



CONTENTS

02	Table of Contents	25-28	Plenary Message: Rev. Luis Daniel Pantaja
03-04	Executive Summary	29	Workshop 02: Religious and Government Partnership Results
05	Presentation of the Participants and Welcome Remarks	30-34	Plenary Message: Dr. Marie Lisa Dacanay
06-09	BioSketch of Resource Persons	35	Workshop 03: Reimagining the Economy Results
10-11	Keynote Speech 01: Dr. Maria Francis Laxamana	36-38	Plenary Session: Dr. Maria Faina Diola
12-13	Keynote Speech 02: Prof. Takahiro Nanri	39	Workshop 04: Communication Plan Results
14-16	Plenary Session: Alice Cruz	40	Review of Assembly Objectives
17-18	Organization Profile: HANDA	41	National and Regional Initiatives Suggestions per country
19-20	Organization Profile: CLAP Philippines	42	Discussion of Results
21	Organizational Profile: IDEA Nepal	43-44	Impressions of the Gathering
22	Organizational Profile: PERMATA Indonesia	45	Role of Media in Ending Stigma and Discrimination of Persons Affected by Leprosy
23	Organizational Profile: Kiribati	46	Media Output during the Regional Assembly
24	Workshop 01 Results	53	Q&A: Why Treating Leprosy as a Special Disease Violates the Rights of the Person Affected by It

About the logo



The hands represent the nations who come together in the Regional Assembly and the logo can be seen as two images: a hand of prayer and flame. "When we come together, in hope—to get our identity back. Flame is fire and that is passion. That is our passion for our vision. It is in being together that we get our hope."

The logo is an original concept of Ka Boyet Ongkiko which was translated into graphics by Joshua Calastro.

This documentation is made possible by Ka Boyet's Team

*Team Leader: Boyet Ongkiko
Design and Layout by Joshua Calastro
Photos by Karl Hanz Reyes*



EXECUTIVE SUMMARY

Together in hope and passion towards our vision.

People's organizations from the Asia-Pacific Region, enjoined by the vision of a leprosy-free world, attended the First Regional Assembly of Organizations of People Affected by Leprosy in Asia-Pacific on March 3-5, 2019 at Hotel H20, Luneta, Manila Philippines.

This is under the initiative of the Culsion Sanitarium and General Hospital (CSGH), together with Coalition of Leprosy Advocates of the Philippines (CLAP) and the Sasakawa Memorial Health Foundation (SMHF). Dr. Arturo Cunanan Jr., Medical Chief 1 of CSGH is the chief convener of this assembly.

The caucus, which included nations namely China, Indonesia, Kiribati, Nepal, Philippines and Japan, took place to discuss the issues of people affected by leprosy on human rights, sustainability, public health program, and preservation of leprosy history is a milestone taken on the way forward for the planned world assembly on September 2019. On the other hand Cambodia, Malaysia and India were invited but were not able to come due to visa problems and for the short notice preparation for the event. Available slots were given to two organizations of people affected by leprosy affiliated with CLAP. One of the goals of the assembly is to create an avenue for the participating people's organizations to become a regional network; and a voice that will speak on pressing concerns of each leprosy patient in their organizations.

OBJECTIVES OF THE REGIONAL ASSEMBLY

That the Regional Assembly of the Organization of people affected by leprosy is a forum:

1. To share the achievements and experiences and best practices of an organization in partnering with various international, national and local agencies; in ensuring the effective delivery of quality health services, reduction of stigma and discrimination, empowerment, improvement of the quality of life brought by socio-economic enterprise; and in increasing the sustainability of people's organizations;
2. To present and highlight the roles and contributions that the people's organizations can provide for the different levels of society and government;
3. For coordination, consultation and joint learning towards the fulfillment of the right to dignity as human beings and citizens;
4. To discuss the means of strengthening/ increasing sustainability for people's organizations;
5. To discuss the means for the development of a functional network and partnership between and among people affected by leprosy; and
6. To propose recommendations for the World Assembly and other strategies and activities on a way forward.

One of the goals of the assembly is to create an avenue for the participating people's organizations to become a regional network...



Participants of the Regional Assembly of Organizations of Peoples Affected by Leprosy in Asia-Pacific (from left to right respectively): (seated on first row) Kurarenga Kaitire-Kiribati, Yuliati-Indonesia, Dr. Maria Francia Laxamana-Philippines, Prof. Takahiro Nanri-Japan, Dr. Arturo Cunanan Jr.-Philippines, Xiuli Qi-China, Kiyomi Takahashi-Japan, (standing second row) Dinesh Basnet-Nepal, Thobias Aleander Manas-Indonesia, Kalep Manikari-Indonesia, Amar Bahadur Timalsina-Nepal, Jennifer Quimno-Philippines, Francisco Onde-Philippines, Yaoquiang Wu-China, Ariel Lazarte-Philippines, Itinnang Uan-Kiribati, Boyet Ongkiko-Philippines, Donna Ruzzel Gacasan, Philippines, Chikako Masuzaki-Japan, Maria Luz Gante-Philippines, and Susan Centeno-Philippines.

The resource persons for the Asia-Pacific assembly helped in advancing the cause to eradicate leprosy in the region. The Philippine Department of Health, represented by Dr. Maria Francine Laxamana, discussed the leprosy situation in the country and the people affected by leprosy. Moreover, Prof. Takahiro Nanri presented the extent of Sasakawa Memorial Health Foundation and The Nippon Foundation's works to the different people's organizations.

Participative discussions are always enriched with workshops that follow every valuable talk. Discussion on the Role of Government and the Religious in ending stigma and discrimination provided lessons to the participants regarding the appropriate approach of religious leaders and the government in advancing the cause of leprosy. One topic is Partnership and Sustainability of Organization which encourages the participants to move into creating a solidarity economy through different social entrepreneurship models. Networking of organization on the other hand, focused on social marketing for better communication of the message to a specific audience.

As a result, the assembly has identified the Philippines as the region secretariat along with the support of SMHF. Furthermore, the assembly seeks to address the following as major themes of concern:

1. Sustainability through Social Entrepreneurship and Fund Raising;
2. Networking with government, non-government, civil societies and other legal entities;
3. Image building and branding;
4. Creation and strengthening of Regional Link thru a secretariat
5. Sustainable Development Strategy (Social Enterprise)
6. Coordination of a Regional Capacity Building Plan

This gives CLAP, a role to fulfill in consolidating necessary information for the region to be able to raise them on June 2019, as the organizing committee for the World Assembly will convene.

The role of the persons affected by leprosy is now recognized and their organizations are also growing bigger and stronger especially in terms of empowerment and stigma reduction and their involvement and partnership in leprosy services. This ensures that the services remain so that the disease is cured, and stigma and discrimination against people affected and their families which pose challenges in living a normal social life can end. There is now a growing interest and actions that the leprosy history and legacy for the future generations with correct information and knowledge about the disease is being preserved and be made widely available as a heritage to humanity.

"We should learn from each other on how we can sustain our organization and reach our vision."

PRESENTATION OF PARTICIPANTS



Dr. Arturo Cunanan, Jr.

Dr. Arturo Cunanan Jr., Medical Chief 1 of Culion Sanitarium and General Hospital, the head convenor of the assembly explained the initiator role of CLAP, Culion Sanitarium and General Hospital together with Sasakawa Memorial Health Foundation. He stated that the regional assembly of the Asia-Pacific Region is set not only to achieve collective end results for the region but also recommendations for the world assembly set on September. He further emphasized, as one key objective, the strengthening of sustainability among the peoples organizations present. "But how long will the foundation be sustaining us, is one of the biggest challenges," said

Cunanan referring to Sasakawa Memorial Health Foundation. "We should learn from each other on how we can sustain our organization and reach our vision." He further commented. For the most part of the presentation of the people behind the assembly, Dr. Cunanan highlighted the roles of the stakeholders present including the Department of Health in the presence of Dr. Maria Francia Laxamana, and Sasakawa Memorial Health Foundation with Executive Director, Prof. Takahiro Nanri and Nippon Foundation. Moreover, Dr. Cunanan exemplified the role of the Nippon Foundation as the first in the world to give free MDT drugs for leprosy patients, before the Novartis took over.

