

Addressing inequality and exclusion – the opinion of people affected by leprosy in Africa and Asia, as to what should be included in any post Millennium Development Goal framework

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Introduction

The Millennium Development Goals (MDGs), international targets set in September 2000 by 189 nations, commit to working towards a measurable reduction in poverty and achieving basic needs and rights for all, by 2015.¹ The UN Declaration (UN General Assembly Resolution 55/2, United Nations Millennium Declaration) on which the MDGs were based upholds the principles of human dignity, equality and equity. It states that every individual has the right to a basic standard of living that includes freedom from hunger, violence, oppression and injustice. However, although the Declaration highlights the need to ensure that the most vulnerable are included in the development process, the lack of specific reference to leprosy, neglected tropical diseases or disability has meant that some of the world's most marginalised people have not been included in development programmes.

The UN recognises that 'there is an urgent need to address the absence of more than 10 per cent of the world's population in the implementation, review and evaluation of the Goals and their targets, evaluation mechanisms and indicators. The lack of a disability perspective is undermining the objective of the Goals, which is to measure human development benchmarks on the way to more inclusive and equitable global development.'²

More than one billion people are still affected by the chronic disabling results of Neglected Tropical Diseases,³ particularly those living in remote rural areas, urban slums or conflict zones. 232,857 new cases of leprosy were reported in 2012,⁴ an increase on the previous year and millions of people still suffer the physical, social and economic consequences of the disease. Disability and stigma mean many people affected by leprosy are socially excluded, and fail to benefit from mainstream development programmes.

As development becomes a numbers game and measures of success are confined to MDG indicators, gaps between the rich and the poor grow. Oxford research on the

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Multi-dimensional Poverty Index (MPI)⁵ found that most poor people live in middle-income countries, over twice as many than in low-income countries. Despite India, the country with the highest number of new cases of leprosy, being a middle income country it has more acute poverty than many African countries combined. According to the latest data on child under-nutrition from 2005-2010, India ranked second to last on 'Child Underweight' out of 129 countries, below Ethiopia, Niger, Nepal and Bangladesh.⁶ Yet India also houses 46 billionaires⁷ as well as 237,000 members of the top 1% of global wealth holders, which equates to a 0.5% share worldwide. There are 1,500 ultra-high net worth individuals with wealth over \$50 million, and 700 with more than \$100 million worth of assets.⁸ There is now a greater need than ever to address inequality both between and within nations.

In times of economic crisis in the West, where international aid is not a vote winner, Governments such as the UK have tried to convince the electorate that Aid offers value for money. Clearly achieving a balance between economy, efficiency and effectiveness is important. However, one of the dangers of focusing on 'value for money' is that 'it can encourage a focus on easy-to-reach groups rather than riskier targets, such as those in harder-to-reach areas, minority groups and others'.⁹ This has led to many agencies targeting those just below the poverty line, rather than the ultra-poor. This is the easy option, where aid can result in targets being met at the lowest cost. However, it often means that Aid fails to reach those most in need. Those already socially excluded and the ultra-poor, including those affected by leprosy and disability, remain marginalised and vulnerable.

With the MDGs coming to an end next year and recognising that people affected by leprosy in most places have still to be mainstreamed into development programmes, The Leprosy Mission committed to advocate for a Post-2015 framework that addresses the priorities of people affected by leprosy. As a first step, the organisation joined the Beyond 2015¹⁰ Campaign calling the UN and its nation states to consider a post MDG framework.

In order to ensure its advocacy effort was legitimate, The Leprosy Mission consulted people affected by leprosy in nine leprosy-endemic countries to ascertain the changes they have experienced over the last 10 years and identify their future development priorities.

Methodology

The Leprosy Mission's field staff undertook 95 group consultations with 4,797 people affected by leprosy across nine leprosy-endemic countries (Bangladesh, DR Congo, Ethiopia, India, Mozambique, Myanmar, Nepal, Niger, and Nigeria). Focus group discussions and community meetings were used in order to gather qualitative data representing the development priorities of people affected by leprosy in order to ensure that their voice was heard in the formation of any Post-2015 development framework. This research aimed to identify general development themes and recommendations which could be included in The Leprosy Mission's positioning paper on Post-2015.

The sampling of participants included purposive methods, as the study specifically targeted people affected by leprosy (both those who had experienced the disease themselves or who had been subject to leprosy-related stigma through being a family member of someone who had been treated for the disease). In addition, convenience methods were used as the research targeted communities that the field staff had planned to visit for other purposes, or out-patients departments at specialist leprosy hospitals where large numbers of people affected by leprosy were present. It also targeted people who were available when researchers

visited. Therefore it must be noted that the lack of random selection used for the study means there is limited validity to generalise the results. However, even though the study has been conducted within a limited timeframe and budget, the results collected hold particular value as qualitative data, reflecting the opinions of people affected by leprosy. It is therefore important that this information is utilised as a basis for advocacy activities so that the voice of this marginalised group can be heard.

