

Current Situation and Challenges Surrounding People's Organizations on Hansen's Disease : Prospects for the 2nd Global Forum

T Nanri*

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Discrimination against persons affected by leprosy or Hansen's disease has deep roots, marginalizing individuals and communities. In September 2019, "Global Forum of People's Organization on Hansen's Disease (POs)" was organized in Manila, the Philippines, as a pre-event of the 20th International Leprosy Congress, which was the largest-ever international gathering of persons affected by the disease and led to "the Manila Declaration" to present the collective voice of all the participants. However, how to realize them was not thoroughly discussed during the forum and thus remains an issue for the future. In light of the fact that the second Global Forum is scheduled to be held in conjunction with the 21st International Leprosy Congress in November 2022, this article aims at clarifying what the forum should strive for in order to put the Manila Declaration into action by 1) examining the significance and impact of the first Global Forum, 2) identifying challenges currently faced by the POs from four domains (performance, staff capacity, internal organization, and external relationships), and 3) providing recommendations in three areas (strengthening and networking of POs, promoting their participation in leprosy related activities through effective advocacy, and sustained support by governments and donor agencies for POs).

Keywords : People's Organizations, Hansen's Disease, 2nd Global Forum, Participation, Capacity Building, Networking, Multi-sector Cooperation

Introduction

Leprosy, also known as Hansen's disease, is said to be one of the oldest infectious diseases in human history. Today, leprosy is curable and treatment in the early stages can prevent disability. However, if treatment is delayed, leprosy can cause progressive and permanent damage and expose those affected by the disease to discrimination. This discrimination has deep roots, marginalizing individuals and communities and limiting their opportunities in life. Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination

and Chairman of The Nippon Foundation, has said, "I often compare the fight against leprosy to the two wheels of a motorcycle. Here, liberation from the disease and liberation from stigma and discrimination are the motorcycle's front and rear wheels, and both have to function properly in order for the motorcycle to advance (Sasakawa 2019)."

In recent years, however, persons affected by leprosy are increasingly speaking out and seeking participation in the implementation of leprosy programs and the formulation of

Corresponding author : Takahiro Nanri, Ph.D., Executive Director, Sasakawa Health Foundation and Sasakawa Leprosy (Hansen's Disease) Initiative, The Nippon Foundation Bldg., 5F, 1-2-2, Akasaka, Minato-Ku, Tokyo, Tokyo, Japan; **Email:** t_nanri@shf.or.jp

related policies. According to a survey conducted by Paula Brandao, a volunteer and research head of MORHAN, a Brazilian social movement founded in 1981, there are at least 41 people's organizations on Hansen's disease (POs) in 25 countries around the world. Alice Cruz, United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, stated, "Participation is key for the long-term elimination of leprosy-related discrimination and for a sustainable inclusion of the affected persons and their family members (United Nations General Assembly 2018)." In 2011, the World Health Organization (WHO) formalized "Guidelines for strengthening participation of persons affected by leprosy in leprosy service". The guidelines stated: "The personal experiences, knowledge and information that persons affected by leprosy have gained through having the disease must be recognized as a valuable asset to enhance the quality of leprosy services. Persons affected by leprosy are the best resource to identify their needs and problems, recommending policy and setting priorities." (World Health Organization 2011)

Since 1990s, The Nippon Foundation and the Sasakawa Health Foundation have been actively supporting efforts of persons affected by leprosy around the world to associate themselves, given the notion that the POs could be a body that would effectively aggregate the needs of the people they are supposed to represent. In September 2019, the two foundations organized the "Global Forum of People's Organization on Hansen's Disease" in Manila, the Philippines, as a pre-event of the 20th International Leprosy Congress. The Global Forum was attended by about 80 representatives of from 18 countries—the largest-ever international gathering of persons affected by the disease. Four days of discussions led to "Conclusions and Recommendations"

(The Manila Declaration) that were agreed upon by all the participants and adopted (Sasakawa Health Foundation 2019). How to realize these "Conclusions and Recommendations" was not thoroughly discussed during the meeting, however, and thus remains an issue for the future.

In light of the fact that the second Global Forum is scheduled to be held in conjunction with the 21st International Leprosy Congress in Hyderabad, India, in November 2022, this article aims at clarifying what the forum should strive for by 1) examining the significance and impact of the first Global Forum, 2) identifying challenges currently faced by the POs, and 3) providing recommendations for putting the Manila Declaration into action.

