Results inHealth
Evidence, Innovation and Practice

Final Evaluation
Zero Exclusion Programme
Final Report
NLR- until No Leprosy Remains (Leprastichting)

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Submitted by
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LIST OF ACRONYMS

ADEMO	Association of Disabled People in Mozambique
BRA	Brazil
CBO	Community-based Organisations
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
EQ	Evaluation Question
ILEP	International Federation of Anti-leprosy Associations
INA	Indonesia
IN	India
KII	Key Informant Interview
MORHAN	Movimento de Reintegração das Pessoas Atingidas pela Hanseníase (Movement of Reintegration of Persons Afflicted by Hansen's disease)
MOZ	Mozambique
NEP	Nepal
NFDN	National Federation of the Disabled- Nepal
NGO	Non-Governmental Organisation
NL	Netherlands
NNSWA	Nepal National Social Welfare Association
NTD	Neglected Tropical Disease
OH	Outcome Harvesting
OPD	Organisation of Persons with Disabilities
OYPMK	Orang Yang Pernah Mengalami Kusta (Persons who have had leprosy)
PMEL	Planning, Monitoring, Evaluation, and Learning
PWD	Persons with Disabilities
RiH	ResultsinHealth
ToC	Theory of Change
ToR	Terms of Reference
SCG	Self-Care Group
SHG	Self-Help Group
UN	United Nations

Acknowledgments

We would like to thank first the programme participants from Brazil, India, Indonesia, Mozambique and Nepal who shared with us their lived experiences of leprosy and leadership in their communities.

Our gratitude also goes to the stakeholders and programme partners whom we interviewed; to the interpreters who facilitated communication during these interviews; and to the persons who kindly responded to our request to substantiate outcomes.

Finally, we would like to acknowledge the crucial support provided by the NLR offices for their invaluable help in facilitating and hosting evaluation activities: Héllen Xavier Oliveira and Marize Ventin (NLR Brazil NHR), Dr. Pradeepta Kumar Nayak and Dr. Pravin Kumar (NLR India), Angga Yanuar (NLR Indonesia), Nand Lal Bastola (NLR Nepal), Clara de Oliveira (NLR Mozambique). With special gratitude to NLR International Office PMEL Officer Valeria Pecchioni, Senior Programme Officers Karin van Knippenberg and Heleen Broekkamp, and Infolep and InfoNTD support officer Josephine Breman-Srivastava for the realisation of this assessment.

To all NLR colleagues: this evaluation would not have been possible without your tireless commitment and professionalism.

Executive Summary

Background of the Zero Exclusion Programme

NLR is an alliance of non-governmental organisations (NGOs) that works towards a world free of leprosy. The Alliance currently includes the NLR International Office in the Netherlands, NLR Nepal, NLR India and NLR Indonesia as an independent NGO, and NHR (NLR Brazil) and NLR Mozambique, which are in a transition phase from country offices towards independent NGOs.

Since 2020 NLR Alliance members have implemented a three-year multi-annual strategy which envisioned: Zero Transmission of the leprosy bacteria – We have to break the chain of transmission in order to eliminate the disease; Zero Disability due to leprosy – Most disabilities can be prevented; Zero Exclusion –No person affected by leprosy should be excluded from society. Each organisation operating in leprosy-endemic countries has developed a package of projects that have addressed Zero Exclusion or more Zeros in combination.

This Evaluation focuses on Zero Exclusion. The Zero Exclusion programme focuses on the improvement of the lives of persons affected by leprosy and persons with disabilities through their inclusion and participation in society. The programme aimed at three key changes:

- Persons with a disability due to leprosy are empowered and able to jointly voice their concerns and needs.
- Duty bearers are accountable and address the specific needs and interests of persons with disability due to leprosy.
- Existing policies and practices become increasingly inclusive.

These changes were environed to lead to one main objective: **By 2022 persons with disabilities due to leprosy in target areas in five countries will have improved their lives by having access to comprehensive services and by participating in community activities.** Because of the delays in implementation related to COVID-19, the strategy was extended to include 2023. To achieve these changes, NLR worked on four intervention areas: supporting Disability Inclusive Communities, empowering Self-Help Groups for individuals with disabilities; training organisations on rights advocacy, promoting active involvement in leprosy control, facilitating community inclusion training; advocating for government adoption of inclusive models; sharing successes for collaborative learning and upscaling with partners like the International Federation of Anti-Leprosy Associations ILEP.

Objectives of the Final Evaluation

ResultsinHealth (RiH) has conducted the Zero Exclusion final programme evaluation, with a main learning purpose and four objectives:

- offering a reasoned overview of interventions executed within the programme's framework in NLR target countries from 2020 onwards;
- analysing key successes (using Outcome Harvesting), challenges, and lessons learned;
- reviewing the underlying theory of change for the projects; and
- providing recommendations on the development of new interventions.