WELCOME ADDRESS



Mr. Francisco Onde

Mr. Francisco Onde, the Chairman of Coalition of Leprosy Advocates of the Philippines welcomed the participants and guests of the assembly during its opening ceremony. He stressed that the past decades have brought about significant changes in public health measures with regards to the control of leprosy. The Introduction of MDT in 1982 and the global commitment to eliminate the disease as a public health issue resulted in the significant decrease in the number of new cases, the adoption of the resolution to end stigma and discrimination against persons affected at the UN General Assembly, and the WHO publication of the guidelines

in "Strengthening Participation of Persons affected by leprosy in leprosy services' were all considered milestones of leprosy services. However, he reiterated that despite of these milestones, "Leprosy still remains a big challenge for humanity; government and persons with or affected by the disease." New cases occur in pocket areas while there is a global trend in the diminishing interest for leprosy. While there are organizations of people affected by leprosy such as CLAP who are engaging in leprosy services in partnership with the government and other stakeholders, sustaining its operations remains a very big challenge.

ASSEMBLY SECRETARIAT

The assembly secretariat involves multiple individuals executing administrative tasks for the assembly. They have closely coordinated with the participants, resource persons and guests for the assembly. Maria Luz Gante (left), Donna Ruzel Gacasan (right) are from Culion Sanitarium and General Hospital while Susan Centeno (center) is from Coalition of Leprosy Advocates of the Philippines.



"Leprosy still remains a big challenge for humanity."

RESOURCE PERSONS



Prof. Takahiro Nanri Ph. D.

Executive Director, Sasakawa Memorial Health Foundation

Professor Nanri is currently works as an Executive Director, Sasakawa Memorial Health Foundation and Associate Professor, Faculty of Tourism and Community Studies, Atomi University, Tokyo, Japan. Other social activities include Board Member, Sasakawa India Leprosy Foundation, Board Member, Japan Society of Social Design Studies. Previously, he worked for Program Advisor and Program Director, The Nippon Foundation (Tokyo, Japan), Director, Sasakawa Peace Foundation USA Inc. (Washington D.C. U.S.A.), Deputy Director, Sasakawa Peace Foundation (Tokyo, Japan), Director, Sasakawa Central Europe Fund (Tokyo, Japan), Convener/Executive Director, NGO Forum on Asian Development Bank Inc. (Manila, Philippines), etc. He holds a Ph.D. in Community Development.



Alice Cruz

UN Special Rapporteur for Ending Leprosy Stigma and Discrimination

Alice Cruz is External Professor at the Law School of University Andina Simón Bolívar – Ecuador. Her doctoral work in sociology focuses on the biosocial dimensions of leprosy and identifies, in countries where leprosy is an endemic neglected disease and in countries where it is an imported and rare disease, the different barriers to access to early diagnosis and to high quality care by persons affected by leprosy, as well as their social, economic, familiar and personal life conditions. She has worked with the Brazilian non-profit organization Movement for the Reintegration of Persons Affected by Hansen disease (MORHAN), where she was involved in the organization of the First International Symposium on Leprosy and Human Rights (Rio de Janeiro, 2012). Ms. Cruz participated in the elaboration of WHO Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services. She served as a member of the International Leprosy Association's Council (2014-2016). Ms. Cruz has conducted fieldwork in Portugal, Brazil, South Africa, Bolivia (Plurinational State of) and Ecuador, and has researched and written on the subject of eliminating leprosy and the stigma attached to it. She has interacted with various stakeholders including public health professionals, medical doctors, civil society as well as persons affected by leprosy.

Over the last 20 years, 16 million leprosy patients have been treated with Multi Drug Treatment. Since 1995, World Health Organization has provided MDT free of cost to all leprosy patients in the world.

rstmh.org



RESOURCE PERSONS



Dr. Maria Faina Lucero-Diola

**Assistant Professor of Public Administration,
University of the Philippines-Diliman**

In 2015, Dr. Diola served as a regular lecturer/trainer for facilitators at the Philippine National Police (PNP), for their PATROL Program (a transformational program for the PNP). In most of 2016, she also served as part of the facilitating team and designed a training guide for training of trainers for the development of Peace and Order and Public Safety Plans (POPS) for local government focal points of the Peace and Order Councils (POCs), as contracted by the EP JUST II Project of the Bureau of Local Government Support (BLGS) POPS Team of the DILG where she facilitated the training for POPS formulation all over the country. In 2018, she headed the NCPAG team that trained volunteers of the local Philippine Council of Agriculture and Fisheries in a series of monthly trainings. She continues to share her expertise in development communication as she occasionally gives lectures on technical writing at the Asian Institute of Journalism and Communication (AIJC).

Dr. Diola has also worked and was posted overseas in two countries -- as visiting researcher at the Taiwan Fisheries Research Institute (TFRI), a government organization in Keelung, Taiwan from 1988 to 1990, and from 1994 to 1999 as writer-editor and Specialist in International Relations at the Japan NGO Center for International Cooperation (JANIC), a major networking non-government organization in Tokyo, Japan. In Japan she volunteered for Filipino NGOs and other Japanese NGOs especially those working on development and environmental issues for the latter.

Dr. Diola has given several special lectures and training related to rural development, development communication, peace and development, voluntary sector management, and environmental issues among civil society organizations and nongovernment organizations (NGOs) for both local and foreign audience, including Japanese professors, students, professionals and development workers. She continues her links with and advocates for food security and land rights with the Asian NGO Coalition for Agrarian Reform and Rural Development (ANGOC), where she had served as Deputy Executive Director in 2008-2009, engaging the ASEAN, ADB, and agricultural research and development organizations and as on-call consultant with the Asian Institute of Journalism and Communication. She served as Board Member of the UP Public Administration Foundation (UPPAF) in August 2015 to March 2016. In addition, Dr. Diola is a member of the Board of Trustees of the Interfaith Center for a Culture of Non-Violence (ICCN); Board Member of the Philippine Watershed Management Coalition (PWMC), where she volunteers in major activities, and has recently been inducted as member of the Management Association of the Philippines (MAP).



Rev. Dan Pantoja

**President and CEO, Peacebuilders
Community, Inc.**

My current spiritual journey has led me to commit my energies to help in the transformational development of the conflicted communities in Southeast Asia based on a Peace Theology. Submitting to God's sovereignty and motivated by the love of Jesus Christ, I envision to contribute to the salaam-shalom between various people groups representing different cultures and ideologies in this beautiful region. This renewed sense of the Holy Spirit's leading energizes me to live, learn, and share with the local communities. I am confident that, through a partnership with the local, national, and global People of God, especially the international peacemaking Christian community, God will heal our conflicted region.

He handled different positions which required people-oriented skills, teaching & communication skills, relationship building, leadership performance, leadership development, measured productivity, and flexible attitude towards unforeseen situations. These positions include working in the fields of collegiate level teaching, community development team-building, senior pastoral staff leadership, investment funds management, global mission leadership and cross-cultural peacebuilding team leadership.

ACADEMIC BACKGROUND

Bachelor of Arts in Theology, Febias College, Valenzuela City, Philippines, 1979

Master of Arts in Asian Studies, University of the Philippines, Diliman, QC, Philippines, 1982

Master of Theology, Vancouver School of Theology, University of British Columbia, Canada, 2002

CURRENT AFFILIATIONS

Consultant on Global Peace Issues, World Evangelical Alliance, New York, NY, USA

President & CEO, PeaceBuilders Community, Inc., Davao City, Philippines

Christian Spiritual Adviser, All-Out Peace Network, Philippines

RESOURCE PERSONS



Dr. Marie Lisa M. Dacanay

President of the Institute for Social Entrepreneurship in Asia (ISEA)

Marie Lisa M. Dacanay, PhD is the founding President of the Institute for Social Entrepreneurship in Asia (ISEA), and a pioneer in social entrepreneurship education and research in the Asian region. She has over 20 years of experience in development management and consulting, as well as in social entrepreneurship and enterprise development in the Philippines and other countries in Asia.

From 2001 to 2008, Dr. Dacanay was Associate Professor and Faculty Champion for Social Entrepreneurship at the Asian Institute of Management (AIM) in the Philippines. At AIM, she served as Program Director for the Master in Entrepreneurship for Social and Development Entrepreneurs. Since 2009, she has been an Adjunct Professor at the Ateneo de Manila University School of Government, where she is lead faculty in the design and delivery of social entrepreneurship masteral and executive courses.