The groups consisted of: members of self-help groups; leprosy-affected in-patients and out-patients from The Leprosy Mission's hospitals in India; people affected by leprosy in communities and colonies; members of the ALEMO (Association of People Affected by Leprosy) group in Mozambique; and members of ENAPAL (Ethiopian National Association of People Affected by Leprosy) in Ethiopia. Groups contained both women and men.

Through the facilitation of these groups/community meetings, answers to four questions were recorded and prioritised. The questions were as follows:

1. What has changed in your community over the last ten years?
2. What are the main issues faced by communities affected by leprosy in our country?
3. If you had control over how the government spent money in your country, which of the above (answers to Q2) issues do you think should be prioritised?
4. What difference would you like to see in your community in 10 years' time? (What would have changed?)

The number of group meetings held in each country varied depending on the number of Leprosy Mission projects and staff availability in that country at that time. Details of groups are shown in Figure 1.

Results

Consultation in Bangladesh involved 118 people in eight groups. Over the past 10 years the main changes people had observed included: improved access to education, reduction in the number of new cases of leprosy, greater community awareness about the disease with a gradual decrease in stigma and greater acceptance of those affected by the disease.

Country	Number of group meetings	Number of people affected by leprosy involved in the consultation
Bangladesh	8	118
D. R. Congo	1	26
Ethiopia	2	12
India	23	460
Mozambique	1	18
Myanmar	12	533
Nepal	29	200
Niger	2	63
Nigeria	17	3,367
TOTAL	95	4,797

Figure 1. Distribution of group members by country.

However, stigma is still an issue and some people are isolated from their community and family. It is difficult for anyone affected by leprosy to marry someone from a family not affected by the disease and the divorce rate of people diagnosed with leprosy is high. There are few employment opportunities and the most marginalised are not generally able to access social security schemes from the government.

Their priorities for government intervention include: ensuring better access to technical and specialist education that results in employment; providing social security schemes for people with disabilities, ensuring disability-friendly infrastructure, and undertaking mass awareness campaigns promoting leprosy and disability inclusion.

They dream of a Bangladesh where leprosy is a part of the general health system and where people affected are swiftly treated, provided with quality care and specialist services, where the government supports income generation activities and people affected by leprosy have jobs, where people with disabilities are valued and not seen as a burden on society, and where social safety nets are available for the most marginalised.

Consultations in DR Congo took place in one group of 26 people. The main changes they had seen over the last 10 years were in relation to a reduction in stigma and improved access to medical treatment. A lady from Sange village explained, "Before, I could not go to the market and sell my goods, people would not buy as they knew I was affected by leprosy, but now I am able to work, to walk and to fetch water." A man from Ndunda explained, "People now visit health professionals by themselves to screen any skin conditions. Before, I visited a witch doctor, but now we have effective medicines. People are no longer ashamed of leprosy and they visit the health centre." The main issues facing people affected by leprosy were highlighted as: difficulty in accessing employment, particularly for those with a disability; stigma is still prevalent so people are afraid to reveal their diagnosis as it could affect their opportunities, particularly in relation to marriage; poor health services as health staff often cannot diagnose leprosy, so treatment is delayed and disability results.

Their top five development priorities for government action were: education, healthcare, stigma reduction/inclusion, employment, and health awareness to prevent disability.

The future dreams for their community included: eradication of leprosy for good, and a community who were sensitised about the disease and that promoted inclusion, where the needs of people affected by leprosy and disability were met.

Consultations in Ethiopia were held with two groups totalling 12 people; all were members of the Ethiopian National Association of People Affected by Leprosy. Over the last 10 years they reported improved infrastructure (roads, telecommunication, electricity), improved healthcare to which they had better access, increased education and employment opportunities. However they still faced issues of stigma due to lack of community awareness about leprosy and also experienced self-stigma and lack of confidence which limited their opportunities. Although access to general health services has improved, it is often of poor quality and there is little thought given to aftercare or rehabilitation.

Their top five priorities for government action were: greater investment in community awareness campaigns on leprosy and the social aspects of the disease to reduce stigma; improved specialist medical services and aftercare; implementation of Community Based Rehabilitation Programmes that empowered people affected by leprosy to access employment and improve their quality of life; and provision of welfare support for the elderly and people with disabilities.

