

The Missing Millions: demanding justice for the millions of people affected by leprosy

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The Missing Millions: demanding justice for the millions of people affected by leprosy

1.1 Abstract

In May 1991, member states of the 44th World Health Assembly (WHA) unanimously passed a resolution to 'eliminate leprosy as a public health problem' by the year 2000. Elimination was defined at that time as 1 person in every 10,000 of the world's population (now defined as 10:100,000). Responsibility to deliver on the WHA's resolution fell to the World Health Organisation (WHO), with the challenge of clarifying and supporting the implementation of informed and effective global policy and practice. Today, organisations working in the field of leprosy estimate that:

- Over 3 million people with leprosy remain undetected.
- Around 4 million people who are officially 'cured' of leprosy because they have completed their drug therapy are now living with significant life-long impacts that include disabilities, mental and emotional health problems, economic exclusion and poverty, social isolation and stigma. Late diagnosis is a significant contributing factor. Many of the life-long impacts that these people are experiencing contravene their basic human rights as defined in various United Nations resolutions and articles.

These people are the 'Missing Millions' that are referred to in this report, and on which participants in the workshop focused. Commissioned by The Leprosy Mission Ireland, from 2015-2016, the researcher developed and implemented a strategy to create new awareness of 'the missing millions', in order to see their needs recognised and catered for in the WHO 2016-2020 Leprosy Strategy. Two key challenges were addressed. (1) Engaging the WHO; this involved a staged approach of engaging with The Global Elders to open doors to The World Health Assembly, in turn leading to dialogue with The World Health Organisation. (2) Producing evidence-informed recommendations; this involved identifying and bringing together twenty-one leprosy-affected people, medical practitioners and influencers from Bangladesh, Brazil, China, Ethiopia, India, Ireland, Mozambique, Nepal, Nigeria and the UK.

This researcher used participatory action methods to compile participant reflections and recommendations, culminating in 'The Missing Millions: demanding justice for people affected by leprosy', a 44-page report in English and Spanish. The report was delivered to the World Health Organisation, contributing to a change of position in the WHO 2016-2020 Leprosy Strategy, recognising the 'missing millions' with revised health and community intervention guidance.

Brown, M. 2016. The Missing Millions: demanding justice for the millions of people affected by leprosy. The Leprosy Mission Ireland. Dublin.

1.2 Development of Recommendations

This report describes the starting problem, aims, participants, methodology and outcomes of a workshop exploring the 'Missing Millions' in the context of the new WHO Leprosy Strategy 2016-2020.

Workshop Aims

- The aims of the workshop were to:
- To question and explore the extent to which the 1991 WHA resolution to eliminate leprosy
- as a public health problem has been achieved.
- To facilitate participants to explore the opportunities offered by the new WHO Leprosy Strategy 2016-20 to address the 'missing millions', people currently
- experiencing leprosy and its consequences but who are not being effectively diagnosed, treated, supported or recorded.
- To explore how effective and efficient national action plans can best be developed
- to implement the new WHO Leprosy Strategy 2016-20.
- To explore how people directly affected by leprosy, if they want to, can best be empowered to play an active, meaningful role in implementing all aspects of the new WHO Leprosy Strategy 2016-20.

In exploring the above questions, participants were asked to reflect on how The Leprosy Mission Ireland could itself respond to the challenges of addressing the Missing Millions.

Participants

Twenty-one participants attended the workshop on an invitation basis, all of whom are involved in health policy and planning in their respective countries, either as government employees or as consultants and advisors. Participants represented Bangladesh, Brazil, China, Ethiopia, India, Ireland, Mozambique, Nepal, Nigeria, and the United Kingdom.

Methodology

The workshop employed participatory methodologies throughout, facilitated by Dr Michael Brown from The Leprosy Mission Ireland. The methods involved individual, small group and large group work, and utilised creative materials and tools to engage in activities that promoted discussion and sharing of experiences, leading to collective outcomes that all participants could take equal ownership of.

Outcomes

Participants addressed the following two questions by working in regional groups:

- How can effective and efficient national action plans best be developed to implement the new WHO Leprosy Strategy 2016-2020?
- How can people directly affected by leprosy, if they want to, best play an active, role,

- locally, nationally, and globally, in implementing various aspects of the new WHO Leprosy Strategy 2016-2020, thereby helping bring about positive change for themselves and others?

The following recommendations were made:

Africa

The most critical thing is getting governments to take ownership of leprosy strategies, to take the WHO Strategy and make it their own at country level. Reference points including the UN Convention of the Rights of Persons with Disabilities, and the UN Convention on Human Rights should be utilised to promote services for people affected by leprosy. Organisations need to analyse situations very well and have solid evidence on which to plan and implement activities. Practitioners can use modern technologies to accurately map out the situation. People affected by leprosy, and experts (even international) in action-planning, should be involved in creating Country Action Plans.