Dr. Dacanay has authored several books and led the publication of various research on social entrepreneurship in Asia. These include the ISEA-Oxfam Report on Poverty Reduction and Women Economic Leadership: Roles, Potentials and Challenges of Social Enterprises in Developing Countries in Asia (2015); Social Enterprises and the Poor: Transforming Wealth (2013) and Measuring Social Enterprise: A Resource Book on Social Enterprise Performance Management (2009). In the Philippines, she also led the research that inspired the crafting of a stakeholders' version of a Poverty Reduction through Social Entrepreneurship (PRESENT) Bill which is now being deliberated by the two houses of Congress.

Dr. Dacanay leads an ISEA-Oxfam initiative supported by the Swedish government that is developing gendered benchmarks for transformational partnerships with small scale producers in agricultural value chains in the ASEAN. She also leads ISEA's partnership with the UN Conference on Trade and Development (UNCTAD) to promote the Business Schools for Impact Asia Initiative.



Dr. Ma. Francia Laxamana

**Assistant Secretary of Health
FICT- Luzon**

Assistant Secretary Maria Francia Laxamana received her medical degree from the University of Sto. Tomas in 1983 and finished her residency training in the Anaesthesia Department of the Philippine General Hospital in 1992. She finished her Master's Degree in Health Services Administration with Major in Hospital Administration from Ateneo De Manila University Graduate School of Business in July 2000, as well as her Master's Degree in Community Health Services from the same institution in July 2001. After which, she was granted an InWENT Scholarship which led her to complete her Certificate in District Health Services and Management in 2004 from the Ateneo De Manila University Graduate School of Business and Certificate in International Course On Global Health Care Financing and Social Health Insurance from Siem Reap, Cambodia in 2009. She is currently pursuing her Doctoral Degree (PhD) in Educational Leadership and Management from St. Joseph College. As Assistant Secretary of Health, her advocacy lies in developing and strengthening policies and strategies to improve availability, accessibility and affordability of quality health care services to the marginalized sector, specifically the PWDs and indigenous people. Her expertise lies in various fields of health, namely: health systems strengthening - public health administration - hospital and health services management - health policy development - programs & project management, implementation, monitoring & evaluation.

In the past years of her work experience in the health development sector, she was able to take part in the health program implementation and evaluation in the different levels of the health system; first-hand experience from the grassroots level (Rural Health Unit in the Local Government Unit), national government (Department of Health), with international development agencies (USAID, EU, Save the Children) to the international health institutions (WHO). With such an extensive work experience in public health and development work, Dr. Laxamana aims to work for the improvement of the quality of health services in the country to ensure better health outcomes for the citizenry.

RESOURCE PERSONS



Joseph "Boyet" Ongkiko

Director, Center for Transformational Development, Asian School of Development and Cross-cultural Studies

He is a practitioner of Development Management and Development Communication passionately serving various groups – LGUs, Government Agencies, Non Government Organizations, Private Corporations – that are mostly working for the marginalized sectors of our society. One who advocates and interweaves effectively the use of Transformational Leadership, Strategic Management and Dialogue Education approaches towards developing efficient, responsive and dynamic organizations and programs for societal engagement – for the glory of God.

Recent Experience

Director :
Center for Transformational Development (CTD)
Asian School of Development and Cross-cultural Studies (ASDECS)
June 2011 to present

Senior Consultant:
Peace Builders Community Inc.,
January 2014 to present

Organizational Adviser and Consultant:

Coalition of Leprosy Advocates of the Philippines
November 2017 to present

God is Able International Foundation,
April 2013 to present

Certified Teacher:
Global Learning Partners,
June 2005 to present

Education

Masters in Development Management
University of the Philippines Los Banos (UPLB), and Asian School of Development and Cross cultural Studies (ASDECS)
2015

Bachelor of Science in Development Communication
University of the Philippines Los Banos
1985

Expertise

Program Development
Organizational Development
Leadership Development
Strategic Communication
Team building
Personal Wholistic Development
Dialogue Education

Skills

Learning and Workshop Design
Teaching by Dialogue Facilitation
Adult Learning
Script writing
Song writing



Dr. Arturo Cunanan, Jr

Medical Chief I, Culion Sanitarium and General Hospital

Currently, Dr. Cunanan is the Medical Center Chief of Culion Sanitarium and General Hospital, head of the Culion Leprosy Control and Rehabilitation Program that is responsible for the elimination of leprosy as a public health problem in Culion in 1998. He is the first director of Culion Sanitarium and General Hospital who is a direct descendant of people affected by leprosy who was isolated and segregated in Culion.

He earned his Bachelor's Degree in Medical Technology – Cum Laude and Doctor of Medicine at the University of Santo Tomas, Masters in Public Health and Hospital Administration at the University of the Philippines – Manila College of Public Health with honors and Doctorate (PhD) in Health System and Policy at the National Institute of Health, University of Leeds, United Kingdom as an International Ford Foundation Scholar.

ACCOMPLISHMENTS

Control of Leprosy as a Public Health Problem in Culion Island

Control of Preventable Diseases like measles, polio, etc. in Culion through Public Health Program – Under Five Clinic – Immunization of all target population in the whole island – Medical Outreach Program - Rural

Strengthening and Organization of Public Health Service in Culion Sanitarium and Culion Rural Health Unit – Training of community / village health workers

Re-organization of Culion Sanitarium into Culion Sanitarium General Hospital – Organizing the Cost Centers and Billing System, OPD and others.

Organized / Established – Culion Museum and Archives

Organized / Strengthened BCCL (Busuanga-Coron-Culion-Linapacan) Inter Local Health Zone – District Health System. Health Financing and Referral System

Implementer of Sasakawa Memorial Health Foundation of Japan projects in Culion and the Philippines related to leprosy and human rights, preservation of leprosy history , empowerment of people affected by leprosy and their associations or groups and various socio-economic projects to improve quality of life of people affected by leprosy and their families

FREE MTD WAS INITIALLY FUNDED BY THE NIPPON FOUNDATION, AND SINCE 2000 IT IS DONATED THROUGH AN AGREEMENT WITH NOVARTIS WHO RECENTLY COMMITTED TO EXTEND THE DONATION TO AT LEAST 2020.



Dr. Maria Francia Laxamana

KEYNOTE MESSAGE 01

Leprosy in the Philippines & Empowerment of People Affected by Leprosy

Dr. Maria Francia Laxamana, the Assistant Secretary of Health, Field Implementation and Coordination Team (FICT)- Luzon, is the first keynote speaker of the assembly.

“Early detection has always been the key in achieving this target, alongside scaling up interventions to prevent leprosy transmission.”

Dr. Laxamana lauded the Culion Sanitarium and General Hospital Museum for successfully being part of Asia-Pacific's Memory of the World by the UNESCO. According to Dr. Laxamana, there is a significant change in the museum from the first time that she has seen it compared to how it looked today--she recalled the memory during the turn-over of the museum, together with Dr. Cunanan. “The transformation from the previous 80s, 90s of Culion up to the 20s, another century it has been a very different one and for all of us to share with different countries,” she remarked, posting the invitation to experience the new Culion Museum.

Leprosy in the Philippines: A Winning Case

In 1899, a report from the US Senate Committee on State of Health in the Philippine Islands singled out leprosy as a significant problem. Culion Leper Colony was built on Commonwealth Act no. 1711 which provided lepers compulsory apprehension, detention and segregation of people with leprosy. Today, leprosy in Culion is practically eradicated bringing hope to the world. But the World Health Organization in 2017 has detected pocket cases in the Philippines which is the highest in the Western Pacific Region. Though reduced to 3.6% of new detection rate yearly, Multibacillary Leprosy reported 1, 197 cases. Grade 2 Disabilities is at 4% with a 2% reduction from the previous year, indicating that self-care, prevention of impairment and disability is being addressed. Children below 15 years old, among the new case detected amount to 4.6% indicating a low proportion.

Leprosy in the Filipino Society

Dr. Laxamana pointed out that ending the stigma of Hansen's disease in the Philippines is still associated to exile, deformity and poverty that has permeated in the society and is “harder to cure than the disease itself.”