Their dream was to see people with disabilities benefiting from development both from government and NGO programmes, improved awareness on leprosy and social integration of

those affected by the disease, improved specialist health services for leprosy, better education and employment opportunities.

Consultations in India involved 460 people affected by leprosy through 23 group discussions. Over the last 10 years the greatest improvements they have experienced are in relation to education, health care, water and sanitation facilities, and a greater awareness about leprosy. The latter is particularly the case in urban communities but stigma still persists in rural areas. Other issues include high unemployment, with many people affected by leprosy forced to beg to survive and lack of government support. For example, health centres are available but often not resourced, private health care costs are out of the reach of the poor, and society is not inclusive. Access to health care may have improved, but the quality of care and provision of government services are still very poor. Also, many people affected by leprosy are still illiterate and not aware of their rights and entitlements.

The priority of people affected by leprosy for government action is first and foremost to provide high quality, affordable health care services. In addition, the quality of education should be improved and there should be social security payments for those most in need. There should be greater employment opportunities that include people with disabilities, and investment in sanitation.

People affected by leprosy dream of an India where stigma and discrimination are eliminated, where people are able to access government schemes that ensure their basic needs are provided for, where those who are able to work can access employment and where everyone, regardless of income, can access quality health care services.

Consultations in Myanmar involved 533 people through 12 group discussions. They highlighted that over the last 10 years they had seen improvements in education, with the building of new schools, as well as other improved amenities such as electricity and improved roads. The main issues faced by communities affected by leprosy are stigma and discrimination with people still excluded from community activities, and poor roads preventing some children from attending school. There is a lack of employment opportunities and a need for better health services.

Their top five priorities for development are: improved healthcare services, improved education opportunities, greater disability awareness and inclusion of disabled people, increased employment opportunities and improved transportation.

They dream that people with disabilities have equal rights and that people affected by leprosy and other disabilities have access to employment. Also, that there is better health care, education and transport provision.

Consultations in Mozambique among 18 members of the ALEMO (the Leprosy People's Organisation) group highlighted that over the last 10 years the main changes they have seen were increases in the cost of living, more cars on the road and the arrival of mobile phones. They stated that the main issues faced by people affected by leprosy were: lack of water in the dry season, insufficient income generation opportunities, inadequate health care provision (other than traditional healers), poor access to education, and lack of identity papers which prevented access to government support.

Their top five development priorities for government action were: increased employment opportunities, identity papers to access social welfare, improved health care, improved access to technology/communications, improved access to education and training.

The future dreams for their community included: land and the necessary tools to farm, a grain mill to help income generation, all children going to school, mobile phones, a village football team, and that there would be no more leprosy in Mozambique.

Consultations in Nepal included 200 people participating in 29 groups. In the last 10 years people affected by leprosy have seen a reduction in stigma and discrimination, although it is still a problem. Amenities such as water, sanitation and electricity have improved. Women are now more involved in community activities and education has improved with more children attending school. The main issues that now face people affected by leprosy in Nepal are social stigma, which is still a barrier to their participation in society and to marriage; lack of employment opportunities or welfare support for those who are disabled; lack of awareness about leprosy; and illiteracy, lack of self-confidence and leadership among those affected by the disease.

Their priorities for government intervention include: provision of inclusive formal and non-formal education, greater employment opportunities, elimination of stigma and discrimination, a greater focus on leprosy treatment, and improved sanitation.

Dreams for the future include a truly democratic Nepal with a society free from stigma, where people affected by leprosy are included in society and have improved employment opportunities, with every house having a toilet.

Consultations in Niger took place with 63 people divided between two groups. They highlighted a reduction in stigma and marginalisation, improved access to education (including girls), ante-natal visits, improved water supply and housing as the main improvements over the last 10 years. However, they also emphasised negative changes such as greater food insecurity, deforestation, lack of rain and the high cost of living. The main issues faced by communities affected by leprosy were: discrimination in health care and education settings, food insecurity, and lack of awareness about leprosy by health workers.

Their top five development priorities for government action were: improved food security (through addressing climate change and disaster risk reduction), health care, education, stigma reduction/inclusion and employment.

The future dreams for their communities included an improvement in living conditions in their top five development areas, so that their communities see positive development and people experience fulfilment.

Consultations in Nigeria took place through 17 community meetings across five states and included 3,367 people. Over the last 10 years health care services have improved and more people affected by leprosy had better access to education. They also have a greater awareness of their human rights. However, although they had seen an improvement in housing, sanitation, access to water and electricity these are still issues in their communities, such as the lack of good roads. They still experience stigma and discrimination, there are few employment opportunities leading to a high prevalence of begging, they feel neglected by the government and although healthcare services are sometimes available they do not have the resources to access them.