Brazil

Right now, there is a coup d'état in Brazil, so people are restless and the future uncertain. The political crisis cannot be changed but the health system can. The Brazilian Constitution states that health is a right of all citizens and the State has a duty to provide it. This constitution should be used to demand health services for people with Hansen's disease. The new WHO Strategy has given clear guidance and instruments that can be promoted and utilised to address the challenges of Hansen's disease. The patient must always be at the centre of decision-making, policies and practice. Effective care requires a partnership between people in need of care, their community, health service providers and health administrators.

China

There is a country plan in China, and it can be looked at in the context of the WHO Strategy to identify areas where the country plan is strong, and areas to strengthened. People affected by leprosy are very much spread out geographically, so bringing them together into self-help groups is a challenge. Organisations should explore ways of forming associations as a way for people to make connections, and they can explore using volunteers to create and sustain associations. The government departments are talking well together and each department knows its responsibilities. This makes it easier to go to the right people to make suggestions at the government level.

South Asia

People affected by leprosy can play active roles in all areas of addressing the disease, including policy-making and actively participating in committees and discussion groups, to being a voice on the end of a telephone helpline. People affected by leprosy need to be promoted as Champions, and Champions of Change, within their own communities. The development of strategies needs to start with a clear evidence base. Organisations must start from the real situation, and not from how they would like, or pretend, things to be. Getting cross-cutting

policies across different government departments is a challenge that needs to be worked on. Inter-country collaboration is essential, so that practitioners can learn from each other and share lessons learned and good practice. We can learn from each other on a regional and global basis and this needs to be facilitated.

In the plenary session chaired by Bride Rosney, participants were asked to focus on The Leprosy Mission Ireland's role in addressing the Missing Millions in the context of the new WHO Leprosy Strategy 2016-2020. The following reflections were collectively drawn out by participants:

- The Leprosy Mission Ireland should continue to promote the Missing Millions, and be a driving force to consistently ask the global leprosy community whether the Missing Millions are being effectively addressed.
- The Leprosy Mission Ireland could be a key organisation to facilitate people affected by leprosy to have a stronger and more impactful voice to positively change societal attitudes and address stigma. This could include supporting them to be 'champions' in local, national and international arenas. Focus could be on building the capacity of people affected by leprosy to participate effectively across the many areas involved in addressing leprosy in local, national and global arenas. This might involve such skills as participatory advocacy and taking up roles within governance and decision-making bodies.
- The Leprosy Mission Ireland could facilitate the collection, hosting and promotion of good practice relating to the new WHO Leprosy Strategy 2016-2020. The Leprosy Mission Ireland could also facilitate an exchange programme between partners around the world to promote learning and the replication of good practice more widely.
- The Leprosy Mission Ireland could play a role, with its global partners, in developing and delivering accredited health training for leprosy health professionals and volunteers.
- The Leprosy Mission Ireland could provide an international dimension, and support the incentives, to help increase interest in leprosy health care in local and national arenas in countries where its partners are working.
- The Leprosy Mission Ireland could be the lead coordinator of an ECHO group, or groups, that utilise the ECHO methodology and tools.
- The Leprosy Mission Ireland could build the capacity of its partners to utilise participatory methodologies, similar to those used in this workshop, within their own work.

In response, the CEO of The Leprosy Mission Ireland, Ken Gibson, stated that the Board of his organisation is committed to being the driving force to keep the global leprosy community focused on the Missing Millions. Ken thanked the participants for their contributions and for the clear workshop outcomes. He promised that TLM Ireland will actively respond where it can, but will be careful not to take space for which it's not equipped. In such instances, TLM Ireland will seek to support partners who are better placed to make direct responses.

1.3 Stakeholder Engagement

What Can It Mean to Be Affected by Leprosy?

Participants divided into four equal groups with a mix of gender and regional representation. Each group was given a range of creative materials and a large sheet of paper. They were asked to create a visual story to show the chain of consequences that might follow when a person contracts leprosy. Each group was given a different type of situation to focus on:

- A teacher who died of TB in a rural village
- A 16-year-old girl married woman in a rural village
- A 16-year-old girl married woman in a rural village
- A father with TB and young family in a rural village



Each group then presented their picture to the whole group and a discussion was facilitated around each of the pictures.

The purposes of this activity was:

- To keep participants on the lives of people directly affected by leprosy.
- To allow participants to work together creatively, get to know each other better and share their own experiences and insights, especially across regions and cultures.
- To build a foundation of understanding in preparation for subsequent activities.