In relation to this, Dr. Laxamana emphasized that disabilities does not happen overnight but after a prolonged period of undiagnosed disease. “Early detection has always been the key in achieving this target, alongside scaling up interventions to prevent leprosy transmission.” As the World Health Organization urged countries, there should be an intensified, all-inclusive approach which can prevent thousand of infections every year.

A public-private partnership strategy in the Philippines has achieved goals to lessen the burden of the disease. The Department of Health's National Leprosy Control Program has the mission for a leprosy-free Philippines by 2020. “It is still a dream in progress,” said Laxamana as she mentioned the need for a bottom-up approach in dealing with leprosy cases and other similar disease in the country. Moreover, Laxamana entailed that the 2020 vision might not be achieved due to low-budget given to leprosy eradication from the government. This initiative provides high-quality leprosy services to all affected communities ensuring equity and social justice to decrease the disease in endemic cities and municipalities by 50%.

...a strong, meaningful and significantly substantial partnerships of the private and the public sector would give chance to leprosy patients live a normal life. "The goal of doing all this effort...is reintegration to the family and to the community."

Strategic Initiatives of the Philippines to end Leprosy

Strengthen local government ownership, coordination and partnership. Political commitment and resources for leprosy programs at all levels should be a priority. "There is no higher level legislation to push us for that," as she emphasized the importance of a legislation for leprosy eradication. She cited that a national legislation signed by the president would engage the local chief executives towards prioritizing leprosy. In the country, the municipal health programs are devolved in the local government unit.

The signing of the Universal Health Care Act includes that all Filipinos will be covered by the national healthcare program. Dr. Laxamana advocated pushing through the healthcare package for psoriasis and leprosy with clinical practice guidelines.

Promoting partnerships with state and non-state actors and promote inter-sector collaboration and partnerships at the international, national and sub-national level.

Strengthening surveillance and health information systems for program monitoring and evaluation (including geographical information systems).

Stop Leprosy and its Complications. Strengthening patient education and community awareness on leprosy. Dr. Laxamana cited the DOH's realization of engaging and collaborating with civil society organizations will provide a strong push. Ensuring prompt start and adherence to treatment, including working towards improved treatment regimens.

Improving and management of disabilities. Strengthening surveillance for antimicrobial resistance including laboratory network. Promoting innovative approaches for training, referrals and sustaining expertise in leprosy such e-Health (LEARNS).

Stop Discrimination and Promote Inclusion. Promoting social inclusion through addressing all forms of discrimination and stigma: This urged Dr. Laxamana to advocate the inclusion of a package on leprosy in the Philhealth, for people to be aware and get away from stigma for a benefit package in the Philippine Healthcare Insurance System. The initiatives of CLAP in empowering persons affected by leprosy as it involves communities in action to improve leprosy services, promote coalition-building among persons affected by leprosy.

Promoting access to social and financial support services would also help persons affected by leprosy and their families to generate income for decent living. Dr. Laxamana cited the support given by the TESDA (Technical Education and Skills Development



Dr. Arturo Cunanan Jr. (left), Dr. Maria Francia Laxamana (center) and Prof. Takahiro Nanri (right) discuss together issues on leprosy after the first keynote address.

Authority) to the persons with disabilities on some technical courses that would help them have a job, even in the hospitality industry.

"In the Department, we enjoin everyone, and anyone, to contribute whatever they can in the fight against disease and disability. Those who have been afflicted by this disease are now seen as major players and partners in the fight against leprosy." She also urged the CLAP in the Philippines and other organizations in the Asia-Pacific Region should work together for a global legislation as a future direction.

Things to Ponder

There should be a collaboration between government agencies and private institutions to continue the development of facilities of sanatoria in the Philippines. Socioeconomic cost of leprosy in the country is the displacement from education and employment of affected persons. Dr. Laxamana recommended a strong, meaningful and significantly substantial partnerships of the private and the public sector would give chance to leprosy patients live a normal life. "The goal of doing all this effort...is reintegration to the family and to the community."

Laxamana cited the leprosaria as an invaluable part of the Department of Health's system, going back to its roots as an institute on its own. She recommended to put them back in the government's radar with increased awareness of its significance and impact on the health system and society.

4Cs of Effective and Efficient Program Implementation

To summarize the points raised in the assembly, Dr. Laxamana used 4Cs to explain how programs are geared towards ending leprosy can be efficient and effective.

Commitment. We participate and commit ourselves to be part of the leprosy program in prevention and control of leprosy.

Cooperation. If we commit ourselves to the leprosy initiative we must give our time and effort and resources for this cause.

Coordination. If we provide our effort and time to the organization then we have to coordinate with our colleagues. If we do not coordinate and document our activities it is nothing.

Collaboration (highest level). If we collaborate vertically (legislations) and horizontally (colleagues and organizations) this would mean having network. This is a good opportunity for network and collaboration.



Prof. Takahiro Nanri

Sasakawa Memorial Health Foundation (SMHF) together with the Nippon Foundation are trailblazers in the global initiative to end leprosy as a public health disease. SMHF has especially assisted many organizations of people affected by leprosy in the world for this initiative.

Three Regional Assemblies and SMHF

With Sasakawa Memorial Health Foundation's initiative for a Global Assembly of Organizations of People Affected by Leprosy, it has currently participated with three regional assemblies in Africa, Asia-Pacific and Latin America. In relation to this, SMHF is planning to organize a committee meeting in June to share the results of the three assemblies in three regions. The development in the committee meeting will help SMHF identify key objectives for the World Assembly on September 7-9, 2019 (tentatively) to be held in Manila. The World Assembly is a pre-event of the International Leprosy Congress on September 10, 2019. On another note, the International Leprosy Congress allotted time for presentation during the opening ceremonies to present the results of the World Assembly.

The Asia-Pacific Assembly is a fast-track of the world assembly.

On Assembly Objectives

Prof. Nanri, emphasized that there should be a discussion of the agenda of each participating countries, that it can also be a way to discuss agenda for the world assembly. He strongly reminded the participants that the foundation respects the initiatives of the participating countries. "We are just providing the venue but you will be the one to discuss, you will be the one who will utilize the venue."

KEYNOTE MESSAGE 02

The Work of the Nippon Foundation and SMHF in the Public Health/Social Aspect of Leprosy Globally

Prof. Takahiro Nanri, the Executive Director of Sasakawa Memorial Health Foundation, is the second keynote speaker of the assembly.

"We are just providing the venue but you will be the one to discuss, you will be the one who will utilize the venue."

Summary of the Africa Assembly

In the African Region, there are only a few active people's organization of people affected by leprosy. The participants are from Ethiopia, Tanzania, Nigeria and Morocco.

Here are the points discussed in the African Assembly:

1. Agreement to formalize the Alliance of African Region.
2. Plans of the alliance will be prepared by the end of April. They will be able to share something in organizing.
3. Initiative for a joint collaboration in the World Leprosy Day to prepare for the activities of the events like campaigns or weekend lunch.
4. The discomfort of being called-persons affected by leprosy.

Difference of SMHF and Nippon Foundation

Nippon Foundation is the mother organization of Sasakawa Memorial Health Foundation and is one of the biggest private organizations in the whole of Japan. The Nippon Foundation has strategies in establishing family foundations. There are foundations on music, sports and Sasakawa Memorial Health Foundation is established solely for addressing leprosy. SMHF is one of the family foundations of Nippon Foundation to specifically work on leprosy programs alongside with Nippon Foundation.

Brief History of the Work

The Nippon Foundation (1962) and Sasakawa Memorial Health Foundation (1974) initiated the work to eradicate leprosy in the world.

Initiating the work together with people's organizations in different countries has two main goals: for empowerment and for strengthening leprosy service.

In 1975, Nippon Foundation and SMHF has been supporting the World Health Organization initiative to end leprosy for over 45 years now. There is still a continued effort for that as almost 80% of WHO fund is from the foundations. The Nippon Foundation has pioneered the release of the free MDTs in 1995-1999 to fight leprosy and is being continued today by Novartis.

One of the highlights of Dr. Nanri's keynote speech is the transition of SMHF and the Nippon Foundation from focusing on physical and medical aspects of the disease during the 90s to focusing latter on its social aspect which include the call to end stigma and discrimination of leprosy.