Their five priorities for government action are the provision of basic infrastructure (water and roads), improved housing and sanitation; increased employment opportunities; and health care staff having improved knowledge of leprosy.

Dreams for the future included more amenities in their community, improved housing, improved hospital facilities, and better quality education which leads to jobs rather than begging.

Although there were occasions when concerns of people affected by leprosy were specific to their community or country, the chart below indicates that ten key areas were prioritised across the nine countries surveyed (Figure 2).

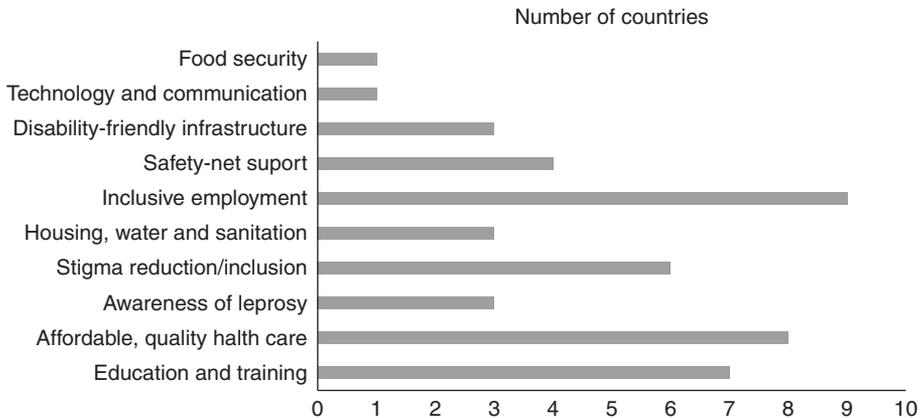


Figure 2. Number of countries highlighting each specific need.

Conclusions

The ten areas of: inclusive employment; affordable quality health care; education and training; stigma reduction; safety net support; disability-friendly infrastructure; awareness on leprosy; housing, water and sanitation; food security; and technology and communication, are the areas of development prioritised by people affected by leprosy from nine leprosy-endemic countries in which The Leprosy Mission works. Many of these are basic human rights under the Universal Declaration of Human Rights and the UN Convention on the Rights of Persons with Disability. As such, failure of governments to address these issues and excluding people affected by leprosy from development is a violation of their human rights. It also goes against the whole philosophy of the MDGs which aimed to uphold human dignity, equality and equity. To ensure people affected by leprosy are not left out of any new development framework it is essential that leprosy organisations help to ensure that the voices of people affected by leprosy are heard.

The author recognises that international decision-makers are unlikely to see leprosy as a priority issue, due to the relatively small number of people affected and lack of awareness of the disease. It is therefore recommended that these priorities, voiced by people affected by leprosy, be advocated for in the context of equity and inclusion, particularly under the banner of disability and neglected tropical diseases. In addition, there needs to be a call for improved data systems so that inclusion of the most marginalised can be measured.

Listening to the voices of people affected by leprosy, it is proposed that any new Post-2015 global development framework:

1. Ensures that poverty reduction goals promote equity and inclusion of those marginalised by disability and neglected tropical diseases such as leprosy.
2. Includes indicators that measure inclusion of the most marginalised in development, specifically including disability-related indicators and targets across all goals.
3. Ensures access to affordable, quality health care that is disability-friendly, accessible to the most marginalised and provides specialist leprosy services within an integrated system.

4. Improves preventative health care systems, so that health education, including that on disability, leprosy and other neglected tropical diseases, is given due priority.
5. Improves the quality and inclusiveness of education and training at all levels, ensuring places of learning are accessible to people with disabilities and are fully inclusive.
6. Increases employment opportunities that include disabled people, valuing their skills and the contribution they can make to the economy.
7. Improves infrastructure development (including roads, schools, hospitals and clinics, water and electricity supplies) ensuring that construction is accessible to people with disabilities.
8. Improves food security for the poorest of the poor through improved access to affordable food but also through provision of safety net support, particularly for people with disabilities and the elderly.
9. Recognises that housing, water and sanitation are basic rights and ensures that provisions are accessible to people with disabilities.
10. Ensures improved technology and communications reach rural areas and are used wherever possible to facilitate the inclusion of people with disabilities.

Contributors

The Leprosy Mission staff in Bangladesh, DR Congo, Ethiopia, India, Mozambique, Myanmar, Nepal, Niger, Nigeria who facilitated the focus group/community discussions and collated the data; ENAPAL& ALEMO who facilitated the participation of their members; Hana Hill and Joshua Miller who assisted with the data analysis; and, most importantly, people affected by leprosy who gave their time to share their opinions and call for change.

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