Jornal do Morhan

Movimento de Reintegração das Pessoas Atingidas pela Hanseníase

2ND GLOBAL FORUM OF PERSONS'S ORGANIZATIONS ON HANSEN'S DISEASE SPECIAL EDITION 68

2nd GLOBAL FORUM OF PERSONS ORGANIZATIONS ON HANSEN'S DISEASE SPECIAL EDITION

Return of the Doctoral thesis in Public Health by Paula Brandão, part of the national board of Morhan

"Evaluation of coalition implementation as a participation and empowerment strategy for persons affected by Hansen's disease in Brazil: the Morhan case"

EDITORIAL

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Presentation

This special edition of Jornal do Morhan is one of the knowledge translation strategies adopted to communicate the results of the research "Evaluation of coalition implementation as a participation and empowerment strategy for persons affected by Hansen's disease in Brazil: the Morhan case", developed by Paula Soares Brandão to obtain the title of Doctor in Public Health by the National School of Public Health Sérgio Arouca (FIOCRUZ-Brasil), under the supervision of Doctors Marly Cruz and Kátia Edmundo.

This work is the result of active listening, participation and empowerment of countless persons affected by Hansen's disease and their families, professionals from different areas of knowledge and governmental and non-governmental organizations in Brazil and other countries. If the construction of a thesis is usually solitary, it is driven by conversations, observations, opinions and, mainly, by relationships. The experiences and expectations of different actors towards the elimination of Hansen's disease, stigma and discrimination that affect

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people and their families were considered since the elaboration of the research project.

The main objective of the research was to evaluate the implementation of the coalition as a strategy of participation and empowerment of people affected by Hansen's disease in Brazil. To achieve it, the historical-social determination of the health-disease process, health promotion and empowerment assessment were used as a reference basis.

The results presented here are part of this evaluative research with an empowerment approach, which focused on the implementation of the actions of the Movement for the Reintegration of People Affected by Hansen's disease (Morhan) during the covid-19 pandemic. As a compromise established between researcher and participants, we will present the mapping and characterization of Organizations of People Affected by Hansen's disease (OPAHs) and the activities developed by them during the pandemic period.
Data collection took place through document analysis, semi-structured interviews with key informants and a self-administered questionnaire with leaders of coalitions of people affected by Hansen's disease in Latin American, African and Asian countries.

The characterization of the organizations was done through self-administered questionnaires and document analysis (articles, websites, Lives and Facebooks), where of the total of 32 PAHOs, only 21 of them responded to the questionnaire. In ten OPAHs, data were obtained through document analysis and in one through a scientific article, due to its historical relevance.

The key informants of the self-administered questionnaire were leaders of the PAHOs. An explanatory e-mail was sent to each of them about the survey, invitation and the 12 questions. After accepting and answering the questions, the first text version was returned to the participants for correction and an informed consent form was attached for the use of the answers.
A roadmap was built with the following key points: a) existence of means that facilitate communication between the organization and people; b) year of foundation; c) mission; d) main activities developed during the Covid-19 pandemic; e) support and/or funding by other organizations; f) activities developed in conjunction with the National Hansen's disease Control Program and g) main difficulties encountered in implementing the actions.
The emails, questions and consent terms were translated into the participants' mother tongue or second language adopted in the country, using Google Translate. In addition, considering the difficulties in signing, by people with physical disabilities due to Hansen's disease, the form was sent in Google Forms link format to facilitate registration.
In the presence of a website and Facebook, the information from the PAHOs was complemented or fully extracted from these sources. Organizations that did not have a website/Facebook, an article about the history and did not respond to the e-mail were excluded from the survey. For the document analysis, websites of non-governmental organizations (NGOs) that work with affected people were also consulted, in order to map the relationships.

The result of this process gave rise to a timeline of PAHOs, with relevant milestones for understanding the expansion of coalitions in recent decades. And to facilitate the understanding of some points, we prepared a glossary with the main concepts used in the research. In this way, we hope to contribute to the strengthening of the organized participation of the community of people affected by Hansen's disease and their families.

Hansen's disease as part of the problem:

Hansen's disease is a Neglected Tropical Disease (NTD), transmissible, chronic and curable through treatment with multidrug therapy (MDT). The main signs and symptoms of the disease are observed and perceived in skin changes and peripheral nervous system functions. These changes, caused by the immunogenic action of Mycobacterium leprae (etiological agent) on the tissues, can result in physical disabilities and/or deformities, especially in the eyes, hands and feet (BHANDARI et al., 2020).

Since the late 1980s, several efforts have been made to achieve the elimination target (less than 1 (one) case per 10,000 population) and reduce the global burden of disease (WHO, 2021a). Hansen's disease was considered eliminated in the year 2000, except for a group of 23 countries that concentrate the notifications of new cases, among which India, Brazil and Indonesia have the highest burden of the disease (WHO, 2020b).

The actions proposed by the WHO, in Global Strategies, and the national plans were not enough to promote the elimination of the disease as a public health problem and the inclusion of affected persons and their families in these countries. Based on this, endemic areas need to reflect on social issues, rethink the interventions adopted and include the affected persons in the processes to eliminate the disease, reduce stigma and discrimination.

In this context, the "Global Strategy 2016-2020: Accelerating towards a world without Hansen's disease" (EGH 2016-2020) was the first to consider the human and social aspects of the disease. Organized in three pillars, the third pillar was designed to promote social inclusion by addressing all forms of discrimination and stigma, eliminating discriminatory laws and/or practices, empowerment and social participation, based on strategies with the persons, families and communities, such as coalitions in health (WHO, 2016).

Coalitions in health can be defined as inter-organizational, cooperative and synergistic organizations that unite individuals and groups in a shared objective. In addition, coalitions are able to publicly support unmet issues, actions or needs and contribute to the formation of "critical mass" about a given social problem, maximizing responses and collective power (Butterfoss, Goodman, Wandersman, 1993)

In the last year of EGH 2016-2020, persons affected by Hansen's disease and their families faced the challenge of the covid-19 pandemic. While Hansen's disease is an ancient and neglected disease, covid-19 is an Emerging Communicable Disease (ETD). In 2020, on the one hand, 127,396 new cases of Hansen's disease were registered in the world, of which 121,358 were concentrated in priority countries (WHO, 2021b). On the other hand, the cumulative number of covid-19 cases reported to the WHO was 79,231,893, with 1,754,574 persons dying from the disease worldwide, until the last epidemiological week of that year (WHO, 2020c).

The covid-19 pandemic and its control measures have aggravated preexisting problems in the daily lives of most persons affected by Hansen's disease in the world. Structural discrimination against persons affected by Hansen's disease culminated in the increase in access barriers faced by them. Among the problems are those related to livelihoods (formal employment, adequate income and social security), basic goods (food and housing), information, health care and essential medicines (including multidrug therapy for the treatment of Hansen's disease) (CRUZ, 2021).

Dr. Alice Cruz (2021), in her report, highlighted that the impact of the pandemic on the affected persons and their families was not only due to the social inequalities to which the majority are subjected, as it also affected the control of the disease. She also stressed that both Hansen's disease and covid-19 are characterized as political phenomena.

Despite the tangible differences between Hansen's disease and covid-19, regarding the historical-social determination of the health-disease process and the provision of care, some situations brought them together. Among them are social isolation, the search for vaccines and new medicines, stigma and discrimination against affected persons and health workers, intersectionalities, vulnerable persons, violation of human rights, the need for adequate information and community participation. to tackle the problem.

Community participation is a challenge for both Hansen's disease and covid-19 control, as there is no right measure or predetermined parameter. For Arnstein (1969, p.216), community participation is also synonymous with citizen participation and community engagement, based on the redistribution of power among citizens excluded from political and economic processes, being an empowerment strategy to induce social transformation. and sharing the benefits generated by it. However, participation can be a powerful tool to promote equity, effectiveness and sustainability of actions, as well as acceptance and legitimacy. Furthermore, participation can generate empowerment at the individual, organizational and community levels (PERKINS; ZIMMERMAN, 1995; VASCONCELOS, 2003; WALLERSTEIN, 1992).

In the last decades, in several countries, persons affected by Hansen's disease and their families have organized themselves, through the formation of coalitions to defend the cause and support the affected persons. Upon being surprised by covid-19, coalitions had to reinvent the way to operate their actions, given the need to protect persons, their families and the community.

Coalitions of persons affected by Hansen's disease

Hansen's disease is a product of the historical-social construction of the disease and the measures for its control. The stigma associated with Hansen's disease and discrimination against persons affected by it remain as policy challenges to eliminate the disease, regardless of the country and its socio-political and economic context. The conditions that generate stigma were attributed to their external manifestations (deformities), cultural and religious beliefs, fear of transmission and/or persons's reaction to a deteriorated image, moral association with "inferior persons" and interventions in public health, such as compulsory isolation (SERMRITTIRONG; VAN BRAKEL, 2014).

Initially, the formation of associations of affected persons was also criticized as producing stigma, as found by Sermrittirong and Van Brakel (2014) in a literature review. The justification was that by restricting the struggle for rights to a specific group, they contradicted the struggle for social justice and equity. However, the formation of groups, associations, networks and coalitions of persons affected by Hansen's disease was recognized as a possible strategy for participation and empowerment (WHO, 2011b, 2016).

The emergence of PAHOs is preceded by non-governmental organizations (NGOs) belonging to the International Federation Anti-Leprosy Associations (ILEP), founded in 1967. ILEP is composed of the American Leprosy Mission (ALM), The Leprosy Mission International (TLMI), Effect Hope, St Francis Leprosy Guild (STLG), Fontilles Foundation (Fontilles), LEPRA, Raoul Foullerau Foundation, FairMed, Deutsche Lepra und Tuberkulosehilfe (DAHW), Leprosy Relief Canada, Associazone Italiana Amici di Raoul Follereau (AIFO), Netherlands Leprosy Relief (NLR), Damien Foundation and Sasakawa Health Foundation (SHF).

These organizations belong to countries in the global north and develop projects aimed at health care, scientific research, social support and rehabilitation related to Hansen's disease and for persons affected by it, in countries of the global south or peripheral countries, where the disease is endemic. Stimulated by a charitable mission in favor of the underprivileged and segregated by the disease, these organizations were supported by a system of donors to implement their range of actions. It is noted that part of these organizations were founded after the establishment of the United Nations (UN) in 1945 and the WHO in 1948, including ILEP, which became a partner and consultant to the Global Leprosy Program.

The increase of NGOs with this profile and the foundation of the first national organization of persons affected by Hansen's disease (OPAH) took place in the face of a transnational assistance and advocacy agenda in favor of the affected persons, proposed by Raoul Follereau to the UN, marked by the creation of the Day of Leprosy (CRUZ, 2013). Furthermore, in the following decades, the struggle for the rights of those affected was also driven by the Universal Declaration of Human Rights (1948) and by agreements such as the International Covenant on Economic, Social and Cultural Rights (1966), the International Covenant on Civilians and Politicians (1966), International Convention on the Elimination of All Forms of Racial Discrimination (1969) and the Convention on the Elimination of All Forms of Discrimination against Women (1981).

The first known OPAH was founded in Korea. The Doctor. Joon Lee, founder of the Korean Leprosy Association in 1947, realized that many patients were able to work without adaptive needs, provided they were encouraged and supported to do so. In this way, he encouraged them to economic empowerment through community engagement in agriculture, poultry and livestock activities. In 1948, representatives of the villages of affected persons gathered in an assembly and formed the Korean Federation of Hansen Associations (KFHA), whose objective was the rescue of rights, lost by compulsory isolation, and socioeconomic rehabilitation (CHAE, 2020) .