Part of this initiative is the National Hansen's Disease Museum which has opened in Tokyo last 2016. During this time, SMHF has worked closely to fight for the human rights of the people affected by leprosy which also include the preservation of leprosy history and the further enhancement of the partnership with all people's organization.

Yohei Sasakawa, the founding president of the SMHF has this vision of a leprosy-free world. He always believed in that commitment to the work is essential in every transaction. His work is extensively seen as he has already traveled to 120 countries in the world to advance his cause on leprosy. His latest engagement is with the Prime Minister of Bangladesh. He has been actively campaigning for the end of leprosy as his advocacy. The Bangladesh Prime Minister agreed to conduct a national leprosy conference this 2019.

Strategic Directions

One strategic direction of the foundations is the advocacy to the United Nations Human Rights Council to take leprosy as a human rights issue. This development has been lobbied eight times in the UN Human Rights Council; before ratified in UN General Assembly in 2010. Dr. Nanri also pointed the Bangkok Declaration Special Scheme (2013) during the International Leprosy Summit. Enjoined by 17 different health ministers from 17 endemic countries, they have agreed to fight leprosy. There are already approved projects in 10 countries in relation to this cause. Furthermore, SMHF also partnered with Vatican to conduct an international conference related to Hansen's. In 2016, they also organized the International Symposium on Leprosy History.

Fighting leprosy has become a world movement and to establish a greater connection with all stakeholders, the Nippon Foundation launched the annual Global Appeal: End Stigma and Discrimination against People Affected



Dr. Arturo Cunanan Jr., (left) and Francisco Onde (right), president of CLAP acknowledges Prof. Takahiro Nanri (center) as the second Keynote Speaker through a certificate.

by Leprosy. This appeal aims to raise public awareness through the media, while also drawing the support from world leaders, representatives of people affected by leprosy, and organizations concerned with human rights. They have to tap influential international network to expand stakeholders in the leprosy community. They have partnered with India International Chamber of Commerce with the latest Global Appeal.

Preservation of history is also important. Dr. Nanri has stressed that the memory of the people affected by leprosy should remain for the future generation to see. SMHF has also been closely working with Culion Museum which is now acknowledged by the UNESCO. This has steered SMHF to launch in 2016 the National Hansen's Disease Museum in Tokyo to document the history of the disease. .

Partnering with People's Organizations

Initiating the work together with people's organizations in different countries has two main goals: for empowerment and for strengthening leprosy service. Here are few examples of people's organizations who are actively working to end leprosy: APAL of India is active in advocacy especially with their state leaders; Morhan of Brazil are providing guidance to persons affected by leprosy through the TeleHansens, with the use of internet, telephone, SMS; ENAPAL has a good income generating strategies. They have successfully asked their government to give them land to construct their office building, which they also can use for income generating purposes for conferences.

Why is it important for the foundation to work with people's organization? This is for empowerment. Empowering people's organizations would contribute to the dignity and ensure self reliance and economic independence. Dr. Nanri emphasized that integration to the society is very important. He urged the participants to boost their participation to leprosy services. The government needs to craft good policies. Peoples organizations provide resources for the government to come up with policies and mechanisms. Hence, proper implementation of policies also requires response from people's organization. Furthermore, participation in leprosy services is important to decrease cases of leprosy and overcome stigma and discrimination for a leprosy-free world.

"On the journey of one hundred miles, after 99 miles we are only halfway." said Dr. Nanri quoting his "big boss". This means that working on the last mile is working with many stakeholders and people's organization because they are the most important partner for the foundation.



Alice Cruz

PLENARY MESSAGE

Human Rights in Leprosy

Its current status and role of United Nations Organization of People Affected by Leprosy in Elimination of Stigma and Discrimination against People Affected by Leprosy

Dr. Alice Cruz, UN Special Rapporteur for Ending Leprosy Stigma and Discrimination

The organizing committee of the assembly learned a few days before the assembly starts, that Alice Cruz was denied of a visa. In order to still include Alice Cruz as a resource person, the committee decided to use the Skype Video Call for her session. Mr. Joseph Ongkiko, the Workshop Master has

designed a complementing workshop to aid Alice Cruz' physical absence, closely working with her through email and in consideration of the goals of her message. There are a few technical difficulties especially on varying internet connection but Ms. Cruz successfully delivered the plenary message through a WhatsApp call.

Workshop Introduction

In every country group, list down your answers to the following:

- Two Human Rights experiences that are most undesirable. (Blue metacard)
- Two Human Rights experiences that are most common. (Yellow metacard)
- Two Human Rights experiences that were most recent (Green Metacard)

The cards with similar idea will be clustered as one theme.

Themes Emerged from the Workshop:

1. Health Service
 - Access to health service
 - Rejected by medical staff
2. Displacement and Segregation
 - Displacement of residency
 - Restriction-have no free access to go outside
 - Segregation
 - Isolation/Segregation
 - Abandon people with leprosy
 - Separation from families/communities
3. Discrimination
 - Discriminatory laws which are still existing
 - Discrimination
 - Education discrimination
 - Discrimination even among PWDs
 - Object of fear
 - Fear of stigma

- Neglect blind patient on food supply
- Teacher avoiding leprosy student in class
- Fired from work

4. Government Intervention
 - Unclear laws (inclusion of PAL in PWD)
 - No equal access to public services.
5. Lack of Opportunity and Disrespect
 - Disrespect
 - Loss of identity
 - Limited opportunity
 - Burglary from disabled patient
 - Leper's patient
 - Swear word to leprosy patient
 - Use of derogatory words
6. Physical Abuse
 - Beaten up disabled patient

Thoughts and feelings:

1. Problems are common.
2. We really have to do something to fight the similar problems in the region.
3. The message has not been absorbed by many people.
4. Children of people affected by leprosy also suffer from discrimination, job employment, marriage.
5. Leprosy is a disease with treatment. There is no such disease in humanity that has this effect on the social aspect of life.

Guarantee of Human Rights

The mandate of the UN Rapporteur is to guarantee a human rights approach to leprosy. This is through strengthening the organizations of persons affected by leprosy to be the spokesperson of their own community and to be able to contribute to decision-making.

“Sasakawa Memorial Health Foundation is really the institution that has supported the most organizations of persons affected by leprosy and in that sense, we should all be grateful to Sasakawa Memorial Health Foundation.” Cruz further expressed that her knowledge on leprosy has developed as a volunteer for MORHAN, in the service of enforcing human rights of persons affected by leprosy and their family members which eventually led her to a position in the United Nations Human Rights system.

On another note, Cruz also stressed that while change happens at a local scale, bridging the local and international scale can help to achieve change. Still, the knowledge provided, good practices and demands of the grassroots level would lead to a change on an international scale.

On Discrimination

Discrimination related to leprosy still persists in laws and policies. According to ILEP's survey on discriminatory laws, there are more than 50 countries who maintain laws that discriminate people affected by leprosy. Even if these laws are not put to practice, they still remain there as a shadow that restrains civil and political rights of people affected by leprosy. There are still cases of extreme vulnerability, marginalization, and abandonment.

The government keeps the laws out of negligence than it deems necessary. “That is why strategic litigation from civil society is key to wake up governments and force them to take action,” added Cruz. Because of the collective effort of the civil society activists in India, as an example, has over one hundred discriminatory laws “fall one by one.” Strong civil society is important to enforce human rights. In addition to this, Bangladesh has abolished the Leper's Act. Governments implement such laws because of ignorance and neglect and governments are becoming more progressive today. Consequently, primary stakeholders should raise awareness even though there is a lack in resources, limited networks, and channels as Cruz added, “Because you don't simply give up.”

However, there is still discrimination on State-services such as education, health, and social security. Discrimination also exists in public health services without feedback mechanisms for authorities to keep aware of such. Mechanisms should be created to receive complaints of discrimination at medical settings accessible to marginalized populations without an educational background.

The MORHAN Experience

MORHAN has a decade-long telephone line for people to ask for information about leprosy,

receive guidance and address complaints on discrimination. TELEHANSEN is officially recognized by the Brazilian government as an outstanding public service. TELEHANSEN is also one of the best examples for popular epidemiology, data collected by civil society to support the work of the State. This is the collection of partial and disaggregated data to create evidence-based policies, especially for human rights enforcement. This is important because many still suffer discrimination in the schools, social security services and even accessing disability rights.

