="list-style-type: none"> • Guidelines do not consider additional or different needs • Policies do not consider the needs of marginalised groups, such as people with disabilities and chronic illnesses/additional access needs, or such policies are not enforced • Standard infrastructure designs do not consider accessibility • Lack of awareness about inclusion, accessibility and possibility of adaptations among key stakeholders • Marginalised groups excluded from consultation and decision-making processes • Hygiene education is inaccessible for people with sensory impairments or people who have missed educational opportunities due to discrimination

Fundamentally, access to WASH services is a human right. Therefore, removing the environmental, attitudinal and institutional barriers rooted in poverty and social exclusion that prevent individuals from accessing that right, is not only beneficial for realising MMDP self-care, but essential for fulfilling basic human rights. Identifying barriers to inclusion is vital to developing and targeting solutions.

Addressing WASH access needs and barriers: a note for future policy and programming

While this briefing note focuses on LF and leprosy, when addressing WASH access needs and barriers in policy and programming, a targeted approach that only focuses on individuals affected by LF and leprosy may not be ideal. The advantages and disadvantages of targeted and non-targeted (inclusive) approaches should be considered (see Box 2 for advantages and disadvantages of each type of approach). One way to balance these advantages and disadvantages may be to use an inclusive WASH checklist,⁴³ which does not single out vulnerable and stigmatised individuals for special treatment, but which does keep this, often invisible, group 'on the radar' of all stakeholders, and at the forefront of all decisions made regarding WASH provision.

Box 2: Pros and cons of targeted and inclusive approaches to address WASH needs and barriers

Pros of an inclusive approach:

- Accessible hardware and infrastructure benefits not just for people with physical impairments and chronic ill-health, but also others with compromised mobility, e.g. older people, pregnant women, children, other community members during periods of illness, etc.
- Many people in endemic communities have unmet WASH needs, not just those living with LF and leprosy. An inclusive approach would improve WASH access for everyone, while ensuring that improvements to WASH infrastructure are fully accessible to the most vulnerable people in the community.

Cons of an inclusive approach:

- Individuals with LF and leprosy are highly vulnerable and, due to social exclusion, largely invisible. As a result, it is very easy to overlook the needs of this group if they are not deliberately targeted or adequately represented.

Pros of a targeted approach:

- WASH needs and barriers of individuals with LF and leprosy are placed at the centre of policy and programming, which can lead to better resourcing and access.
- Individuals with LF and/or leprosy are represented throughout decision-making processes, ensuring that their voice is heard and their needs are met.

Cons of a targeted approach:

- Targeted interventions can be damaging to individuals living with LF and leprosy, by publicly revealing their disease status, exposing them to associated stigma. Accounts of LF patients refusing free treatment at government clinics for fear of their condition being publically identifiable indicate that the stigma associated with these diseases is sufficiently strong to threaten the success of targeted WASH programmes.
- Targeted interventions could exacerbate frail relationships between affected individuals and the 'healthy' population, if the 'healthy' population feel that affected individuals are getting 'preferential treatment'. This phenomenon has been observed in HIV and WASH contexts.

Box 3: Key tools and resources for programming

Inclusive WASH – a free learning portal for WASH practitioners and researchers:
www.inclusivewash.org.au

Loughborough University Water, Engineering and Development Centre's *Equity and inclusion in WASH* resources:
<https://wedc-knowledge.lboro.ac.uk/collections/equity-inclusion>

WaterAid's *Compendium of accessible WASH technologies*:
www.wateraid.org/what-we-do/our-approach/research-and-publications/view-publication?id=aff6d098-00f2-42e5-b9a0-22ec2b264a5e

The way forward

A thorough understanding of the role of WASH in MMDP self-care, and WASH access needs and barriers, provides WASH and NTD sectors with the foundations needed to adequately address integrating WASH to improve self-care, and consequently improving the health and wellbeing of people affected by LF and leprosy. In taking forward integrated approaches for self-care, the following types of work will be **priority sector needs and facilitators of success**.