1. **1st Global Forum of People's Organizations on Hansen's Disease**

The purpose of the first Global Forum was to disseminate a unified voice of the POs at the 20th International Leprosy Congress, which followed the forum, and for POs to share plans, ideas and experiences, learn from one other to strengthen themselves. The forum addressed a number of themes that POs had identified as important with regard to their organizational capacity, sustainability, and capability to meet expectations of the people they represent. As noted above, Conclusions and Recommendations were adopted with the unanimous agreement of all participants and can be summarized thus:

- Full and impactful participation of POs in policy-making processes concerning leprosy must be assured and their voices must be reflected there.
- POs must actively advocate for quality leprosy services within an integrated health structure as well as to abolish remaining discriminatory laws and practices.

- POs should strengthen existing networks and create truly functioning regional and global networks.
- Governments and other partners should be open and willing to fund projects that address the sustainability of POs with special attention to vulnerable populations such as women, children, immigrants, refugees, etc.

The fact that the Global Forum gave POs around the world a unified voice had a significant impact in raising awareness of the existence of persons affected by leprosy. In fact, the Global Forum resulted in some active exchanges among the POs via social media and online conference tools, strengthening the horizontal ties among them. As evidence of this, a joint awareness-raising campaign was organized for World Leprosy Day 2020 in which POs from 17 countries participated. In addition, there have been cases of international solidarity and collective action by POs on their own initiative. For example, when Italian Foreign Minister Luigi Di Maio used “leprosy” as a negative metaphor in May 2020 (Gonzalez 2020), a letter of protest was swiftly addressed to him under the names of POs from around the world. These are examples of the ripple effects resulting from the Global Forum.

2. What are the challenges faced by the POs?

Bond, a network of development NGOs in the United Kingdom, has developed “Bond Impact Builder Outcomes, Indicators, and Tools” to help organizations monitor and evaluate their projects and programs. It provides outcomes and indicators in 10 areas of NGO work. Capacity Development is one of these and sets goals to strengthen organizations in four domains: 1) performance, 2) staff capacity, 3) internal organization and 4) external relationships. We

also need to consider challenges for supporting organizations. I will borrow this framework as a basis for analyzing the challenges and issues currently faced by the POs.

2-1. Performance

The most significant challenge is that many POs have a weak financial base and lack a stable source of income. In addition, they tend to lack a clear organizational strategy and activity plan, and this could be an obstacle to proper management of an organization, which often results in an inability to produce sustainable outcomes.

2-2. Staff capacity

Due to a lack of sufficient financial resources, many POs are forced to operate their organizations on a volunteer basis. However, the capacity of these volunteers often needs to be strengthened. Thus, POs are not staffed in an effective way, which makes it impossible to properly carry out important tasks such as organizational management, fundraising, project implementation and public relations.

2-3. Internal organization

For the POs, another challenge is to develop an appropriate governance structure to achieve the organization’s vision, missions and goals. For example, a minimum governance structure needs to be developed that includes a functional board of directors, a strong secretariat, administrative, financial, and program divisions within the secretariat, a membership system, and an organizational charter, operational manual and guidelines.

2-4. External relations

In order to strengthen an organization, it is necessary to gain support from various stakeholders (e.g., donor agencies, NGOs, governments, research institutions, businesses

and the general public). Therefore, organizations need to establish an effective communication system with key stakeholders and actively disseminate information about the outcomes of their activities. However, many of the POs have not yet established such a system because their capability to engage in public relations is limited. Another challenge is to raise public awareness of leprosy-related organizations. Unfortunately, the level of their recognition is significantly lower than that for other NGOs such as those working on child sponsorship and environmental protection.

2-5. Challenges for supporting organizations

It is in fact not possible to address these issues solely through the efforts of the POs. Therefore, I would like here to touch upon the controversial issues for governments and donor agencies who support the POs.

First, in many countries, government support at the policy level to create an enabled environment to foster POs' activities is not sufficient. Although the situation differs from country to country, below are some examples.

- It is not easy for the POs to obtain legal status.
- There are strict regulations on receiving financial support from foreign donor agencies.
- The government regards POs as beneficiaries or merely agents and not as genuine partners.
- There are still discriminatory laws and practices targeting persons affected by leprosy and their family members.

In recent years, while it is true that the participation of POs in leprosy related activities has been increasing gradually, problems have

arisen in the field. For examples, a notice of participation comes at the very last moment, POs are not given sufficient opportunities to speak out, and it is difficult for them to sustain their participation because they are not provided proper compensation (e.g., daily allowances and transportation fees). Furthermore, in many countries, leprosy is not considered an important agenda, so it is rare that leprosy issues are taken up by departments other than the Ministry of Health—for example, those in charge of social welfare, education, justice and law—and interdepartmental cooperation hardly takes place.

Another major challenge is to expand the role of donor agencies such as private foundations and international NGOs. These existing donors provide financial support mostly on a project basis. However, given that the POs are organizationally weaker than other NGOs, another challenge is to go one step further in building relationships, which means to show that donor agencies are willing to go beyond just providing funds, such as by offering advice on how to strengthen the POs.