The second PAHO screened was the Tanzania Leprosy Association (TLA), founded in 1978 by a group of professionals working with persons affected by Hansen's disease. In the early 2000s, TLA transformed to work and be led by affected persons. However, the first persons to hold representative positions at the institution were only elected in 2011, according to a report at the SHF seminar in January 2021.

In Brazil, the Movement for the Reintegration of persons Affected by Leprosy (Morhan) founded in 1981, despite being registered as an association, having in its name and ethical principles the status of a social movement, is also characterized as a coalition. The foundation of Morhan became a landmark for the participation of persons affected by Hansen's disease in the country. Due to its character and composition by volunteering, involvement of different segments and levels of society, it fights to guarantee human rights, eliminate discrimination and promote the inclusion of affected persons and their families (MENDONÇA, 2009; VIEIRA, 2015).

Morhan was one of the founders of the first international organization of persons affected by Hansen's disease - the International Association for Integration, Dignity and Economic Advancement (IDEA) in 1994, based in the United States. According to the 21st edition of Jornal do Morhan, curiously, the organization was led by three presidents. Bacurau (national coordinator of Morhan) was responsible for mobilizing persons to overcome barriers to full social participation, Mr. S.K. Jung (South Korea) encouraged efforts for the socio-economic development of the affected persons and to Mr. P.K. Gopal (India) the organization's administration and external relations.

The creation of IDEA encouraged the emergence of other associations at the national level. In 1996, the HANDA Rehabilitation & Welfare Association in China and the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) in Ethiopia were founded. In 1998, IDEA Nepal was founded, being the first national PAHO to adopt the IDEA identity.

The first explosion of national PAHOs took place in the first decade of the 21st century. During this period, 11 associations were recognized, some nationwide, such as the Association of persons Affected by Leprosy (APAL) in India, founded in 2006 through forums with affected persons, NGOs and the government.

At the heart of this expansion are regional and local agency PAHOs, or even those that have adopted the IDEA philosophy, being represented by groups of persons. Thus, we have the foundation of the Mozambique Association of Persons with Leprosy (ALEMO) in 2000, of Maham Charity in Iran and of Nepal Leprosy Trust & Self-Help Groups (NLT & SHGs) in 2001, of IDEA Ghana and IDEA Nigeria in 2003, Dhanusha Self-Help Groups Federation (DSHGF) in Nepal in 2005, Perhimpunan Mandiri Kusta (PerMaTa) Nasional and South Sulawesi in Indonesia in 2007, IDEA Niger and Atma Swabhiman in India in 2009.

Between 2010 and 2019, a new increase in PAHOs took place, stimulated by agreements and recognition of the rights of affected persons. This transformation was marked by publications such as the Principles and Guidelines for the elimination of discrimination against persons affected by Hansen's disease and their families (UN/2010), the Guide for strengthening the participation of persons affected by Hansen's disease in health services (WHO/2011), Resolution 29/5 on the elimination of discrimination against persons affected by Hansen's diseaseand their families (Human Rights Council/2015), Resolution 35/09 which establishes the mandate of the Special Rapporteur for the elimination of discrimination against affected persons (UN /2017) and the Global Strategy 2016-2020: For a world free of Hansen's disease, in which the third pillar is dedicated to promoting inclusion and abolishing discriminatory laws (WHO/2016).

In India, the country with the highest absolute number of cases in the world, there were Sam Uttan (2011), Society Leprosy Affected Person Andhra Pradesh (SLAP-AP) in 2014, PramilaEkAsha (2017) and Saksham Kushthanteya Swabhimani Santha (SKSS) in 2019. In Southeast Asia and the South Pacific (both WHO administrative regions) the Bogra Federation for Leprosy and Disability Development (BOGRA) and Advancing Leprosy disadvantaged personss Opportunities society (ALO) were created in Bangladesh, as well as the Coalition of Leprosy Advocates in the Philippines (CLAP) in 2014. Among the youngest associations is the Myanmar Association of Persons Affected by Leprosy (MAPAL), founded in 2019.

The Africa region has also seen the growth of associations of affected persons represented by the IDEA Refaco Kenya Foundation (2013) and Association Sénégalaise de Lutte Contre La lèpre et Les MTN (ASCL/MTN) in Senegal in 2014. In addition to those created in 2018 which are the Organization of persons Affected by Leprosy in Congo (OPALCO) in the Democratic Republic of Congo, Purple Hope Initiative (PHI) in Nigeria and the National Association persons Affected by Leprosy Sierra Leone (NAPAL).

The Federación Nacional de Asociaciones de Personas Afectadas por Lepra-Hansen de Colombia (FELEHANSEN) was founded in 2014. Morhan and FELEHANSEN represented the Latin American region at the I Global Forum of PAHOs held by SHF in 2019, in the Philippines.

Another type of initiative by the affected persons has also materialized - the international whatsapp group (WIG). The first group (WIG1) is made up of representatives from several of the mapped PAHOs and NGOs, as well as the UN Special Rapporteur and members of the ILEP Panel of Women and Men Affected by Leprosy, a federation advisory group created in 2017.

Last but not least, we have the WIG2 composed of women affected by Hansen's disease, who participated in the Global Forum, and invited. This group gained prominence in supporting the mandate of the UN Special Rapporteur on the rights of persons affected by Hansen's disease and their families, in the mobilization of women led by the Morhan Department of Policies for Women, for the elaboration of the annual report in 2021 and 2022.

Coalitions of persons affected by Hansen's disease are considered strategic for health promotion through capacity building, advocacy and mediation actions. How about getting to know a little about some of the PAHOs mentioned here?

PAHOs of The Americas:

Movement for the Reintegration of persons Affected by Hansen's disease (MORHAN)

Morhan was founded by a group of persons affected by Hansen's disease and their families, health professionals, activists from other social movements and students, on June 6, 1981 in the city of Bauru, state of São Paulo - Brazil.
Since its foundation, Morhan has been governed by statute. Over the years, changes in the socio-political context related to Hansen's disease and the persons affected by it led to a reformulation of the general objective and statute itself. Thus, the main objective of Morhan is to[...] to promote educational measures aimed at prevention, early diagnosis, treatment, rehabilitation, information, social promotion, awareness, preservation and rescue of the citizenship of the person affected by Hansen's disease , aiming at their complete social reintegration.

Morhan's vision is to become a reference in information about the disease, support for persons affected, the fight for respect and guarantee of human rights. And as a mission, to facilitate society's understanding of Hansen's disease as a chronic, transmissible disease, curable by drug treatment and the elimination of discrimination against affected persons and their families . The fulfillment of Morhan's purposes and mission takes place through its participants, the structural organization and the occupation of both institutionalized and non-institutionalized public spaces.

Participants are classified into three categories: founders, full members and benefactors. The founders are those who had their name registered in the founding minutes, such as Francisco Augusto Vieira Nunes (Bacurau), who became an icon of the movement, due to his leadership, thoughts, trajectory and engagement . Effective members are all those registered after the association was created. The benefactors are those who have contributed in actions or financially to the greatness of the movement or the cause, provided they belong to the previous categories and elected by Organs deliberative bodies of the organization .According to the Morhan Statute, the centers are like branches of the movement's headquarters, so they can be installed in any city in the country where persons are interested in developing their actions. There is no restriction on the number of nuclei, however all of them must follow the entity's statute, appropriate to each hierarchical level. The nuclei represent and make up the basis of the movement. In addition, through the nuclei the collective identity of Morhan was built.
The organizational structure at the national level is composed of Nuclei, State Coordination and National Coordination. As of 2021, the national coordination began to be formed by the executive coordination, the collegiate board and the council of former directors.

The National Morhan has deliberative and administrative bodies. The National Coordination, the Board of Former Directors, the Supervisory Board and the General Assembly are considered deliberative. Meanwhile, the Departments, Commissions, Working Groups and the Ethics Council are administrative bodies. Some of these bodies emerged and were modified in terms of nomenclature, composition and function throughout the organization's trajectory.

Since its foundation, Morhan's main guidelines have been actions aimed at health information, communication and education, community and social participation, the promotion of self-care, the establishment of partnerships, the qualification of professionals (in health, education and social service), the improvement of health and rehabilitation services, socio-economic reintegration, advocacy and the expansion and consolidation of Morhan.

According to the Morhan Statute, the departments, councils and commissions have the purpose of elaborating guidelines and proposals, in line with the movement's guidelines. Morhan's main departments are Training, Projects and Research, the Legal Department, the Women's Policy Department and the Intergenerational Policy Department. The organization also has a communication advisory team and other technical advisors.

The infrastructure of Morhan Nacional includes a headquarters, a communication center, partnerships with non-governmental organizations and project financing. The Nuclei are structured according to the local reality and the ability to mobilize resources.

Over the years, Morhan has developed partnerships with a variety of Brazilian organized civil society entities and foreign non-governmental organizations, among them AIFO and the Sasakawa Health Foundation. These partnerships contributed to strategic information, communication and education projects, as well as to the development of intersectoral actions aimed at the main agendas defended by the movement.Information, Education and Communication are among the main activities developed by Morhan since its foundation. Together, they configure the gear of training actions and support advocacy and mediation actions to promote human rights, among them – the right to health.

In its 40 years of existence, the movement followed the evolution of information and communication technologies applied to health education. Among the strategies adopted are Jornal do Morhan (1982), TELEHANSEN (1996), e-mail and website (2000), Teatro Bacurau (2004), Cadernos do Morhan (2006), Facebook (2013), Youtube channel - TV Morhan (2017), EAD do Morhan (2017), Instagram do Morhan Nacional (2020), Lives from projects (2020), Twitter do Morhan Nacional (2021) - communicational products, scientific social networks of Morhan.

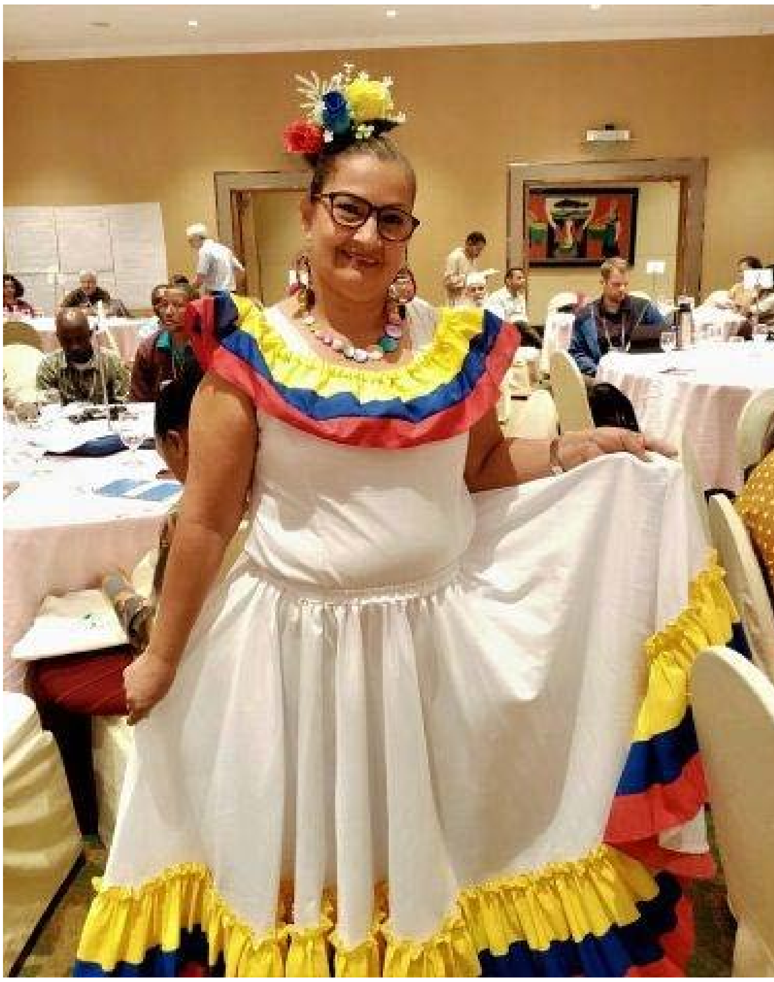
In matters related to the defense of the case, the representation in social control bodies such as the National Health Council (1990), the laws to repair the violation of rights, with emphasis on Law 11.520 of 2007, which deals with the compensation of persons that were compulsorily isolated in Brazil, the creation of the women's department (2018) and the creation of new centers and volunteer engagement, configuring the socio-historical sustainability of the movement.