- 1. Recommit to morbidity management and disability prevention as a central pillar and priority of LF and leprosy programmes.** Routinely offering MMDP interventions that deliver effective self-care strategies can significantly reduce the global burden of these two diseases. A considerable portion of the public health problems associated with LF and leprosy are related to disability and deformity caused by disease, yet MMDP had been largely overlooked to date (see page 6 - 7).
- 2. Define new programme outcomes and objectives.** Global roadmaps for eliminating LF and leprosy include clear mandates for preventing suffering and disability associated with disease. Yet, current monitoring excludes information on interventions for individuals infected with chronic disease. Since 'what gets measured, gets done', meeting the goals of preventing suffering and disability caused by disease requires mechanisms to measure progress (see page 6 - 7).
- 3. Develop a strong evidence base on the links between WASH and NTDs for self-care, and MMDP more widely.** While the role of WASH for self-care (see page 10 -11) is evident, demonstrating the impacts of improved WASH access on disease burden can leverage support from donors and decision makers for integrated programmes.
- 4. Conduct further research to assess the minimum daily water needs for disabled people and those with additional needs due to chronic illness.** The exact WASH needs for LF and leprosy self-care are not well understood (see pages 10-11). Calculating both minimum water needs for long-term self-care regimes and maximum 'safe' walking distances can inform policy, practice and guidance for successful MMDP. A thorough assessment of WASH needs can facilitate a thorough appraisal of the feasibility of self-care programmes in areas with poor WASH infrastructure, and provide a solid grounding for the identification of solutions to poor WASH access.
- 5. Ensure that interventions to tackle stigma form a core part of all MMDP interventions.** As illustrated when exploring barriers to WASH access (see page 13 - 15), for many people living with LF and leprosy, social stigma is just as disabling, if not more so, than physical impairments themselves. Any adaptations to infrastructure and environment design are futile if stigma prevents affected people from accessing WASH services.

6. **Deliver fully-inclusive WASH services to poor communities where these diseases are endemic.** Fully-inclusive WASH solutions allow affected individuals to make use of WASH services without 'identifying' their health status, while simultaneously improving access for other 'differently abled' community members. Inclusive, rather than targeted approaches, meet the needs of the whole community in areas where WASH access is typically a challenge for all. This includes ensuring accessible and user-friendly infrastructure, as well as making consultations and awareness-raising interventions inclusive, taking account of the needs and perspectives of all community members.
7. **Integrate self-care programmes across causes of disability.** Given the clear similarities between LF and leprosy chronic presentation and self-care considerations, integrating self-care interventions could improve the efficiency, cost-effectiveness and sustainability of programmes. Additionally, bringing both groups of affected individuals together strengthens the disabled community, increasing their access to social opportunities and resources, while facilitating efforts of de-stigmatisation.⁴⁴
8. **Build capacity, share best practise and implement training around issues of joint interest.** By addressing knowledge gaps among stakeholders from both sectors and identifying cross-sectorial connections, collaborative opportunities can be more readily recognised.
9. **Identify shared communication opportunities and messaging.** 'Harmonised' messaging in endemic communities, for example around hygiene practices, can 'amplify' impact and support long-term behaviour change among affected individuals and their communities, such as treatment compliance and/or reduction in stigma.
10. **Ensure that those affected by LF and leprosy are involved in design and monitoring.** For integrated programmes to be fully inclusive, appropriate, and effective, people living with LF and leprosy must be involved at every stage of consultation, from planning and design to monitoring and review.

Conclusion

The timing is right. There are currently opportunities for the WASH and NTD sectors to capitalise on to ensure integrated and holistic approaches to eliminating LF and leprosy. The strategic aim from the GPELF that 'by 2015, all national elimination programmes will have active morbidity management programmes' has just been met, yet is not being seen in practice, while the current leprosy strategy has ended. There will be a need to support putting LF MMDP into practice, and to develop a new leprosy strategy. It is possible to ensure gaps in past strategy and programming are addressed, and that MMDP is prioritised equally alongside disease prevention and treatment. We cannot leave the already disabled behind. This briefing should provide a strong starting point for influencing and putting change into practice.

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⁴¹ An improved water source assumes water from the source is safe (free from outside contamination, particularly disease causing pathogens) by nature of its construction. The Joint Monitoring Programme for Water Supply and Sanitation (JMP) considers piped water, a public tap or standpipe, a tube well or borehole, a protected dug well, protected spring, and rainwater to be 'improved' sources.

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