Main findings

ResultsinHealth (RiH) has conducted the Zero Exclusion final programme evaluation, with a main learning purpose and four objectives:

- desk review of proposals and annual reports for each country, including quantitative indicators of 24 projects, in-country project evaluations and thematic reports.

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- 33 key-informant interviews with NLR staff and stakeholders across 6 countries.
- 34 Outcome descriptions developed or finalised through 5 Outcome Harvesting workshops with country teams.
- 13 Outcome descriptions substantiated by external stakeholders.
- two validation workshops (with NLR International Office staff & NLR Alliance).

Effectiveness: NLR's programme Zero Exclusion achieved significant progress in strengthening organisations like Self-Help Groups/Self-Care Groups (SHGs/SCGs) and Community-Based Organisations (CBOs)/Organisations of Persons with Disabilities (OPDs). Towards this goal, NLR deployed a wide range of approaches: mobilising members of these groups, ensuring peer counselling and self-care, facilitating small funds management, access to services & advocacy by SHGs/SCGs/CBOs/OPDs. These strategies proved successful: persons affected became local leaders and contributed to grassroots empowerment; they gained better access to comprehensive services; they have empowered themselves in financial and socio-economic terms and have improved their education.

The advocacy endeavours under Zero Exclusion have led to partial change. The main achievements took place in several areas: building advocacy capacity, obtaining organisational recognition, engaging in partnerships, attracting new advocates, ensuring media coverage, and fostering political will mainly at local level; advocacy reached a higher level through fruitful collaboration with the disability movement and Neglected Tropical Disease (NTD) movement; and some policy change was achieved, mainly at local level (villages, municipalities, districts, provinces). Zero Exclusion achieved less results in policy change at national level and advocacy at international level. Also, some advocacy areas like attracting new champions, building constituency, fostering public will, changing attitudes and beliefs, and reframing the issue of stigma, have received less programmatic priority, which might explain for a part the more modest results in advocacy compared to strengthening of groups, organisations, and persons affected by leprosy.

Impact: The Zero Exclusion programme has contributed to impact as persons affected by leprosy have experienced positive changes in their living conditions. Not only have they gone through personal transformations and seen their family ties strengthened. Also, they have become more included in society, gained economic empowerment, and in some cases participated in politics. The changes from new policies are not yet visible or achieved in all five countries because it takes more time for the program to show results.

Sustainability: Achievements in terms of social and economic empowerment as well as local ownership are broadly acknowledged as being the most sustainable. In the area of social empowerment, Leadership Skills, Health Seeking Behaviour, and Increased Recognition are meant to last. This also applies to two achievements in the area of economic empowerment: Improved Livelihoods and Self-Reliance. Also, local ownership of the programme and advocacy results are likely to persist beyond the programme termination.

Less likely to last without multi-level advocacy and capacity strengthening are changes related to the functioning of SHGs/SCGs, involvement of the government and the health institutions. SHGs/SCGs fragility is likely, especially with regard to their advocacy role. Furthermore, without constant advocacy pressure, it will be hard to maintain government commitment.

Best practices: The best practices realised under Zero Exclusion all revolve around an approach centred on the needs of persons affected, that have contributed (in various degrees per country) to enhance inclusion in terms of medical care, well-being, access to rights and services, socio-economic empowerment and to some extent stigma reduction:

- **Community-based engagement** through SHGs and CBOs has brought affected persons together and mobilised them;
- **Empowerment through Rights-Awareness, Self-Care and Advocacy** has enabled them to obtain comprehensive care, and better services and improve their socio-economic inclusion;
- **Sustained Communication, Interaction, and Support** of groups and individuals were provided through structured meetings, community visits, peer support, assistance on job skills and socio-economic opportunities;
- **Holistic Advocacy** effectively involved a broad range of stakeholders and linked leprosy advocacy to the disability and NTD movements;
- **The government was engaged** in training officials about rights of persons affected and with a disability and facilitating dialogue structures;
- Partner NGOs engaged in **long-term capacity strengthening** with NLR support, which contributed to changes in the communities and local policies.

Conclusions: lessons learned and challenges

Support to groups and organisations of persons affected: the Zero Exclusion programme had two key lessons learned:

i) maintaining support to SHGs/SCGs and CBOs/OPDs was effective in gathering, mobilising and and organising persons affected.

ii) integrating mental health and psychological support in SHGs/SCGs contributed to the well-being of persons affected.

The main challenge consisted in keeping persons motivated within the SHGs/SCGs.
Advocacy: three lessons were learned in the advocacy area:

i) The engagement of persons affected by advocacy was effective and had an empowering effect on them.

ii) Advocacy primarily at the local level (villages, municipalities, districts) was the most direct way to bring about tangible change for the persons affected and their families.

iii) Collaboration with broader movements, mainly disability, but also other health-related issues, has been fruitful both at local and national levels.