And finally, Morhan became a national movement in its first five years of existence, due to the increase in the number of centers in all regions of the country. Over the decades, the acceptability and legitimacy of the movement on the international scene resulted from its fidelity to its mission and defense of persons's rights at the national level.

National Federation of Asociaciones de Personas Afectadas por Lepra-Hansen de Colombia (FELEHANSEN)

The Federación Nacional de Asociaciones de Personas Afectadas por Hansen de Colombia (FELEHANSEN) was founded in 2014, headquartered in Bogotá, with almost 1050 members. The organization is made up of persons affected by hansen's disease, family members and persons engaged in social work. All members work on a voluntary basis, however a support fee is paid to the federation in order to obtain the legal permanence of the organization (FELEHANSEN, 2021).

FELEHANSEN's mission is "to unite and strengthen associations of persons affected by hansen's disease, in the process of inclusion and social participation, and thus improve their quality of life and their environment" (FELEHANSEN, 2021). FELEHANSEN's vision is "because we are and must be managers of our own development, through the Inclusive Community Development strategy, we will be able to raise awareness about persons in Colombia and the world" (FELEHANSEN, 2021).



The main activities developed by the organization are the active search for symptomatic persons for hansen's disease; monitoring of affected persons during and after treatment; sensitization to friends, family and community; holding lectures in schools and universities for students in the health area; advocacy to guarantee the human rights of the persons affected; promotion and participation in World Leprosy Day activities (FELEHANSEN, 2021).

FELEHANSEN, since its foundation, has been developing actions, articulated with the DAHW/GLRA and other organizations (national and international, public and private), in several departments of the country. Linking associations to health services in the country has been one of the fundamental purposes of the federation. The federation has both Facebook and a website for communicating with members and publicizing activities in society. No difficulties were reported in carrying out their actions (FELEHANSEN, 2021).

International Association for Integration, Dignity and Economic Advancement (IDEA)

The International Association for Integration, Dignity and Economic Advancement (IDEA) was founded in 1994, in the city of Petrópolis-Rio de Janeiro-Brazil, during an international seminar that brought together fifty participants, including professionals and persons affected by hansen's disease from India, China, United States, South Korea, Cuba and Brazil.

This meeting recognized the need to create an international non-governmental organization capable of providing a global and local forum to bring together persons affected by hansen's disease and allow the sharing of ideas and experiences, identifying challenges and advocating for change (IDEA, 2021).

According to the 21st edition of Jornal do Morhan (1995b), the organization was headed by three presidents. Bacurau (national coordinator of Morhan) was responsible for mobilizing persons to overcome barriers to full social participation, Mr. Jung (South Korea) encourage efforts for the socio-economic development of the affected persons and to Mr. Gopal (India) the organization's administration and external relations.

IDEA is made up of both persons affected by hansen's disease and those not affected who carry out actions on a voluntary basis. The following partner entities are registered: Leprosy Relief Canada, International Federation of Anti-Leprosy Associations, Global Partnership for Zero Leprosy, Leprosy Research Initiative, International Leprosy Association, World Health Organization Global Leprosy Program, Prins-Solani Consulting: Education, Culture and Heritage Specialist, International Coalition of Historic Sites of Exclusion, Resistance and Resilience, Peers for Progress and Uniting to Combat Neglected Tropical Diseases (IDEA, 2021).

The organization was established to promote connections between organizations and individuals, both those who have experienced the disease and those who have not, with its leaders composed primarily of persons who have had hansen's disease (IDEA, 2021). In this way, IDEA's mission is to "create a network around the world, of persons who have experienced hansen's disease and their families, to mutually empower each other, guarantee human rights and promote inclusion" and as a vision "a world where inherent dignity of all human beings is respected" (IDEA, 2021).

Throughout its existence, the programs and actions carried out by IDEA have varied from country to country, depending on the needs identified locally and the experience of the leaders.

The focus of action is divided into four areas: advocacy, empowerment (psychosocial support, self-sustainable programs, training, self-care groups, International Day for Dignity and Respect, participation in international meetings and participatory research), leadership (identifies, provides and facilitates leadership opportunities for persons who have experienced hansen's disease), heritage (founding member and Secretariat of the International Coalition of Historic Sites of Exclusion, Resistance and Resilience; and recording oral history) and education (through education and awareness together with local, national and international communities about hansen's disease, understanding the lives of persons who have suffered the disease, about disease-related discrimination) (IDEA, 2021).

[1] All information contained herein was extracted from the IDEA website and Jornal do Morhan.

African PAHOs:

Mozambique Association of Persons with Leprosy (ALEMO)

ALEMO was founded in 2000 and in its composition has voluntary members both affected and not affected by hansen's disease. The organization does not have a Facebook or website. The mission is to "unite and organize persons affected by hansen's disease to work together in the fight against hansen's disease, stigma and discrimination and poverty" and the vision in "all persons affected by hansen's disease, be integrated, influential, self-sustainable and respected". in the community" (ALEMO, 2021).

The main activities developed by ALEMO are lobbying and advocacy in communities about Hansen's disease, the organization of persons affected by hansen's disease in communities, in groups of associates, with a certain leadership; working visits to members to address their concerns looking for ways to resolve them; accompany suspected and identified persons with hansen's disease to health facilities for diagnosis and treatment; teach and train members in various areas of knowledge to create conditions for self-sustainability; through the acquired knowledge and the use of innate talents in persons affected by hansen's disease, promote promotional and income-generating activities to improve their lives; practice of self-care (ALEMO, 2021).

The main activities developed in partnership with the government are community advocacy and practice to support self-care groups (ALEMO, 2021). In addition, they reported that the greatest difficulty encountered in carrying out actions with the affected persons, since its creation, is the lack of transport, since this makes it difficult to visit persons and groups, as well as the expansion of the association at the level national.

Association Sénégalaise de Lutte Contre La lèpre et Les MTN (ASCL/MTN)

The Senegalese Association for the Fight Against Leprosy and Neglected Communicable Diseases was founded in 2014. All members of the association are persons affected by hansen's disease and other NTDs, volunteers and do not have enough income to contribute. DAHW-Senegal supports institutionally and organizationally and technically contributes to the implementation of the membership structure. In 2020, ASCL/MTN received support from the Sasakawa Foundation as part of the fight against COVID-19 (ASCL/MNT, 2021).

The organization's mission is to support persons affected by ASCL/MNT is a member of the National Leprosy Control Committee and works in partnership with the National Leprosy Control Program, but recognizes that there is still a need for improvements in the participation of persons affected by hansen's disease within the program. The lack of financial and logistical means to carry out the activities is the main difficulty encountered by the association in implementing its activities. The association does not have a website, but it does have Facebook (ASCL/MNT, 2021).

Ethiopian National Association of Persons Affected by Leprosy (ENAPAL)

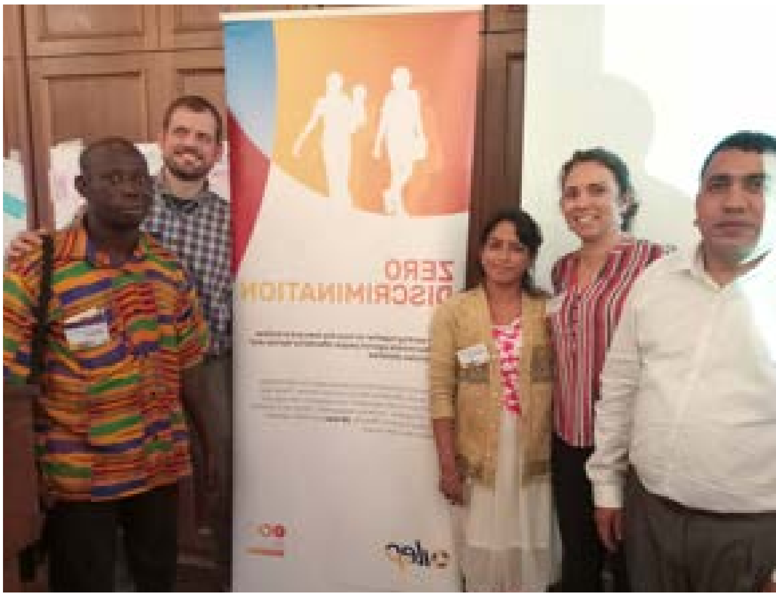
ENAPAL was founded in 1996 in Ethiopia, but registered as an organization of Ethiopian residents and societies in 2009. It is made up of seventy associations that bring together more than twenty thousand members in branches across the country. The entity has both a website and Facebook for the dissemination of information and activities.

The organization has partnerships with several international and national institutions such as: ILEP, Sasakawa Health Foundation, Addis Ababa City Administration, Human Rights Watch, University of Amsterdam, Jersey Overseas AID, ActionAid, Habitat for Humanity, The Leprosy Mission International, Embassy of Japan, HandiCape International, GLRA-Ethiopia, Ethiopia National Federation of Associations of Persons with Disabilities, Ministry of Health, Ministry of Labor and Social Affairs (ENAPAL, 2017).

ENAPAL's mission is to "enable persons affected by hansen's disease in Ethiopia to fully participate in the country's development, eliminating misconceptions, discrimination and exclusion; increase their dignity through awareness of health and hansen's disease, socioeconomic development and organization in their localities for solidarity" (ENAPAL, 2017).

The organization hopes to see "a generation free of misconceptions, discrimination and exclusion of persons affected by hansen's disease" (ENAPAL, 2017). To this end, its main activities are hansen's disease related rehabilitation; disability prevention; disease awareness; training of members and associations; reducing stigma and discrimination through economic empowerment of members and membership to alleviate widespread poverty; and the training of members and associations (SHF, 2021).

IDEA Ghana

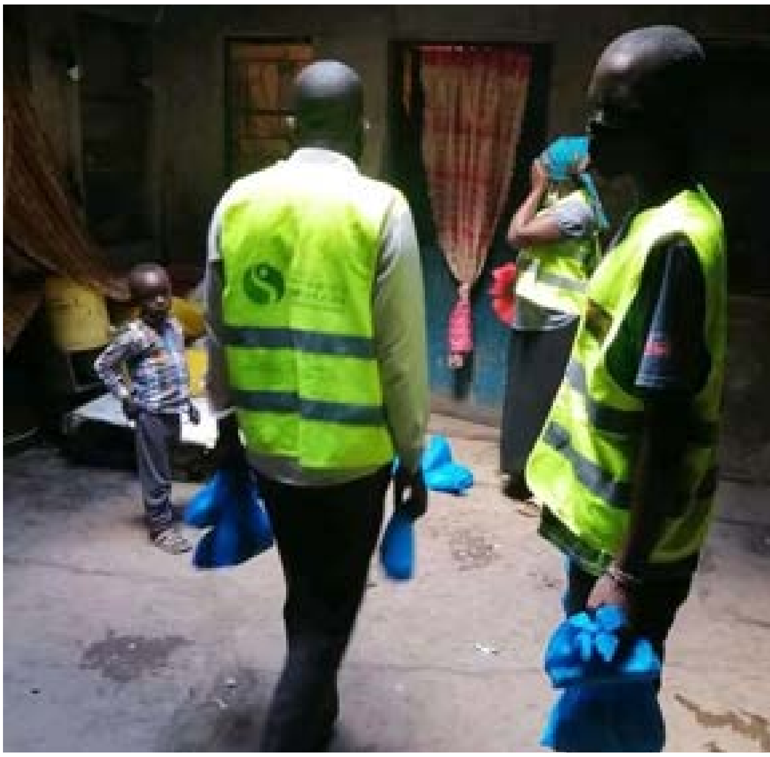


IDEA Ghana was founded in 2003 and has about four thousand three hundred members, all on a voluntary basis, including persons who have not been affected by hansen's disease. The organization's mission is to "fight hansen's disease" and its vision to "ensure that Ghana is free from stigma and discrimination", as well as "to include all persons affected by hansen's disease in the societies of Ghana" (IDEA GHANA, 2021).