3. What is needed to implement the Manila Declaration?

A close examination of the Manila Declaration agreed upon at the 1st Global Forum reveals three main tasks: 1) strengthening and networking of the POs; 2) promoting participation of the POs in leprosy services and policy-making processes through effective advocacy; and 3) obtaining sustained support from governments and donor agencies. Taking into account that it will be unrealistic for POs to achieve all of these goals right away, this section recommends what the POs and their supporters should strive for as a "first step."

3-1. Strengthening and networking of the POs

- With regard to strengthening the POs as an organization, they should clarify “where they are now” by conducting initial organizational evaluation and identifying their own problems. For example, evaluation items include: (1) whether the organization’s vision, mission, goals, strategies, and activity plans are clearly stated; (2) whether a governance structure exists to properly execute them; (3) whether the human resources are in place to move them forward; and (4) whether they have secured a sufficient budget. Then, they should prioritize the issues that need to be addressed and develop an action plan for strengthening the organization.
- Networking of POs will only make sense if it is not just an aggregation of related organizations, but rather a form in which each organization adds value to its original work—which is to properly represent the voices of its beneficiaries—by participating in the network, and in which participating organizations can mutually contribute to each other. Therefore, when a network is going to be formalized, the POs should clarify (1) what the purpose of the network is, (2) what value will be added to the original work of each organization by participating in the network, and (3) how they themselves can contribute to the network.

3-2. Promoting participation in leprosy services and policy making processes through effective advocacy

- In order to conduct effective advocacy, each organization needs to define its strategy and action plan. For example, according to the Manila Declaration, common advocacy

themes include “proper implementation of UN Principles and Guidelines (United Nations General Assembly 2010),” “abolishment of discriminatory laws and development of affirmative measures to eliminate discrimination,” and “establishment of a mechanism to discuss leprosy issues across ministries.” In order to do so, the following questions need to be answered: 1) Which of the four themes listed above should be given priority? 2) Who should be targeted in what time frame? 3) What messages could be delivered? 4) What kind of research should be carried out in preparation for such work? (5) What would constitute efficient staffing levels? (6) What kind of support should be obtained from outside experts, and from whom? In addition, if the legitimacy of the POs, i.e., who they are representing, can be assured, their advocacy will be strengthened.

- It is important to share their activities with key stakeholders. If an organization has already achieved remarkable results in a particular area of advocacy, it is highly recommended that they be documented and that these achievements be proactively disseminated. This can lead to acquiring new donors and supporters, building public trust, and participating in new opportunities.

3-3. Sustained support by governments and donor agencies for the POs

- The government should first position the POs as true partners who can contribute to problem solving, allow them to participate in policy making and program implementation, and create an enabled environment for their development from a mid- to long-term perspective. As a first step, I would like to propose the following: (1) Establish

a forum for regular exchange of information and opinion with representatives of the POs to understand the situation and challenges surrounding them and consider appropriate measures for improvement, and (2) When requesting the participation of the POs in these activities, establish a framework that takes into consideration the sustainability of the opportunity, such as providing transportation fees and a daily allowance.

- I would also like to propose that donor agencies carry out an evaluation on whether their current support is based on the real needs of the POs. Then, these donors should adopt an approach based on “thinking and growing together with the POs”, by which I mean they should actively engage in roles other than funding, such as sharing information on grant schemes from other donor agencies, providing advice on how to strengthen the organizations, and introducing experts who could become active volunteers and supporters of the organizations. Another option for them is to jointly work with the POs to cultivate areas that have not been well covered in the past, e.g., obtaining CSR budgets from business sector, launching social businesses, and expanding membership programs.

4. Toward the 2nd Global Forum

As already mentioned, The Nippon Foundation and Sasakawa Health Foundation are planning to hold the 2nd Global Forum in November 2022. As with the previous Forum, it will be important to take advantage of the fact that all the key stakeholders in the global leprosy community will be gathered in one place for the International Leprosy

Congress, creating an opportunity to present them with the collective voice of persons affected by leprosy. However, that alone is not enough this time. I hope that the POs participating in the 2nd Global Forum will seize the chance to take things to the “next level”, that is, to consider what they should set out to achieve at the Forum, beyond simply getting together. Going forward, the Manila Declaration adopted three years ago must serve as a benchmark. At this year's Global Forum, it will be necessary for the participants to examine what has been accomplished since the last Forum and what remains to be done. In particular, there should be a discussion about the reasons why certain objectives have not been met and what challenges are involved.

While it will not be easy to realize all parts of the Declaration any time soon, and there is no way to solve 100% of the challenges currently faced by the POs, it should be possible to clarify what needs to be done as a next step. I hope the analysis and recommendations presented in this article will be of some help to the POs when they discuss these issues at the next Global Forum.

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