The Ethiopian Experience

Ethiopia has provided self-employment opportunities for women affected by leprosy and this ensured social inclusion. Micro-credit with capacity-building is also a successful practice. “Economic independence is still a major issue to be addressed and good practices at the community level have shown how it boosts a turning point in people's lives,” highlighted Cruz.

While this is happening, it is still true that there is an institutionalized discrimination on public job opportunities. There are cases that prohibit persons affected in the application process. Cruz cited the recent partnership of MORHAN and the Public Defenders Office to monitor discrimination, receiving complaints and taking legal action accordingly.

Cruz strongly recommended all organizations of persons affected to partner with Human Rights Institutions in respective countries. With an emphasis on this initiative, she remarked, “Leprosy is much more than a disease and partnerships outside the health field can help with intervening in the social, economic and political violations on the ground of leprosy, as well as fostering inclusion and dignity.”

Discrimination in the Family

Leprosy is still a ground of divorce, allowed by the law--mandated or not. Women who are incapable of economic independence might opt to beg or end up in prostitution. On the other hand, men as the provider of the family suffer discrimination when the disease will stop them to provide because of treatment, leprosy reaction and physical impairment--by their close relatives. Unfortunately, due to the suffering by prejudice and stereotypes of people affected by leprosy, there are stories of depression and suicide attempts.

The FELEHANSEN Story

FELEHANSEN in Colombia provides door-to-door counseling and support in their communities. The members search for signs and symptoms of leprosy for early diagnosis and eventually preventing physical impairments related to the disease. “People feel stronger when they are together and peer counseling can change a person's life, also giving that person the opportunity to change another person's life.” Certainly, organizations play a role to shift people's mindset to eliminate stigma and discrimination.

In Africa, the traditional leaders are ensuring inclusion of persons affected by leprosy who were segregated. In Brazil, traditional healers are given basic information on the treatment of the disease. Community authorities should be prime actors to raise awareness and social inclusion.

How about Family?

Girls have “severely restricted” marriage opportunities, children are discriminated in schools and many children of persons affected by leprosy have no right to property of the land in which they have lived. Leprosy has become more than a disease but an identity label for exclusion. There is an entire generation of children of persons affected by leprosy traumatized by separation from their parents and isolation from society. They have experienced torture, abuse, violence, sexual violence and still cannot find their place in the society. In connection to this, Cruz claims that forced segregation was a crime against humanity. A document sponsored by Cruz was sent to the International Law Commission that acknowledges leprosy as a ground for crimes against humanity. If achieved, reparation measures will be given as a right to persons affected by leprosy and family members, as a State’s obligation.

United Nations Mandate

In particular, Cruz is currently preparing a report on “Stigmatization as Dehumanization: Wrongful Stereotyping and Structural Violence against Women and Children affected by Leprosy” with a goal to generate alternative pieces of evidence and disaggregated data on the civic, political, social and economic and cultural dimensions of leprosy to support evidence-based human rights policies. There are more than 20 responses from different States, 600 responses from persons affected by leprosy and more than 20 testimonies were already gathered for the report. The data suggest that ongoing discrimination against women and children have an impact on their well-being and mental health.

Focusing on the mainstreaming of leprosy in the human rights systems has increased engagement in the fight to end stigma. The work Cruz on this note is a bridging system to leprosy organizations for them to engage directly with the human rights system. It would create a positive outcome in the lives of the people affected by the disease.

In enforcing the human rights of persons affected by leprosy and their family members, we can base a policy model from the P&G and the international treaties and conventions to effectively assist States to enforce human rights. Cruz mentioned that working together with a policy can help States to implement it on a local scale.

Furthermore, Cruz emphasized that participation of the organizations affected is the key to a long-term elimination of leprosy-related discrimination and for a sustainable inclusion. The government and non-government sectors should help in empowering organizations to end the stigma and discrimination.

The world is already near to a post-elimination era in the leprosy world. Elimination does not mean leprosy will not exist. There should be ways to sustain efforts to achieve multi-sector governance of leprosy, which should involve people affected by leprosy in decision-making for health, education, labor, social security, and justice.

HIGHLIGHTS from the Participants

1. Some shameful laws and unacceptable laws still exist. (Kiribati)
2. MORHAN’s experience with TELEHANSENS can be replicated in the Philippine setting. (Philippines)
3. As an organization of people affected by leprosy, we have to raise our voice to our government to ask them to “listen to us.” (Nepal)
4. There are government initiatives in law creation but not much in implementing. (Indonesia)
5. We are impressed with the work of India and Brazil with support from the national government. Because in China, the government’s focus is only on control and treatment and not much attention in human rights and elimination of discrimination. We should learn from them how they got support from the government. (China)
6. Door-To-Door counseling in Colombia is also done in the Philippines through SPP. (Philippines)
7. How can we measure the burden of stigma and discrimination? (the Philippines through Dr. Cunanan)
 - How can we put it as an agenda in our government?
 - How can we address this in our countries with governments existing policies and guidelines?
 - What are the basic steps for a country/ organization to follow in relation to issues of human rights?
 - How do we measure success in decreasing social stigma?
 - What are the different common plan of actions as a region we can do?
8. What are discussion points that can lead to an agenda for the world assembly?
9. From your point of view, where can your organization start in scaling your advocacy into a national level? (Prof. Nanri)

There should be ways to sustain efforts to achieve multi-sector governance of leprosy including them in decision-making in health, education, labor, social security, and justice.



Yaoquiang Wu and Xiuli Xi (l-r) prepares to present their work during one workshop.



HANDA OF CHINA

History of HANDA, how it was formed and a number of its members

Dr. Yang Lihe, founder of HANDA started his research and work on leprosy in the 1960s when he was around 30. His life had since then connected tightly with the fate of people suffering from this disease. He witnessed the injustice, prejudice, ignorance and harsh life of leprosy patients and people affected by leprosy. Inspired by the establishment of IDEA-- the International Association for Integration, Dignity and Economic Advancement--in Brazil, Dr. Yang came up with the idea of establishing an organization owned by and working with people affected by leprosy in China. After a two-year preparation HANDA--was established in August 1996. "HAN" in the name was in memory of the Norwegian doctor Gerhard Henrik Armauer Hansen who discovered the leprosy bacillus and his spirit in pursuing scientific truth; "DA" was in memory of Father Damien's spirit in serving people. That was how HANDA came into being. Currently, there are about 3,500 members of HANDA in Guangdong, Guangxi and Yunnan provinces.

Main programs/activities

After the establishment of HANDA, Dr. Yang put forward a concept of comprehensive rehabilitation economically, physically, socially and psychologically and empowerment. Physical rehab: self-care training, wound care, eyesight restoration, mobile prosthesis workshop, etc. Economic rehab: skill training, marketing, community development. Social and psychological rehab: awareness raising (the March 11th event), resource mobilization, capacity building, empowerment and participation of people affected by leprosy in social activities (Chinese Chess Tournament, exhibitions, give speech and performances to the public, lodge their request to the government.)

Best practices

1. The composition of institutional governance body: the highest decision-making body is the board of committee, with 2/3 of the members composing of the people affected by leprosy. This fully indicates the autonomy of people affected by leprosy. We also engage professionals to the board so as to expand more potential resources and contribute more ideas for a sustainable development
2. Volunteer resources mobilization: Assure the delivery of quality service; Promote HANDA and expand the influence of HANDA; Bring resources to HANDA
3. Include staff with professional background: enhance the delivered services with professionalism and effectiveness
4. HANDA always applies four key elements in a high-quality social service, namely GMPD—Governance capability of the organization; Management: establish an effective management mechanism of an institution; Project—optimize the service manager to ensure professional and effective service; and Development—strive to its own sustainable development
5. Stick to the principle of needs and people's participation oriented: All project activities designed based on the actual needs of people, people are empowered to participate in each aspect of the project. Timely adjustment to the project is made based on the changing of the needs.



Mr. Wu (standing) is the current president of HANDA, a 20-year-old NGO helping people affected by leprosy in China.

Challenges

Fundraising: Currently, locally-raised funds comprise of 50% of the financial resources. However, those funds are usually project-based; most are on-off in nature and not sustainable.