The main activity developed by IDEA Ghana is raising awareness through the gathering of families separated by hansen's disease . During the COVID-19 pandemic, visits were made to persons affected by the disease and preparation for World Leprosy Day, through meetings with stakeholders, this is the main activity developed in partnership with the government. The main difficulty the organization faces in carrying out the work is the availability of transport and the lack of support from other organizations (IDEA GHANA, 2021; SHF, 2021).

IDEA Refaco Kenya

IDEA Refaco Kenya is an organization of persons affected by hansen's disease founded in 2013 as the Refaco Care Foundation. In 2019, the foundation moved to Idea Refaco Kenya. All members act on a voluntary basis (“those who have little or more support others”). The organization is made up of affected persons and there are some members not affected by hansen's disease, such as children, fathers, fathers and mothers. Between 2019 and February 2021, due to the pandemic, the Sasakawa Foundation supported the organization in an aid project (IDEA REFACO KENYA, 2021).



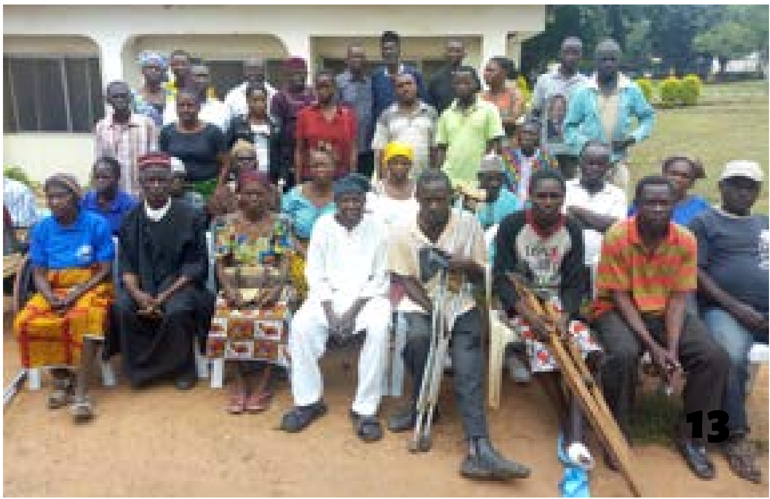
IDEA Refaco Kenya’s mission is “to help humanity prosper by enabling all those affected, infected and unaffected by hansen's disease to work together to see the world without hansen's disease” and the vision “to improve the health of persons affected by hansen's disease and maintain the dignity of all” (IDEA REFACO KENYA, 2021).

Since 2010, the organization has offered free primary education to all its members and members' children, as well as primary care and medical care for all members of the entity (IDEA REFACO KENYA, 2021).

The main activity, in partnership with the National Leprosy Control Program, is to raise awareness of the disease at the national level. However, as an organization they face many challenges for the development of actions, among them are the fact that most do not have a wheelchair, do not have a bus and obtain/maintain funds for actions (IDEA REFACO KENYA, 2021).

IDEA Niger

IDEA Niger was founded in 2009 as an organization of persons affected by hansen's disease, of mixed order (affected and non-affected persons), in which members are volunteers. The organization uses Facebook as social media to publicize its activities, as it does not have a website (IDEA NÍGER, 2021).



The organization receives support from TLM-Niger for the operation of the IDEA office, field activities, improvement of the socio-economic living conditions of persons affected by hansen's disease and other persons with disabilities in Niger. As well as the Sasakawa Health Foundation, which provides financial and technical support for activities to mitigate the negative impacts caused and aggravated by the advent of covid-19 and to strengthen activities to improve the socioeconomic conditions of life of persons affected by hansen's disease and others. with disabilities in Niger. In addition to these two NGOs, IDEA Niger is also supported by Danja (technical and logistical support) and the Nigerian Federation of Persons with Disabilities (IDEA-Niger is a member of the FNPH) (IDEA NIGER, 2021).

IDEA Niger's mission is in line with that of IDEA, following its declaration in which the organization must "1. promote the human rights and dignity of all human beings throughout the world, with a focus on individuals affected by hansen's disease, also known as a leprosy, to ensure they live fulfilling lives as fully participating members of their community; 2. facilitate an international network of support, so that persons from all over the world can discuss their shared experiences and build strength with each other to face the challenges they face;3. advocate on behalf of individuals to address stigma, discrimination, segregation, isolation and derogatory terminology that profoundly affects persons's lives; 4.promote the use of positive images, inspirational words, artistic talents and other forms of self-expression,to replace outdated images and stereotypes with a holistic understanding of individuals whose lives have been challenged by hansen's disease; 5. Invest in each individual's potential so that they can regain their rights to live wherever they want, marry whomever they want, worship wherever they want, provide for themselves and their family and ensure that their children receive an education;
provide for themselves and their family and ensure that their children receive an education; 6. Actively involve individuals who have been personally challenged by hansen's disease / hansen's disease in the governance and management of IDEA, and in the conceptualization, planning and implementation of programmes, including the global campaign to eliminate stigma, empowerment process, self-reliance projects, grant programs of study, psychological support, professional and public education and media awareness (IDEA NIGER, 2021)."

IDEA Niger's vision is to become a benchmark for promoting inclusive development through "integration, dignity and economic progress", both nationally and internationally in a society that respects human dignity (IDEA NIGER, 2021).
According to IDEA Niger representatives, before the COVID-19 pandemic, the organization carried out awareness-raising activities; commemoration of international days such as the International Day of Fight against Leprosy; support for income generation activities (Income Generation Actives-IGAs) and microcredit; support for housing and construction of latrines and sanitation; education support; literacy support; vocational training; business training; counseling; mobility support, self-care group support; training on the rights of persons with disabilities and advocacy, among others (IDEA NIGER, 2021).

IDEA Niger develops together with the National Leprosy Control Program activities to raise awareness about hansen's disease in the community, in schools and churches. It also supports the referral of suspected cases to the nearest health post for diagnosis and treatment. The main difficulties encountered in the development of actions are: funding, illiteracy and ignorance of members and some leaders (IDEA NÍGER, 2021).

IDEA Nigeria

IDEA Nigeria was founded in 2003. All IDEA Nigeria members are volunteers, including its national and state executive members. There are no members not affected by hansen's disease. The organization receives support from TLMI, at the national level, ie The Leprosy Mission Nigeria (TLMN) (IDEA NIGERIA, 2021).

IDEA Nigeria's vision is to “promote a stigma-free society where the rights of persons with hansen's disease are protected” and as a mission to: “work in partnership with all relevant stakeholders to eliminate stigma and discrimination; empower and promote sustainable social, mental and economic well-being of persons and communities affected by hansen's disease; and their rights respected in Nigeria” (IDEA NIGERIA, 2021).

In 2020, the organization's planning was the reactivation of IDEA state centers that were not functioning in seven states (Lagos, Edo, Cross River, Kogi, Kwara, Imo, Anambra state), the organization of a special seminar in the state of Lagos to enlighten relevant stakeholders about IDEA and its activities, carrying out an advocacy visit to the State Civil Service Commission in Ogun State, mapping the various social services available to persons affected by hansen's disease in the State of Rivers; training key leaders on fundraising and writing proposals for grants; vocational training (for barbers, tailoring, shoe making, telephone repair, computer repair and shoe making) of identified members, the holding of a biannual meeting of national executives and an annual general meeting of IDEA members (IDEA NIGERIA, 2021) .

IDEA Nigeria mentions carrying out activities to celebrate World Leprosy Day, in conjunction with the National Leprosy Control Program, such as a meeting with the ministerial press led by the Minister of Health; awareness walks; interviews and discussions in the media (television and radio) and visits to hospitals and/or communities affected by hansen's disease (IDEA NIGERIA, 2021).

According to IDEA Nigeria (2021), Nigeria has 36 states and the territory of the federal capital and the main problems faced are the training of leaders and organization of activities at the state level, as reported “the activities in about 60% of the state level IDEA are not well organized and outlined. In addition, the capacity of executive members of IDEA state divisions needs to be developed, except for IDEA state sections in TLMN-assisted states” (IDEA NIGERIA, 2021).

National Association persons Affected by Leprosy Sierra Leone (NAPAL)

The National Association of persons Affected by Leprosy (NAPAL) was founded in 2018 to advocate on behalf of its members, who may be directly or indirectly affected by hansen's disease. The organization has over four hundred members, all on a voluntary basis, and various partners including Ministry of Social Welfare, Sierra Leone Union on Disability Issues, National Commission for Persons with Disabilities, Disabled Rights Movement, German Association of Leprosy and Tuberculosis Relief (GLRA) (NAPAL, 2021; SHF, 2021).

NAPAL is a non-political, non-sectoral, non-tribal and non-religious association. The organization’s mission is to “advocate for the eradication of stigma, promote the social inclusion of all persons affected by hansen's disease and contribute to the eradication of hansen's disease through community involvement, early case detection and referrals” (NAPAL, 2021) .

The association aims to promote the physical, social and mental well-being of persons affected by hansen's disease through cordial relationships and understanding between persons; empowerment through job training, small businesses and any other form of income-generating and self-reliance activities; and reducing the dependency rate among persons affected by hansen's disease (NAPAL, 2021).

NAPAL develops activities to promote early notification of hansen's disease cases, home care to prevent disabilities due to hansen's disease, advocacy and awareness of stigma due to hansen's disease, empowerment of affected persons through voice technologies, educational support for dependents , community involvement in WASH (basic sanitation and clean water provision), quarterly support meetings, building and strengthening the network with other persons affected by hansen's disease locally and internationally, providing housing and other types of social support to those affected , administrative support for the association's district offices and reactivation of offices in four districts and construction of a central association office (NAPAL, 2021).

The main action carried out in partnership with the National Leprosy Control Program is the celebration of the world day to combat hansen's disease. The entity does not have a Facebook or website to publicize the actionsand communicate with other affected persons and partner organizations. Among the difficulties encountered is the financing of actions, since members are volunteers and usually use their own resources to fund activities and the necessary structure to be responsible for projects (NAPAL, 2021).

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Organization of persons Affected by Leprosy in Congo (OPALCO)

OPALCO was founded in 2018, in the Democratic Republic of Congo, as an organization of persons affected by hansen's disease and receives support from both TLM and Action Damien. Most members are volunteers and affected by hansen's disease, but there are members who contribute financially and those who are not affected by the disease (OPALCO, 2021).

The organization's mission is to "improve socioeconomic conditions and promote the rights of persons Affected by Leprosy" and the vision that "the person affected by hansen's disease leads an inclusive life without discrimination" (OPALCO, 2021).

OPALCO develops awareness activities, in churches and on World Leprosy Day, organized by the National Leprosy Elimination Program. According to OPALCO, the main difficulty faced by the organization is the lack of regular funding (OPALCO, 2021).