Across the five countries, NLR and partners had to face challenges in dealing with the insufficient response from the government – due to various factors like poor awareness about leprosy and disability rights, other priorities and high turnover among government officials, – as well as with limited capacity among health services' staff. Also, partners struggled to raise the joint engagement with the disability movement and the NTD movement to the international level.

Overall:
Lesson learned: If we look more broadly at the programme set-up, the holistic approach centred on the needs of the persons affected appears very effective. The capacity challenge remains how to deploy monitoring tools that reflect this focus and more appropriately document the change for the persons affected and their interactions with the wide range of relevant stakeholders. Other challenges are related to three areas of intervention: fighting the pervasive stigma associated with leprosy; strengthening linkages between the local and the national level; and dealing with resource constraints, hampering the ability to meet all needs (e.g. education, and services) and deploying advocacy more fully.

Recommendations

Continue:

Support to group, organisations and persons affected by leprosy:

- **Holistic approach:** NLR should persist in its holistic strategy, emphasizing the dual goals of Zero transmission and Zero disability, while maintaining the integration of mental health and well-being. The organization's work on socio-economic empowerment and ensuring the participation of affected persons in political decision-making has proven beneficial and should continue.
- **Building leadership, community support and networks:** Strengthening leadership among persons affected by leprosy and enhancing self-help groups and peer support remains crucial. These efforts are key to empowerment and reducing stigma.
- **Economic empowerment and livelihood initiatives:** The integration of health and socio-economic aspects has shown promise, particularly through collaborations with the private sector for economic self-reliance. Continuing these initiatives is recommended.

Support to group, organisations and persons affected by leprosy:

- **Engagement with the Private Sector**: NLR is advised to engage more intensively with the private sector, building on existing achievements to further economic self-reliance among affected individuals.
- **Grassroot Organisations**: Expanding partnerships to new locations with grassroots organizations will aid in adapting strategies to local contexts effectively.

Advocacy Aspects:

- **Empowering through Education and Awareness**: addressing the critical need for awareness campaigns and tailored education is key. These campaigns should use more regularly the methods, channels and technology NLR has at its disposal to address local beliefs, leverage patient stories, reach out to remote communities; and intensify education and awareness raising through school education and training for health professionals at local health care facilities.
- **Government Engagement**: Enhancing interaction with government officials and other governance structures is crucial for influencing policy changes, particularly at the national level. NLR should work to build these partnerships more effectively, including in the realm of social assistance.
- **Expand Advocacy Areas**: To achieve comprehensive advocacy, NLR should broaden its focus areas. This involves addressing new champions, attitudes, beliefs, and public will, not just at the local and national levels but also internationally, whenever possible.
- **Collaboration with Broader Movements**: Strengthening ties with the disability and Neglected Tropical Diseases (NTD) movements at the national level will support policy change efforts. Moreover, enhancing cross-sector collaboration and capacity building on shared issues is recommended.

Overall: Improve adaptive and participatory programme design; for example, develop and implement feedback mechanisms that involve affected individuals and communities in the planning and evaluation stages of programs. This could be done using community forums (eg. SHGs/SCG meetings, *Musrembang)* to gather insights and adapt programs in real-time based on participants' needs and suggestions.

Integrate inclusion in other programme activities ;
Example: In leprosy control and/or prevention programs, strengthening the incorporation of specific activities aimed at promoting social inclusion, such as community education sessions that involve both affected individuals and the wider community to foster understanding and support.

Strengthen PMEL on stigma, participation and other issues: NLR might wish to develop clear qualitative criteria, as well as existing quantitative criteria on empowerment and inclusion to assess level and extent of impact and consistently apply them; also capture the linkages and mutually reinforcing effects between the four abovementioned intervention areas; use more consistently the tools of stigma reduction and continue promoting to conduct research studies to understand the personal experiences of those affected by leprosy regarding stigma and social exclusion. Pair these insights with quantitative data, such as the number of individuals participating in self-help groups, to assess and enhance the impact of NLR's interventions.

Strengthen engagement and PMEL on international advocacy issues: monitor and document more thoroughly the international advocacy efforts deployed by NLR. We suggest that NLR creates a detailed report or database tracking NLR's efforts and outcomes related to international advocacy, such as submissions to the Universal Periodic Review (UPR) or involvement in campaigns for the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). This could include case studies highlighting successful advocacy initiatives or policy changes influenced by NLR's work.

The Zero Exclusion programme, led by the NLR Alliance, has made significant strides toward empowering individuals affected by leprosy, advocating for inclusive policies, and fostering societal inclusion. Despite challenges, including delays due to COVID-19, the programme has achieved notable progress in social and economic empowerment, advocacy, and community engagement. Moving forward, it is crucial to continue supporting these efforts, enhancing engagement with wider sectors, and broadening advocacy to ensure lasting impact and further progress toward a world free of leprosy-related exclusion.