The second challenge for HANDA is how to survive and grow in China's unique social environment. There are many constraints of NGOs but at the same time no clear rules to follow.

Another challenge for HANDA is addressing the changing of the needs in a timely way. As people affected by leprosy are getting older, their needs have altered from simply physical care to medical and nursing care.

Plans for the coming years

1. Enhancement of staff's fundraising capability as well as building up HANDA's brand image with the application of new media so as to attract more people to support
2. More communication with government: enable government aware of the role/contribution of HANDA, hopefully, to get the support from the government
3. Development of new project to meet the nursing and medical needs of people, and leprosy history preservation project; expand our services to wider areas in China to cover more leprosy villages and serve more people.

New direction

HANDA will still play an important role in improving the quality of life of people affected by leprosy in the next 10 to 20 years. But our positioning must change when the number of people (i.e. PAL) reduces. One direction we may consider is to extend our eye, foot, and other services to the disabled, particularly the disabled elderly. Another direction is to provide consulting, capacity building, mentoring services to other POs or non-profit organizations in China or even other developing countries.

HANDA will still play an important role in improving the quality of life of people affected by leprosy in the next 10 to 20 years. But our positioning must change when the number of people (i.e. PAL) reduces.

QUESTION AND ANSWER

Q: How would capacity building be possible for example if the Philippine would like to avail services from you?

A: You must have funding support for you to be able to come to our country or we could come to you.

Q: You are a diverse organization with different stakeholders. How do you manage the difference in opinion of the stakeholders?

A: When the organization started to accept people not affected by leprosy our board members were against it. We have a lot of explanations until they agreed. There are some arguments but the professionals listen to everybody and resolve differences.

Comment: Noting the external environment where HANDA is working in China, where there is inclusion also of non-leprosy affected people. HANDA has a good issue of sustainability, we have to learn from them how they are continually raising funds.

With the aging population of the members of the organization, we need to learn how to tailor-fit to the needs of the members.

Francisco Onde, president of CLAP (I) shares insights with Mr. Wu and Xiuli in a breakout session.





Filipino participants together with assembly secretariat and Dr. Arturo Cunanan Jr., (fourth from left).



CLAP OF PHILIPPINES

CLAP is established with the Securities and Exchange Commission on March 06, 2014. CLAP's mission as an active partner for development provide quality service that will impact and change lives of the coalition stakeholders; as active partners for national transformation they support communities of people with leprosy and people affected with leprosy to have full in community participation. The vision is empowered to live to a life of freedom. This organization is initiated by Dr. Arturo Cunanan Jr.

The main office of CLAP is in Cebu in a sanitarium called Eversley Childs Sanitarium. The Luzon chapter is composed of 8 organizations ACHI in Culion, Palawan, Stardolls Multi-Purpose Cooperative in Caloocan, PGH Hansen's Club, Grupo Intala, Jose Reyes Hansen's Club and Bukal ng Buhay and another two is in Bicol Sanitarium of PWD and Bicol Sanitarium Association of Hansenite Organizations. In the Visayas, there are five organizations namely, the Negative Barrio, IDEA Philippines Association of Negative Lepers, Holy Family Association for Economic Development. Two are in Cotabato, Sulu, and Zamboanga.

The Jose Reyes Hansen's Club initiates economic empowerment through soap making and a new

venture on farming, goat-raising and poultry management. The patients who are under the medication are in a home provided for them. The Stardoll make dolls from rags and bags. The Bukal ng Buhay is more involved in strengthening people's organization that also do home visits. Holy Family Association is involved in micro-credit, toga rental, and a daycare center already registered in the Department of Education. In Sulu, income generation is through pedicab driving. Bagong Pag-asa Cooperative in Cotabato is into agricultural initiatives.

Strengthening Participation of People Affected by Leprosy in Leprosy Service (SPP) is one flagship program which has been launched last November 29, 2018, in two pilot cities, Manila and Cebu. New cases found through the SPP will be transferred to medical facilities and also including several workshops. CLAP is also helping in preserving the history of leprosy through museums. Activities also include capacity-building for entrepreneurship, livelihood and leadership training.

CLAP has the uncertainty of external funding with limited funds from the government. CLAP has no internal funding. These are the challenges of CLAP. On the other hand, the future direction of CLAP is replicating the TELEHANSENS and partner with government agencies in the country.

Photo collage of CLAP members during the assembly.



There are 5 Roadmaps of CLAP monitored by the coalition which should align with their (i.e. POs) programs.

QUESTION AND ANSWER

Q: Does CLAP help do the marketing? Do you have stable customers of clients?

A: *We tried marketing it to other cities.*

Q: How is the central committee of CLAP formed?

A: *There is an annual general assembly where each year, three officers would end a term to give way for new leaders.*

Q: Is it allowed for local chapters to get a fund outside CLAP?

A: *Yes. Because they have already existed even before CLAP was formed.*

Q: Do they have a legal identity in their local government?

A: *Yes. Most of them are [organized] cooperatives who are registered in the CDA and others are registered in SEC.*

Comment: The good thing about the coalition is having 19 different organizations joined and have one big voice.

Q: Do you need to monitor the work progress of each member?

A: *Each cluster (Luzon, Visayas and Mindanao) has 3-4 board member on the board of directors. In the local setting, the board members also report the situation. During board meetings, the member report on the cluster situations. If problems arise, the nearest board member will attend to it. There are 5 Roadmaps of CLAP monitored by the coalition which should align with their programs. Proposals then are referred for funding in Sasakawa.*

Q: The Philippines has one of the most developed civil societies. Does each member participate in civil society? The members of CLAP also participate in these kinds of the scheme. What kind of existing schemes are they participating in?

A: *CLAP members in other localities are involved in their barangay local government unit. In Cotabato, they are living outside the sanatoria and the government recognized their efforts and has helped them.*

Q: How about their engagement with other NGO?

A: *Some are involved in different NGOs while many are still marginalized. As an example, the Negative Barrio has joined the Urban Poor Group in Cebu. Most of NGOs are also not interested in the leprosy work.*



Dinesh Basnet (left) and Amar Bahadur Timalisina (right) represents IDEA Nepal, one of the three organizations in Nepal who has the advocacy to fight social stigma and discrimination of leprosy.



IDEA NEPAL

Association for IDEA Nepal is a non-governmental and non-profit making organization established in 1998 in Pokhara, Kaski, Nepal. Association for IDEA Nepal is an organization formed by a group of people affected by leprosy for the people affected by leprosy. Association for IDEA Nepal mainly focuses on the advocacy and awareness activities related to leprosy and IDEA Nepal have been continuously working for the people affected leprosy since its establishment date.

Association for IDEA Nepal is currently focused on the formation of self-advocacy groups at local level. IDEA Nepal is implementing a project to form a provincial level assembly of people affected by leprosy to raise voice and to advocate for people affected by leprosy from the local level. IDEA Nepal believes that the advocacy by the people who are sufferers is more effective than the people who are just empathetic to the writhe. Similarly, IDEA Nepal will continue its past activities like Day Celebrations, Advocacy and Awareness, Empowerment and Capacity Building.

IDEA Nepal is distinct from other organization as it consists of board members who are themselves the people affected by leprosy. The board members of IDEA Nepal has faced the issues and challenges that are being faced by the people affected by leprosy in society so the board members have good knowledge and experience to develop interventions that are helpful to the fellow sufferers.

IDEA Nepal is a small NGO which is conducting activities with support from limited organizations. IDEA Nepal is looking to broaden up its horizon and staff members to reach out to every individual affected by leprosy in Nepal. IDEA Nepal is developing proposals and looking for donors to help IDEA Nepal reach its destination.

The World Health Organization targets to eradicate leprosy by 2020; still around 3,152 new leprosy patients are diagnosed in Nepal every year. No NGOs working in Nepal has the data and status of people affected by leprosy. Hence, IDEA Nepal plans to develop itself as a data hub of leprosy in Nepal. IDEA Nepal is developing proposals and looking for helping hands/donors to help the IDEA Nepal in building itself as a data hub of leprosy in Nepal.

QUESTION AND ANSWER

Q: What is an example of discriminatory law?

A: *The Divorce. If one has leprosy then it can be a ground for divorce.*

Q: Are there any other leprosy organization in Nepal?