Purple Hope Initiative (PHI)

The Purple Hope Initiative (PHI) was founded in 2018, as an organization of women and children affected by hansen's disease and other diseases and/or disabilities living in Nigeria. It is a registered, non-profit association supported by the Sasakawa Health Foundation and has 1035 registered members. The institution's headquarters are in Lagos and it has Facebook (SHF, 2021).

As for the composition of the organization, PHI members are not volunteers and do not contribute financially, except for those who received a small loan for their business and formed a cooperative enterprise for themselves (PHI, 2021). The organization's mission is to "positively reposition the hopelessness of its members", as it has as its vision "to restore the dignity of members, speaking with one voice against any form of discrimination and exclusion" (PHI, 2021).

The main actions developed by the organization are advocacy, training / capacity building, early detection of hansen's disease, economic and social independence of its members through empowerment, support for the education of children and adults, creation of a self-care group / help and counseling, best practices by the Water, Sanitation and Hygiene Program (WASH, Water, Sanitation and Hygiene) (PHI, 2021).
The main difficulties faced by PHI to implement actions with persons affected by hansen's disease are the lack of resources to carry out strategic plans; non-accessibility to the various colonies where members are located; insurgency and covid19 threats; illiteracy; bad network services and different language, in addition to the non-governmental commitment. (PHI, 2021).

Tanzania Leprosy Association (TLA)

The Tanzania Leprosy Association (TLA) was founded in 1978 by a group of professionals who worked with persons afflicted with leprosy and then the association transformed to be led and work with persons afflicted in the early 2000s. In 2011, the organization's first election, where persons affected by hansen's disease were elected to representation positions (SHF, 2021).

LA members contribute a small amount (less than a dollar a month) at their respective branches for the purpose of helping each other in times of need. The organization has a mixed composition, since not all members are affected by hansen's disease, such as those who are children of the affected persons and are part of the organization's staff. TLA is supported by the Sasakawa Health Foundation and DAHW/GRLA, which are associated with ILEP, and also by LUV +UK (TLA, 2021).

TTLA's mission is to "improve the living conditions of persons affected by hansen's disease and contribute to the elimination of leprosy and stigma towards persons affected by the disease in the country, empowering them with skills and tools to improve their livelihoods". Meanwhile, the vision is "to have a hansen's disease-free nation and a community of persons affected by hansen's disease that are socially and economically empowered, self-sufficient and respected in society" (TLA, 2021).

Before the pandemic, the organization carried out advocacy activities; health awareness and education; income-generating activity and physical and social rehabilitation (SHF, 2021).

Notable in recent years, the meeting on hansen's disease in Ethiopia in February 2019; the Global Forum of Organizations of persons Affected by Leprosy in September 2019 (Manila/Philippines); Leprosy Day Campaign in Primary Schools in January 2020; Income generation projects for three TLA branches (in three regions) with a total of 170 associates, in February 2020 (TLA, 2021).

The actions developed together with the National Tuberculosis and Leprosy Control Program are the sharing of information and activities on World Leprosy Days. The main challenges encountered by the TLA include insufficient resources (especially in terms of maintaining funds), the need for training in skills and knowledge of the community of persons affected by hansen's disease, as they are a marginalized group and with a mentality used to receiving care and donations. (TLA, 2021).

Western Mediterranean PAHO:

Mahamcharity (Iran)

Mahamcharity was founded in the Islamic Republic of Iran in 2001. The organization has NGO status and is made up of both affected and unaffected persons who work on a voluntary basis and can also contribute financially. Furthermore, the organization does not receive support from any institution linked to ILEP, from non-governmental or governmental entities - national or international. The organization has a website and a new one is under construction, but it does not have Facebook (MAHAMCHARITY, 2021).

Mahamcharity's mission is "to financially, culturally and socially empower persons affected by hansen's disease in Iran and eradicate hansen's disease through training and case detection, by being the practical arm of national and international missions" (MAHAMCHARITY, 2021). Meanwhile,

South Pacific PAHOs

Coalition of Leprosy Advocates in the Philippines (CLAP)

The Coalition of Leprosy Defenders in the Philippines (CLAP) was founded in 2014. CLAP is made up of 19 organizations/groups of persons affected by hansen's disease in the Philippines. The organizations are present in the islands of Luzon (Association of Culion Hansenites (ACHI), Bicol Sanitarium Association of persons with Disability, Inc. (BSAPWDI), Bukal ng Buhay, Grupong mga Rehistradong Pasyente with Mahusay in Oryentasyon, Inc. (GROUP), IDEA Philippines, Stardolls Multi-Purpose Cooperative (SMPC), PGH Hansens Club, Jose Reyes Memorial Hospital Hansens Club, Surok Uni), in the Visayas Islands (Cooperative for Better Living Western Visayas Sanitarium, Holy Family Association Women for Economic Development (HFAWED) , Negative Barrio Welfare Association, Inc. Vila Socorro Home Owners Association) and islands of Mindano (Bagong Pag-asa Cooperative (BPC), Cotabato Sanitarium Hansenites Cooperative Multi-Purpose (CSHMPC), Leprosy Association of Muslim Mindanao Interactive Society, Central Sanatorium (ISLAM), persons affected by the hansen's disease organization in the Mindanao area (PALOMA), Pedicab Sulu Drivers Association, Sulu Negative Leprosy Women's Association).

The CLAP is made up of persons affected by hansen's disease. However, many members of the organization belong to the second and third generations of those affected and few are volunteer advocates. Members contribute a minimal annual fee, but most community activities are voluntary. The organization does not receive current support from any organizations linked to ILEP or other organizations, although the SASAKAWA Health Foundation has made annual grants from 2012 to 2017. Activities are coordinated with the National Leprosy Control Program (NLCP) through the project " strengthening ofParticipation of persons Affected by Leprosy in Leprosy Services (SPP)" (CLAP, 2021).
CLAP's mission is to "deliver transparent and quality services that will impact and change the lives of coalition stakeholders. In addition, support communities of persons affected by hansen's disease to have full community participation". And as a vision "to enable persons to live a life of freedom, dignity and self-sufficiency for national transformation" (CLAP, 2021).

Before the COVID-19 pandemic, CLAP carried out actions based on five axes:

1

Public Health: Strengthen the participation of persons affected by hansen's disease without hansen's disease services, with the aim of improving access to quality hansen's disease services; assist in the early detection of cases; contact tracing, case referral, participation in household and school surveys (active case detection), Testimonials/experiences.

2

Socio-enterprise: Get involved in viable income-generating ventures.

3

Human Rights and Media Advocacy: Collaborate in the study of social stigma and coordinate the community-based rehabilitation (CBR) project in partnership with government agencies, local government units (LGUs) and non-governmental agencies (NGOs).

4

Preservation of the history of hansen's disease: Participate as the main stakeholder in the archive, documentation of oral history and promotion of the history of hansen's disease.

5

Education: Provides educational, vocational/technical assistance to qualified students or students identified as persons affected by hansen's disease" (CLAP, 2021).

The main difficulties in carrying out regular activities are the lack of a regular source of funding, the geographical challenge due to the fact that the national territory is an archipelago and the reduced interest in the country for the leprosy service (CLAP, 2021).

HANDA Rehabilitation & Welfare Association (HANDA)

HANDA Rehabilitation & Welfare Association (HANDA) was founded in 1996 as a member of IDEA in China. HANDA is a non-governmental organization with more than 5,000 members and thousands of volunteers, however a third of the board of directors is composed of persons not affected by hansen's disease, since 2008 (ILEP; SMHF, 2018).

According to the statute of HANDA, in its Article 3, the mission of the organization is: “to comply with the laws, regulations and policies of the country and to practice the fundamental values of socialism. The association adheres to the overall leadership of the Communist Party of China and establishes the Communist Party of China organization to carry out party activities in accordance with the provisions of the Constitution of the Communist Party of China. Provide the necessary conditions for party organization activities, respect social morals and customs and improve the quality of life and quality of life of vulnerable groups such as hansen's disease patients and hansen's disease recoveries through social, recoveries through social, psychological rehabilitation activities , physical and economic, and eliminate discrimination. Promote the dignity and respect of vulnerable groups, such as hansen's disease patients and recovered persons” (HANDA, 2021a).

According to ILEP and SMHF (2018, p. 17) HANDA's values are “equality, participation, empowerment and dedication”, which leads them to work on the following work motto “Help persons help themselves”. HANDA, throughout its existence, has developed and continues to develop activities aimed at preventing disabilities and physical rehabilitation, including the provision of protection and rehabilitation services for different types of disability, as well as the production and distribution of protective and orthopedic. In addition to socio-economic development activities, through skills training, support for the implementation of community enterprises and microloans. Empowerment and psychological support by peers through the training of group leaders and those residing in the villages, where the affected persons and their families are concentrated. And, also, networking and awareness, through volunteer work (HANDA, 2021b; ILEP; SMHF, 2018).

No specific data were found on HANDA's performance with the National Leprosy Control Program. However, there are reports of international, national and local partnerships in the book commemorating the 20th anniversary of the association's foundation, among which are ILEP member NGOs such as SHF, AIFO, TLMI and ALM (HANDA, 2006).

The main difficulties reported for the participation of persons affected by hansen's disease in health services, according to the systematization of the experience carried out by ILEP and SMHF (2018, p. 23,24) were “the stigma, the limitation of funds, the limitation of qualified professionals to work in NGOs and with hansen's disease, limited participation in health services due to discrimination and internalized stigma, and the permanence of the charity approach in many groups” (ILEP; SMHF, 2018).

HANDA does not have Facebook, but it does have a website (https://www.handa-idea.org/). The information contained herein was obtained through the analysis and translation of the website with the support of Google Translate (Mandarin to Portuguese), in particular the association's Statute, the book commemorating the 20th Anniversary of HANDA (English version) and the book published by ILEP and SMHF (2018) on good practices of organizations of persons affected by hansen's disease, as there were no responses to emails sent to the indicated contacts.

Asian PAHOs: ◀

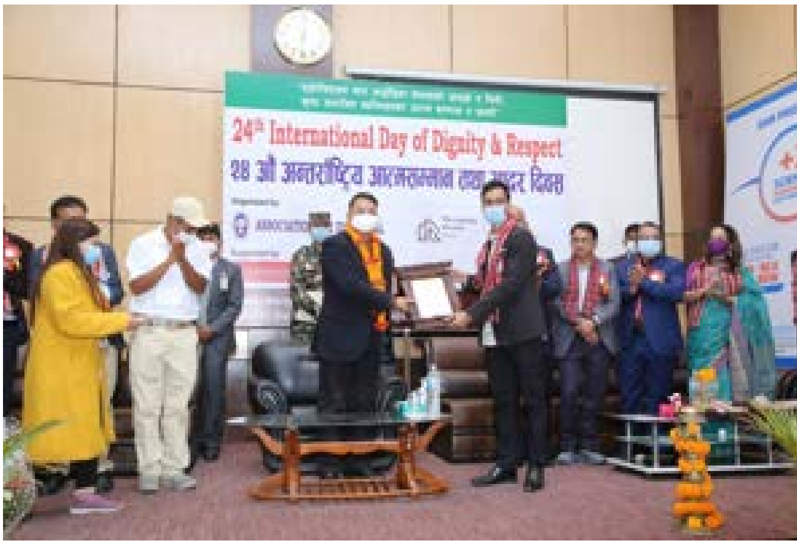
Advancing Leprosy and Disadvantaged persons's Opportunities Society (ALO)

The Advancing Leprosy and Disadvantaged persons's Opportunities Society (ALO – Bangladesh) was founded in 2014, but was not registered with the government until 2020. The society operates in twenty out of two districts in Bangladesh. ALO has about 17.4B8r3B4p7yhRXuBWLqsQ546WR43cqQwrb XMDFnBi6vSJBeif8tPW85a7r7DM961Jvk4hdry ZoByEp8GC8HzsqJpRN4FxGM9 groups are made up of persons affected by hansen's disease, persons with disabilities and persons in extreme poverty. The organization receives support from the Sasakawa Health Foundation and The Leprosy Mission International – Bangladesh (SHF, 2021).