Brazil

Key Reflections

Right now, there is a crop of TB in Brazil, on people's nerves and the future reactions. We can't change the political will that we want to change the health system. The Brazilian Constitution says that health is a right of all citizens and the State has a duty to provide it.

We see this as the contribution to demand for health services for people with leprosy.

The new WHO Strategy has great challenges and opportunities that can be presented and addressed to address the challenges of leprosy disease.

The greatest need always is for the center of decision making policies and practices. However, we can't ignore the importance of people in health care. Some community health workers provide and health administration.



South Africa

Key Reflections

People affected by leprosy are very active and all of us are affected by the disease, including policy makers and active participants in leprosy elimination and leprosy eradication. We need to be a leprosy-free country. People affected by leprosy are very active and all of us are affected by the disease, including policy makers and active participants in leprosy elimination and leprosy eradication. We need to be a leprosy-free country.

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China

Key Reflections

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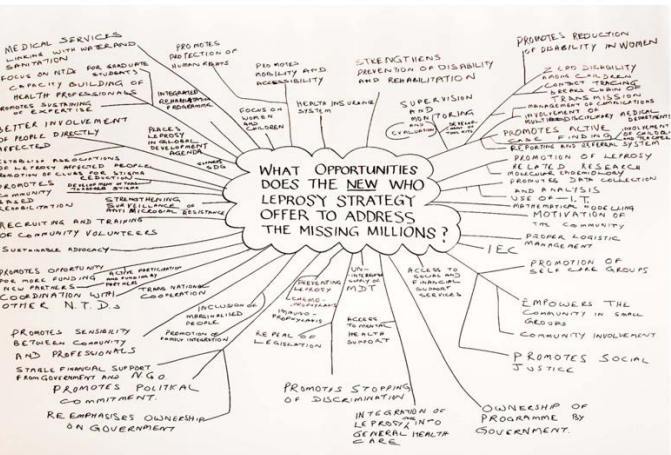
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India

Key Reflections

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Workshop Evaluation

The final session of the workshop asked participants to provide their feedback. The facilitator conducted a discussion session facilitated by Muzamir Bismillah, and the other group of the facilitator, Muzamir Bismillah. Participants were asked to discuss their own experiences and identify the most important points for the workshop. They were asked to provide feedback on the workshop and the facilitator's role. The workshop was very successful and participants were very engaged. The workshop was very successful and participants were very engaged. The workshop was very successful and participants were very engaged.



Brazil

We think it was an important because they need the most in contact with patients, and we want to be on the capacity of nurses and doctors.

I was quite motivated and clearly my thinking on some new ideas.

The workshop really helped me clarify my thinking on some new ideas.

I was able to take time away from my work and think through.

I was good for my learning.

I had a lot of new contacts to persons with disability and persons with leprosy in my country.

I was able to learn from other participants. I was able to learn from other participants. I was able to learn from other participants.



South Africa

In Nigeria, we want to get people affected by leprosy directly involved in the development of our strategy plan. In Nigeria, we want to get people affected by leprosy directly involved in the development of our strategy plan. In Nigeria, we want to get people affected by leprosy directly involved in the development of our strategy plan.

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China

We are promoting an holistic definition of leprosy. We are promoting an holistic definition of leprosy. We are promoting an holistic definition of leprosy. We are promoting an holistic definition of leprosy. We are promoting an holistic definition of leprosy.

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Expanding Leprosy - A Personal Story

Paula Barreto presented her personal story of contracting leprosy.

In Brazil, leprosy is still a disease that causes fear and stigma. Paula Barreto shared her personal story of contracting leprosy. She described the challenges she faced, including the stigma and discrimination she experienced. She also discussed the importance of community support and the role of healthcare workers in providing care and support. Paula Barreto shared her personal story of contracting leprosy. She described the challenges she faced, including the stigma and discrimination she experienced. She also discussed the importance of community support and the role of healthcare workers in providing care and support.



Barreto's story highlights the need for a more holistic approach to leprosy care, one that addresses the social and psychological aspects of the disease. She emphasized the importance of community support and the role of healthcare workers in providing care and support. Barreto's story highlights the need for a more holistic approach to leprosy care, one that addresses the social and psychological aspects of the disease. She emphasized the importance of community support and the role of healthcare workers in providing care and support.

Facilitating Challenges

Participants divided into three groups in order to consider the following questions:

- What are the biggest challenges that we face today?
- Identifying people who have leprosy?
- Engaging people who have leprosy?
- Supporting people after medical treatment?



Biggest Challenges for Identifying People with Leprosy

People are afraid to be treated and will not come to the health center. People are afraid to be treated and will not come to the health center. People are afraid to be treated and will not come to the health center. People are afraid to be treated and will not come to the health center. People are afraid to be treated and will not come to the health center.

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1.4 Recommendations Report



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