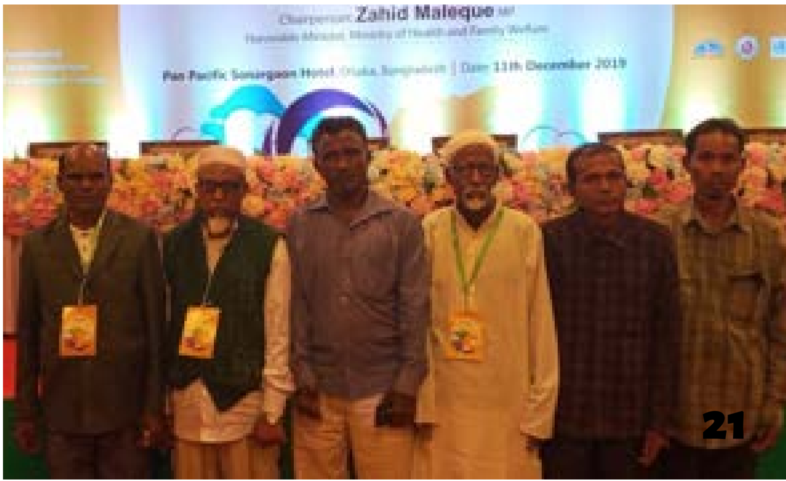
ALO's mission is "dedicated to being on the side of persons affected by hansen's disease and disabilities. We work to empower disadvantaged persons in society to ensure a "society for all". We strive to connect and enable persons to achieve all of their rights, dignity and rightful place in society – for a dignified and healthy life" (ALO, 2020). And as a vision to have "a dignified society where persons affected by hansen's disease and disability can fulfill their potential, rights and in the fullness of life" (ALO, 2020).

For this, ALO believes in empathy, integrity, affiliation and unity. Its strategic focus is "increasing opportunities, dignity and empowerment, social integration, research and learning, resource mobilization and providing assistance and solutions to the challenges of leprosy and disability" (ALO, 2020).

Before the COVID-19 pandemic, the main activities carried out by ALO were: a) training, development of partnerships for federations/associations formed with representatives at the head of self-help groups; b) assist federations/associations through advocacy for the establishment of rights for persons affected by hansen's disease, with disabilities and in extreme poverty and c) partnership for the socio-economic development of group members (SHF, 2021).



Among the activities developed are awareness-raising about COVID-19, workshops on the project's operation process, dissemination of SHF's main messages, digital ulcer treatment monitoring service (Digital UlcerCare), maintenance of service centers in the nine districts, distribution of masks, soap and food to persons affected by hansen's disease, offering activities and funds for income generation, distribution of guidance leaflets and distribution of resources for persons in extreme poverty to survive during confinement. Aid was also distributed in Chattogran with support from TLMI-Bangladesh and funds/resources were raised with society donors for distribution of goods among persons affected by hansen's disease (SHF, 2021).



Association of persons Affected by Leprosy (APAL)

The Association of persons Affected by Leprosy (APAL) was founded in India in 2013. The institution's patron is Mr. Yohei Sasakawa. The association emerged from the National Forum of India by and for persons affected by hansen's disease from across the country, in 2006 (APAL, 2019).

APAL is present in 16 Indian states and has the collaboration of organizations such as the World Health Organization, Nippon Foundation, National Leprosy Eradication Leprosy (NLEP), LEPRA Society, The Leprosy Mission (TLM), AIFO, GLRA/DAWN India, Damien Foundation, Netherland Leprosy Relief (NLR), ILEP, Sasakawa India Leprosy Foundation, Disable persons's International (DPI), Human Rights Law Network, NCPD, Swiss Emmaus Leprosy Relief Work – India (Swiss) and ILU-HA (APAL, 2019).

APAL’s mission and vision is “to work for the socio-economic empowerment and well-being of persons affected by hansen's disease” (APAL, 2019). The main objectives of the association are:
“‘ - promote respect and dignity in the lives of persons affected by hansen's disease and persons with disabilities to work in partnership to ensure that they live protecting life with dignity;
- in association with the Government, Non-Governmental Organizations and International Agencies to improve the social and economic conditions of persons affected by hansen's disease and persons with disabilities;
- provide education to the community on hansen's disease, general health and the environment;
- collect information from various sources on the topic of hansen's disease and persons with disabilities in India and function as a consultancy and
- combat prejudice, discrimination, segregation, rejection, the use of derogatory t

Before the COVID-19 pandemic, the scope of activities developed by APAL for the socioeconomic training of the affected persons and their families were part of the scope of activities; programs for training and organizing colony leaders in the states; workshops for women and youth; training for leaders, youth and colony members; human rights redress; program to disseminate the message of the National Appeal on hansen's disease, stigma and discrimination; work with national and international governmental and non-governmental agencies for the integration of persons affected by hansen's disease; and participation in regional and national conferences of persons affected by hansen's disease (APAL, 2019).

Atma Swabhiman

Atma Swabhiman was founded in 2009 in India. According to its representative, the organization was created to face the challenges of persons affected by hansen's disease and the term “Atma Swabhiman” means self-dignity. The organization is formed exclusively by persons affected by hansen's disease, on a voluntary basis. Eventually, in emergency circumstances, there is a nominal financial contribution to support only those affected, mainly because the members come from a population in conditions of socioeconomic disadvantage. In addition, Atma Swabhiman is supported by the Sasakawa Health Foundation and other entities (ATMA SWABHIMAN, 2021).

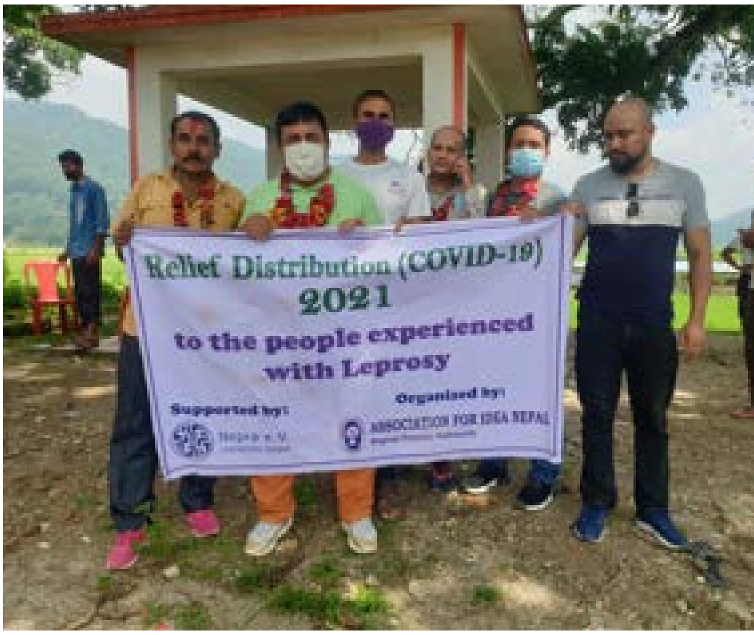
Atma Swabhiman's mission is to promote “socio-economic rehabilitation, reconstruction of lives, ongoing care and support for persons with extreme vulnerabilities, including public sensitized and aware about hansen's disease and affected persons to be understood with inclusion, integration and a better life”. with dignity” (ATMA SWABHIMAN, 2021).

The organization's vision is to promote the inclusion and integration of persons affected by hansen's disease. To this end, in collaboration, it promotes, supports and coordinates activities:“
- relief, socio-economic, care and support aimed at meeting the challenges of persons affected by hansen's disease;
- resolving conflicts within the colonies and with neighboring communities, advising and promoting harmony;
- appeals, raising resources and support for the most vulnerable children, women, the elderly and persons with disabilities living in colonies;
- efforts to network, collaborate and link for the rights, scheme, land, housing, water, sanitation and rehabilitation of affected persons, including the demand for education for children and livelihoods for affected persons;
- sensitization, awareness and public calls for a life with dignity and inclusion for those affected” (ATMA SWABHIMAN, 2021).

IDEA Nepal

TIDEA Nepal is a non-governmental organization founded in 1998. The organization is supported by both the Sasakawa Health Foundation and The Leprosy Mission, which are members of ILEP. The association's members are volunteers, but there are five employees who are paid and few members are not affected by the disease. In addition to these, they receive support from Nepra and V Germany, IDEA Korea, as well as local volunteers (IDEA NEPAL, 2021).

IDEA Nepal’s mission is to work towards “an integrated and inclusive society without hansen's disease and discrimination, where persons are self-sufficient and live in dignity” and as a vision “to support the Triple Zero campaign and the Sustainable Development Goals through advocacy, awareness , economic support, capacity building and partnerships” (IDEA NEPAL, 2021).



Prior to the COVID-19 pandemic, IDEA Nepal developed awareness-raising activities such as "Celebration of World Leprosy Day" and "International Day for Dignity and Respect", capacity building workshops, peer support programs, training and conduct, in all the seven provinces of Nepal from IDEA Nepal Provincial Assemblies (IDEA NEPAL, 2021).

IDEA Nepal does not have any programs in collaboration with government agencies in Nepal, but plans to address them in the near future. Among the main difficulties encountered in carrying out the work were the lack of education, poverty, geographical difficulties, discriminatory laws and stigma (IDEA NEPAL, 2021)

Myanmar Association of Persons affected by Leprosy (MAPAL)

The Myanmar Association of Persons affected by Leprosy (MAPAL) was founded in 2019 in Myanmar (SHF, 2021). The association is made up of persons affected by leprosy and their families, all on a voluntary basis. Only 14 members do not fit this profile, including a person with a disability. MAPAL receives support from TLM Myanmar and grants from the Disabled Rights Fund (DRF), Sasakawa Health Foundation (SHF), The Leprosy Mission England & Wales (TLM E&W), Johanniter International Assistance (JIA) (MAPAL, 2021).

MAPAL's mission is “Regardless of race, religion, wealth, age and sex, the Association ‘of Persons Affected by Leprosy (MAPAL) of Myanmar will apolitically and selflessly address the issues of persons affected by hansen's disease and their families, keeping their lives healthy, with better socioeconomic status and having full access to basic human rights without discrimination, in coordination and collaboration with government organizations, INGOs/international NGOs and stakeholders” (MAPAL, 2021).

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And as a vision the “full participation of persons affected by hansen's disease in Myanmar society, without discrimination” (MAPAL, 2021). To this end, it carries out awareness-raising actions on hansen's disease, advocacy against discrimination, organizational development and training of association members (SHF, 2021).

The association has worked together with the National Leprosy Control Program through the peer education strategy, during the Leprosy Awareness Campaigns. Among the difficulties encountered by MAPAL members in carrying out the work is the need for funding for the formation of new sections to support the national mobilization of persons affected by hansen's disease in the country. Other problems are the pending national registration of the organization due to the current political situation (deposition of the current government by the military) (MAPAL, 2021).

Nepal Leprosy Trust & Self-help Groups (NLT & SHGs)

Nepal Leprosy Trust & Self-help Groups (NLT & SHGs) was founded in 2001 in Mahatri and Hansa, Nepal. NLT & SHGs was a pioneering Community Based Rehabilitation project. Currently, Self-Help Groups from four districts are registered as non-governmental organizations, totaling 112 groups and 2,255 members. Among the members are 220 persons with lymphatic filariasis. persons affected by hansen's disease are the main facilitators of the groups (SHF, 2021).
NLT & SHGs are part of the Lalgadh Leprosy Hospital and Services Center (LLHSC) Community Outreach program founded in 1996 by the Nepal Leprosy Trust. The mission of the NLT & SHGs is expressed below:

"At LLHSC, we strive to provide high-quality, preventive, curative, and rehabilitative compassionate healthcare, and we also work through community outreach, social support, and training programs. Our goal is the ultimate elimination of hansen's disease, health improvement, socioeconomic development and uplift, human rights empowerment and empowerment, especially through participatory community development" (NLT&SHGS, [n.d.]).

The vision of NLT & SHGs is to train for self-care, disability prevention and empowerment (SHF, 2021). For this, before the pandemic, it developed the following activities: a) regular meetings (weekly and monthly); b) practice of self-care (highly focused on prevention); c) rescue activities and livelihoods; d) awareness of hansen's disease and NTDs (currently Covid-19); e) supplication and referral for Hansen's disease - channel for diagnosis; f) local coordination with government agency and district agency; g) defense of rights (social inclusion). Most groups are focused on regular prevention (SHF, 2021).
During the covid-19 pandemic, activities continued with continuous practice of self-care; distribution of warm clothing to group members; support for the development of professional skills; support for children of persons affected by hansen's disease; student education about COVID-19; Meeting/demonstration and lobbying with the provincial government; advocacy for the cancellation of discriminatory laws and free health insurance for all persons affected by hansen's disease, as well as the commemoration of the 68th World Leprosy Day (SHF, 2021).

Perhimpunan Mandiri Kusta Nasional (PerMaTa Indonesia)

Perhimpunan Mandiri Kusta Nasional or PerMaTa Indonesia was founded in 2007. PerMaTa Indonesia is made up of four branches, namely PerMaTa South Sulawesi, PerMaTa East Java, PerMaTa NTT and PerMaTa Gowa, which together have around 2,100 members (ILEP; SMHF , 2018; SHF, 2021).

PerMaTa Indonesia's main activities are advocacy with local government, schools, etc; empowerment of persons affected by hansen's disease to improve their quality of life; awareness (campaign against leprosy); peer support; maintain/develop good relationships with local government, health facilities and other organizations (SHF, 2021).

‘of Persons Affected by Leprosy (MAPAL) of Myanmar will apolitically and selflessly address the issues of persons affected by hansen's disease and their families, keeping their lives healthy, with better socioeconomic status and having full access to basic human rights without discrimination, in coordination and collaboration with government organizations, INGOs/international NGOs and stakeholders” (MAPAL, 2021).

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Perhimpunan Mandiri Kusta South Sulawesi (PerMaTa South Sulawesi)

Perhimpunan Mandiri Kusta South Sulawesi (PerMaTa South Sulawesi) is an association of persons affected by hansen's disease founded in 2007 in Indonesia, in the province of South Sulawesi and is linked to PerMaTa Nasional. All members of the association are affected persons and work on a voluntary basis. However, they sometimes contribute financially to counseling and support activities for persons undergoing treatment. In addition, in the case of actions supported by NGOs, volunteers can receive financial support according to the task performed (PER MA TA SOUTH SULAWESI, 2021).

The organization does not have an email and website, bu

t it does have Facebook and some Whatsapp members. The organization is supported and voiced by the Sasakawa Health Foundation as well as NLR Indonesia. In addition to international organizations, it receives full support from YDTI, through the formation of coalitions of organizations for persons with disabilities in activities to

Prior to the COVID-19 pandemic, activities carried out by PerMaTa South Sulawesi included: 1) training for persons affected by hansen's disease for counseling and dissemination of information about hansen's disease in the community; 2) advocacy with local institutions to press for regional regulations regarding the management of hansen's disease and disabilities, as in Indonesia, leprosy is considered a type of disability; 3) encouragement of "friendly villages" of hansen's disease and persons with disabilities in Jeneponto district, which are supported by NLR Indonesia; 4) support for mutual aid groups; 5) efforts to socialize information about hansen's disease in the community, schools and social networks so that persons understand the disease; 6) support health professionals in tracking persons with suspected hansen's disease and assisting these persons so that they can seek treatment until they are cured; 7) advocacy activities with the government in relation to food aid and health insurance for persons affected by hansen's disease; 8) training of young persons who had hansen's disease, contributing to their strengthening and self-stigma improvement; and 9) training youth affected by hansen's disease to teach afflicted women with disabilities who are illiterate to read (PER MA TA SOUTH SULAWESI, 2021).

PerMaTa South Sulawesi carries out, together with the National Leprosy Control Program, the sharing of information with the community, the active search for new cases of hansen's disease in the community, providing assistance to patients diagnosed with the disease both in treatment at the health center and in the hospital. , in order to support persons's recovery and break the chain of transmission (PER MA TA SOUTH SULAWESI, 2021).

The main difficulty reported is the fact that many persons affected by hansen's disease do not admit that they had hansen's disease and hide, as well as refuse to invite their families to join the association (PER MA TA SOUTH SULAWESI, 2021).

Pramila Ek Asha

Pramila Ek Asha was founded in India in 2017. Members of the association are volunteers and contribute financially. The association does not receive support from ILEP members or other governmental and non-governmental institutions. In addition, it has a website and facebook to communicate (PRAMILA EK ASHA, 2021).

The organization's mission is to "end stigma towards persons affected by hansen's disease and their families and provide social justice for transgender persons, HIV and persons affected by hansen's disease" and as a vision "to end discrimination against persons affected by hansen's disease and family members and protect the rights of persons affected by hansen's disease with disabilities, socially retarded persons and persons affected by HIV" (PRAMILA EK ASHA, 2021).

Before the COVID-19 pandemic, Pramila Ek Asha carried out public awareness actions on hansen's disease and HIV; several lectures/classes at different school, university and community levels to raise awareness about hansen's disease; the distribution of food material in several hansen's disease colonies; the distribution of books/pens/copying and motivation of colony children for a better future, etc. (PRAMILA EK ASHA, 2021).

Saksham Kushthanteya Swabhimani Santha (SKSS)

Saksham Kushthanteya Swabhimani Santha (SKSS) is an organization of persons affected by hansen's disease founded in 2019. All members of the organization are affected persons and contribute at the time of registration as a lifetime member of the organization, until May 15, 2021 the organization had 183 lifetime members. The entity is supported by ALERT-INDIA and since November 2020 it has developed a project in partnership with the Sasakawa Health Foundation (SKSS, 2021).

The mission of SKSS is the empowerment of persons affected by hansen's disease to overcome/neutralize/correct the violation of rights and contribute to the development of society as responsible citizens. Thus, the of motto of the organization is “Achieve a world free of hansen's disease and together to end leprophobia”. In addition, it aims to: empower persons affected by hansen's disease who live in the community; promote the human rights persons affected by hansen's disease and protect against the violation of rights; contribute to the National Leprosy Eradication Program (NLEP) by reducing the burden of disease among persons affected by hansen's disease living with disabilities (SKSS, 2021).

SKSS, in its vision, will strive for an inclusive society 'Free from the Fear of Leprosy' and 'Zero Discrimination' towards persons affected by hansen's disease and their affected persons in the community and the health system; and low awareness and promotion of self-care among affected persons living with disabilities. In search of solutions, board members are trying to create a viable system with adequate infrastructure to drive a long-term results-oriented action plan (SKSS, 2021).

Society Leprosy Affected Person Andhra Pradesh (SLAP AP)

The Society Leprosy Affected Person Andhra Pradesh (SLAP AP) was founded in India in 2014. The organization is formed exclusively by persons affected by hansen's disease on a voluntary basis. The NGO LEPRA, linked to ILEP, provided financial support to SLAP AP, but due to lack of funding sources, this support was interrupted. However, the entity receives support from Brighter Future Development Trust and APAL-India (SLAP-AP, 2021).

The mission of SLAP AP is "to provide relief to persons with disabilities in society, in particular persons affected by hansen's disease in colonies and in the community" and the vision is to "empower persons affected by hansen's disease and their families to live in dignity and prosperity" (SLAP-AP, 2021).

The activities developed by SLAP AP focus on meeting the following objectives:

"1. Offer relief to persons with disabilities in society, especially hansen's disease patients in the colony and in the community, the poor, orphans and the physically, mentally and due to old age and illness in the community.
2. Assist in the education of persons affected by hansen's disease, their children, the poor and the oppressed.
3. Assist in the free treatment of persons affected by hansen's disease for rehabilitation.
4. Raise public awareness of the need for help and rehabilitation through various media.
5. Provide vocational training for persons affected by hansen's disease" (SLAP-AP, 2021).

In this sense, the main activities are fundraising for the maintenance of well-being activities in the community of persons affected

Sby hansen's disease, provision of equipment for the rehabilitation of persons with disabilities (in accordance with the rules of the Government of India) and compilation/ publication/distribution of works carried out by society groups, in addition to materials on community-based rehabilitation for persons with disabilities (SLAP-AP, 2021).LAP AP develops together with the National Leprosy Control Program awareness and advocacy actions, case detection, support for immediate treatment, advocacy for their social rights, clothing material, MCR (Multicellular rubber) type protective footwear (SLAP-AP, 2021).

The main difficulties pointed out in the organization of persons affected by hansen's disease are due to the fact that "most persons affected by hansen's disease who live in colonies hansen's disease patients are illiterate and, most of the time, are outside the area where they live to earn a living" (SLAP-AP, 2021). The other issue raised is that despite the SLAP AP being able to organize persons affected by hansen's disease who live in the colonies into groups, the organization mentions difficulties in implanting the groups with those who live dispersed in the community. The organization does not have a website, but it does have Facebook and the email changes according to current management.

Activities carried out by the PAHOs during the Covid-19 pandemic:

BThe actions of the PAHOs converge to the defense of human rights. However, the notion of defense of rights does not often accompany that of citizenship and political life. In most of the statements, the principle of non-discrimination is manifested in the proposal to eliminate hansen's disease, stigma and discrimination against affected persons, as well as in the need for social inclusion. Socioeconomic empowerment (education, culture, work and income) and social participation appear as the main levers to achieve dignity and equality of conditions.

During the covid-19 pandemic, the mission of the PAHOs was present through engagement with the community to form coalitions and a socio-technical network. These associations enabled the development of strategies, which considered the local reality, to implement the best protection, care and support measures possible, effective and acceptable by community members. According to Table 1, the strategies were mainly focused on IEC activities, support for life maintenance and self-care, due to the SHF incentive, through a funding notice for projects lasting four months. The economic support and advocacy actions were carried out by PAHOs with some degree of experience and support for this type of action;

Table 1. Actions taken by Organizations of Persons affected by Hansen's disease during the COVID-19 pandemic in 2020.

Activity Type	Activities developed during the Covid-19 pandemic.	Organizations of Persons Affected by Hansen's disease																												
		Africa and Eastern Mediterranean												Americas			Asia and South Pacific													
		TLA	ENAPAL	ALEMO	IDEA Ghana	IDEA Niger	IDEA Nigéria	IDEA Kenya	ASCL/MNT	OPALCO	PHI	NAPAL	Mahan Charity	Morhan	IDEA*	FELEHANSEN	IDEA Nepal	DSHGF*	NLT & SHGs	BOGRA	ALO	APAL	Atma Swabhiman	Sam Utthan	SLAP-AP	PramilaEkAsha	SKSS	MAPAL	PerMaTa Nasional	PerMaTa S.S.
Information, Education and Communication	Adequate information through social media (Whatsapp, Facebook, Instagran, Twitter and/or Youtube).					■					■			■									■			■		■		
	Adequate information through SMS (text messages to cell phones) and calls.			■			■																							
	Adequate information through local radio and press.						■							■					■											
	Production and/or distribution of educational material about Covid-19 and Hansen's disease													■							■									
	Awareness campaign about Hansen's disease and Covid-19.										■	■		■					■	■	■	■	■		■	■		■		■
	Digital inclusion training.										■	■		■		■														
	Training for protection against Covid-19 (individuals, families and the community).								■	■		■		■						■						■				
	Meetings and training of local leaders.															■				■		■	■							
	Training for income generating activities.		■							■																				
Support for life maintenance	Acquisition and/or making of facial masks.	■												■									■							
	Provision of face masks.	■	■				■		■					■					■		■	■	■			■	■		■	■
	Provision of personal care and cleaning items.	■	■			■	■	■	■	■	■	■		■		■	■		■		■	■				■	■	■	■	■
	Provision of hand washing basins.										■												■							
	Food provision.		■			■	■	■		■	■	■		■		■	■		■	■	■	■	■		■	■	■		■	■
	Provision of drugs and primary health care.							■					■									■			■		■			
Self-care support	Self-care group meetings.																		■		■		■							
	Use of social media technology (video calling) to support chronic wound care.																				■									
	Home visits to articulate care and provide information.				■	■					■			■								■								
	Social welcome and psychosocial counseling.				■	■		■					■	■						■		■								■
	Encourage the maintenance of Hansen's disease treatment.				■	■		■				■		■													■			
	Provision of dressing supplies.				■	■		■				■										■								
	Provision of kits and educational material for the assessment and prevention of disabilities.																					■								
	Provision of protective shoes.																								■					
	Distribution of toys and educational materials for children to return to school (educational support).											■		■			■													
	Construction of bathing facilities.		■																											

Mediation and Advocacy	Articulation with other vulnerable groups (persons with disabilities and those affected by other Neglected Tropical Diseases).													▨		▨					▨									
	Meetings with government authorities, including Hansen´s disease Program managers.													▨					▨	▨		▨	▨				▨			▨
	Articulation with national NGOs for support interventions.													▨								▨					▨			
	Fundraising with local donors to expand food supply.													▨																
	Fundraising to provide a fund to support the income of families that are no longer supported by the government.																				▨						▨			
	Advocacy with the government for the fulfillment of the rights of affected persons and their families (health, social support and education).													▨					▨	▨	▨								▨	▨
	Advocacy through petition to guarantee the right of affected persons to treatment with multidrug therapy during the pandemic.													▨																
	Monitoring the availability of multidrug therapy (MDT) for patients.											▨		▨																

Source: Self-administered questionnaires, interviews, websites, Facebooks and Sasakawa Health Foundation webinar.

Four issues deserve attention. The first concerns the defense of the rights of the affected persons with the different governmental sectors and society by the PAHOs, through advocacy actions. It was noted that the PAHOs represented the voice of the community and not particular positions. The second is the lack of articulation between these organizations and the Leprosy Control Program, at different levels (local, regional and national), highlighting the integration, mainly, in activities of the World Day to Combat Leprosy. The third is the support provided to PAHOs by NGOs linked to ILEP. The NGOs that stand out, in terms of the number of PAHOs supported, are SHF, TLMI and DAHW.

And the last one concerns the limits reported by the organizations for carrying out the activities. The main barriers found were: a) difficulties in raising funds and continuous funding of actions, b) low level of schooling of the community and members of organizations, c) barriers to access such as geographic dimension of countries, availability of transport and accessibility of members , d) lack or inadequacy of the organization's infrastructure, e) local language and official language (various dialects) as a limitation of communication and production of some interventions, f) the existence of laws and culture that discriminate against affected persons and their families, g) poverty and h) political issues.

Conclusion

The mapping of coalitions of persons affected by hansen's disease, during the first and second year of the covid-19 pandemic, contributed to the analysis of the global context of insertion, participation and action of organizations of persons affected by hansen's disease in defense of their rights, families and the community.

In observation, the Global Strategies for the elimination of hansen's disease 2016-2020 and 2021-2030, which in their scopes recommend the active participation of persons affected by hansen's disease in the planning, implementation, monitoring and evaluation of interventions at the national level. Through the identification of the main limits for the development of interventions by the PAHOs, recommendations are presented for the global, national and local levels.

At the global and national level, it is recommended to review the mechanisms of support and strategic funding for organizations of affected persons, the elaboration of intersectoral policies for social inclusion and promotion of the health of persons affected by hansen's disease and their families, created by the Global Leprosy Program of advisory council of PAHOs, insertion of these organizations in the planning and evaluation of the Leprosy Control Program interventions.

At the local level, collaboration between PAHOs, NGOs linked to ILEP and the Leprosy Control Program is recommended, in order to integrate and improve interventions. For this, persons must be at the center of the processes, respecting cultural aspects and avoiding colonization of knowledge-practices, as well as considering the Principles and UN guidelines for eliminating discrimination against persons affected by disease and their families.

The PAHOs must also periodically review with their members the mission and vision of the organization, encourage the participation of persons not affected by hansen's disease and those in other situations of vulnerability, considering the intersectionalities (class, gender and race) with the disease that affect them. These persons. Finally, the PAHOs need to register and increase the visibility of their actions, through information, education and communication tools for advocacy.

Studies like this suffer from limitations in scope. However, this study managed to map 32 PAHOs, distributed in 21 countries, of which 12 are considered priorities for hansen's disease control by the WHO. Therefore, it is necessary to emphasize the importance of coalitions of persons affected by hansen's disease for the defense of rights and health promotion.

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Persons, Places and Time:

Organizations of Persons Affected by Hansen's disease

1874
The Leprosy Mission International (TLMI)

1892
Effect Hope

1895
St Francis Leprosy Guild (STLG)

1906
American Leprosy Mission
America

1909
Fontilles Foundation (Fontilles)

1925
LEPRA

1946
Raoul Foullerau Foundation

1947
Korean Leprosy Association
Korea
Asia

1948
Universal Declaration of Human Rights

1957
Deutsche Lepra und Tuberkulosehilfe (DAHW)

1961
Raoul Foullerau Foundation

Associazone Italiana Amici di Raoul Follereau (AIFO)
Europe

1961
Leprosy Relief Canada
America

1964
Damien Foundation

1966
International Covenant on Economic, Social and Cultural Rights

International Covenant on Civil and Political Rights adopted.

1967
Netherlands Leprosy Relief (NLR)

1969
International Convention on the Elimination of All Forms of Racial Discrimination.

1969
Foundation of the International Federation of Anti-Leprosy Association (ILEP)

1974
Sasakawa Helth Foundation
Asia

1978
Declaration of Alma Ata
Health for All in the year 2000.

1978
Tanzania Leprosy Association (TLA)
United Republic of Tanzania
Africa

1981
Convention on the Elimination of All Forms of Discrimination against Women

WHO declares AIDS pandemic

1981
Movement for the Reintegration of People Affected by Hansen's Disease (Morhan)
Brasil
America

1982
Introduction of polychemotherapy

1986
I International Conference on Health Promotion,
Ottawa letter.

1988
II International Conference on Health Promotion,
Adelaide Declaration.

1991
44th World Health Conference - Commitment assumed by WHO member countries to eliminate Hansen's disease by the year 2000.
III International Conference on Health Promotion,
Sundsvall Declaration.

1994
International Association for Integration, Dignity and Economic (IDEA)
Brasil
America

1996
Ethiopian National Association of Persons Affected by Leprosy (ENAPAL)
Etiópia
Africa

1997
IV International Conference on Health Promotion,
Jakarta Declaration.

HANDA Rehabilitation & Welfare Association (HANDA)
China
Ocidental Pacific

1998
IDEA Nepal
Nepal
Asian Southeast

2000
Strategic Plan for the Elimination of Leprosy in Endemic Countries

2000
ALEMOI
Mozambique
Africa

2001

Mahan Charity!
Iran
Eastern Mediterranean

Nepal Leprosy Trust & Self-Help Groups (NLT & SHGs)!
Nepal
Southeast Asia

2003

IDEA Ghana!
Ghana
Africa

IDEA Nigéria
Nigéria
Africa

2005

Dhanusha Self-Help Groups Federation
Nepal
Southeast Asia

2006

Global Strategy for Reducing the Hansen's Disease Burden and Sustaining Hansen's disease Control Activities.

Convention on the Rights of Persons with Disabilities.

2006

Association of People Affected by Leprosy (APAL)
India
Southeast Asia

2007

Perhimpunan Mandiri Kusta Nasional (PerMaTa Nasional)
Indonesia
Southeast Asia

Perhimpunan Mandiri Kusta Nasional (PerMaTa South Sulawesi))
Indonesia
Southeast Asia

2009

IDEA Niger
Niger
Africa

Atma Swabhiman)
India
Southeast Asia

2010

Principles and Guidelines for the elimination of discrimination against people affected by leprosy and their families

2011

Publication of the Guide for Strengthening the Participation of People Affected by Leprosy in Health Services

Enhanced Global Strategy to further reduce the leprosy burden (2011-2015).

2011

Sam Utthan
India
Southeast Asia

2013

IDEA Refaco Kenya Foundation (IDEA Kenya)
Kenya
Africa

2014

Association Sénégalaise de Lutte Contre La lèpre et Les MTN (ASCL/MTN)
Senegal
Africa

Federación Nacional de Asociaciones de Personas Afectadas por Lepra-Hansen de Colombia (FELEHANSEN)
Colombia
America

Coalition of Leprosy Advocates in the Philippines (CLAP)
Philippines
Western Pacific

Bogra Federation for Leprosy and Disability Development (BOGRA)
Bangladesh
Southeast Asia

2015

Resolution 29/5 deals with the "Elimination of discrimination against people affected by leprosy and their families to promote policies that facilitate their inclusion and participation was adopted by the Human Rights Council.

Advancing Leprosy disadvantaged peoples Opportunities society (ALO)
Bangladesh
Southeast Asia

Society Leprosy Affected Person Andhra Pradesh (SLAP-AP)
India
Southeast Asia

2016

Global Strategy 2016-2020: For a leprosy-free world.

2017

Resolution 35/09 establishes the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their families for three years.

2017

PramilaEkAsha
India
Southeast Asia

ILEP Panel of Women and Men Affected by Leprosy

2018

Outline of the mandate vision, priorities and working methods were presented by Dr. Alice Cruz to the 38th session of the UN Human Rights Council.

2018

Organization of People Affected by Leprosy in Congo (OPALCO)
Democratic Republic of Congo
Africa

Purple Hope Inciative (PHI)
Nigeria
Africa

2018

Outline of the mandate vision, priorities and working methods were presented by Dr. Alice Cruz to the 38th session of the UN Human Rights Council.

National Association People Affected by Leprosy Sierra Leone (NAPAL)
Sierra Leone
Africa

2019

Report on stigmatization as dehumanization: illicit stereotypes and structural violence of women and children affected by leprosy was presented by Dr. Alice Cruz to the 41st session of the UN Human Rights Council.

I Global Forum of Organizations of People Affected by Hansen's Disease - Manila/Philippines

2019

Saksham Kushthanteya Swabhimani Santha (SKSS)
India
Southeast Asia

Myanmar Association of Persons affected by Leprosy (MAPAL)
Myanmar
Southeast Asia

2020

In March 2020, the WHO declared the COVID-19 pandemic.

Report on a policy framework for rights-based action plans was presented by Dr. Alice Cruz to the 44th session of the UN Human Rights Council.

2021

Global Strategy 2021-2030: Towards zero leprosy.

Sasakawa Health Foundation promotes the webinar 'Zero leprosy for whom in the post-COVID world? and proposes to hold the second Global Forum of organizations of people affected by leprosy.

Report on the disproportionate impact of the COVID-19 pandemic on people affected by leprosy and their families: root causes, consequences and the path to recovery was presented by Dr. Alice Cruz at the 47th session of the UN Human Rights Council.

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