A: *There are three in Nepal.*

Q: Do you work together?

A: *We work differently but in major issues, we collaborate.*



Thobias Alexander Manas (far right) is the chairman of the movement of leprosy advocates in Indonesia together with Yuliati, a second generation leader and Kalep Manikari (standing, far left) their translator.



PERMATA INDONESIA

In 2006, leprosy control programs in several provinces in Indonesia have achieved elimination in accordance with WHO standards. Although the number of new sufferers is decreasing, leprosy still leaves various problems in the community, especially social problems. There are still many sufferers living with stigma and discrimination from the surrounding community which results in many of them not continuing school, having to live in leprosy shelters, living with disabilities and having to work as beggars. This condition ultimately shackles lepers living below the poverty line and loses their self-esteem and rights as human beings.

Permata Vision Indonesia: Free of stigma and discrimination towards a decent quality of life.

PerMaTa Mission: Advocating the care for fellow lepers, realizing equal rights and obligations for people affected by leprosy in the economic, social, political, spiritual, educational and health services sectors and improving the quality of human resources with education and training for people who moderate and ever having leprosy and his family.

PerMaTa Indonesia has several programs

A. National Program

1. Capacity Building Organizational and Membership
2. Rights Advocacy
3. Networking
4. Economic Social
5. Expansion of new areas
6. Monitoring

B. Program Unggulan/Rutin

1. Capacity Building for the administrators and their members. A program aimed at improving the quality of PerMaTa Indonesia's organizations throughout the region.
2. Anti-Discrimination Advocacy and Campaign. A program that aims to reduce stigma and discrimination against leprosy and raise awareness to the community to provide information about leprosy correctly.
3. Community Empowerment. A program aimed at improving the quality of life of Indonesian PerMaTa members through several economic activities.

4. Empowerment of young people affected by leprosy
5. Case discovery
6. Leprosy Inklusif Forum

C. The obstacles experienced by PerMaTa are:

1. Lack of interest of people affected by leprosy to organize.
2. Lack of activity support facilities.
3. The distance that is far from 1 branch to another branch
4. People who have and have had leprosy close themselves.
5. Communication between management from national to branch, and vice versa.
6. The issue of leprosy is not a government priority.

D. Our expectation going forward are

1. The desire to involve more young people who are and have had leprosy to become agents of change in the elimination of stigma and discrimination against people affected by leprosy.
2. The central government until the regions have continuous attention
3. Health services that are friendly to leprosy
4. Early case finding
5. The inclusion of young people for the sustainability of the organization.

QUESTION AND ANSWER

Q: How many young people are affected by leprosy in Indonesia?

A: We don't exactly know the number and it is only in one province that we have data. There are around 20 cases of youth with leprosy.

Q: Do young people hide their sickness in Indonesia?

A: They don't want to be recognized that is why PerMaTa is working with them in the communities to remove fear and have them take their medicine.

Comment: People with leprosy will not experience stigma if you are economically viable. Economic empowerment is recognized by PerMaTa as a way to end stigma.



Ms Kurarenga Kaitire and Mr Itinnang Uan aims to organize a people's organization in Kiribati.



KIRIBATI

Kiribati has still to organize a people's organization, hoping to be enabled through the Regional Assembly. The islands of Kiribati have been assisted with a continuous supply of medicine.

There is no steady income flow for leprosy patients in the progress of the disease. There were two kinds of patients in the country: one has grown with poverty and the neglected. While efforts for economic sustainability have been pushed through, they were not fruitful because of the lack of education.

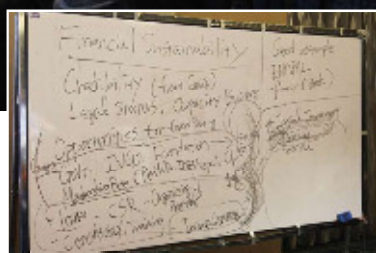
Kiribati is trying to create a business cooperative for all to be freely audited

by the government but run by the board members. Kurarenga is the leader of entrepreneurship--she might have struggled but people acknowledged her because of the businesses she gave to the public. They envision to change many things in Kiribati.

QUESTION AND ANSWER

Q: Why is refrigerating corpse an income generating project in Kiribati?

A: It is a cultural way to respect the dead until the family members come from different part of the country. Burying dead in their houses is cultural with a very small land area where it is a luxury to bury the dead.



WORKSHOP 01 RESULTS

The participants are tasked to discuss among other, the key areas of the assembly: sustainability, preservation of leprosy history, public health program and human rights. They are tasked to discuss the best practices of each in their respective country. Furthermore, they are also given the liberty to join whatever tables where metacards of the specific key areas are placed. The following were the discussion points raised in each table group:

SUSTAINABILITY

1. Aside from grant and membership fee, what kind of opportunities do you think you have?
2. What are your sustainability strategies? This is a reality and the organizations should think of ways to be sustainable.
3. If you need seed money, you need to have a good strategy to present to donor organizations.
4. What kind of strategies do organizations have to avail institution support?
5. Plan income generation to persuade us to give support.
6. If we talk about sustainability and Sasakawa provide support, what can be indicators that might prove you are successful?
7. What are concrete ways to say that your organization is sustainable?

PRESERVATION OF LEPROSY HISTORY

1. Website
2. Mobile Museum Unit
3. Oral History
4. Videos
5. Pictures

PUBLIC HEALTH PROGRAM

1. Role modeling
2. Increase People's self-confidence
3. Bring the public to get into the village
4. Public health is important to control leprosy disease.
5. SPP (Strengthening Participation of People's Affected by Leprosy)
6. Home Visit (door to door)
7. Early detection

PLENARY MESSAGE

ROLE OF RELIGIOUS ORGANIZATION AND GOVERNMENT IN EMPOWERMENT AND ENDING SOCIAL STIGMA AND DISCRIMINATION

Presented by Rev. L. Daniel Pantoja, B.A., M.A., Th.M.

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(peacebuilderscommunity.org)*

*Chairman of the Board of Directors, Coffee for Peace,
Inc. (coffeeorpeace.com)*

“The process of becoming stronger and more confident, especially in controlling one's life and claiming one's rights.”

RATIONALE

Rev. Luis Daniel Pantoja started his discussion on the role of the religious organization with stories. He even stated that he is a storyteller. The journey towards peace building in a war-stricken area is not easy as it may seem. Rev. Pantoja has recalled his experiences with the Bangsamoro, with the New People's Army and their relationship with the indigenous tribes, where he and his wife became honorary members of the tribe as he submitted to the chieftain who eventually became his mentor.

This is a major step in their vision towards peace-building in the indigenous people's community and even with the minority groups in Mindanao. They had the vision to use coffee for peace-building hence, Coffee for Peace. They started to empower people through coffee—from seed to cup. They have established Coffee for Peace as a brand with a strong message to share in every coffee bean. They have involved the different communities they are working with educating them the proper way of coffee planting, harvesting, processing and even roasting. Today, they have received several international awards for their brand and recently, the United Nations Development Program has acknowledged the value of the quality of the brand together with its mission.

Indeed, they have helped empower the different people's communities they are working with towards significance and economic success. The following is the key message points prepared by the resource person himself.

MAIN IDEA

People have inherent power. I wonder if we really do empower people. I find my ministry as a religious worker to be more effective when I simply walk with them on their journey towards a growing discovery of their internal and inherent power. That they need to be empowered may presume they do not have power and in itself may be a form — wittingly or unwittingly — of social stigmatization and discrimination.

EMPOWERMENT

Some use this term to mean “authority or power given to someone to do something”.

I like this definition better: “The process of becoming stronger and more confident, especially in controlling one's life and claiming one's rights.”

In business management, this term can be understood as “a practice of sharing information, rewards, and power with employees so that they can take initiative and make decisions to solve problems and improve service and performance.”

Marginalized sectors of society, such as the Person Affected by Leprosy (PALs), have to initially find in their inner being the power they have. Real power is first and foremost a journey towards a growing discovery of the person's internal and inherent power.



Rev. Luis Daniel Pantoja



Rev. Luis Daniel Pantoja affirms the initiatives of the organizations during the workshop after his plenary session.

Like many marginalized sectors of society, a PAL needs a framework that would help see herself/himself as a whole person —

We are a faith-based inclusive development organization. Our counseling process or training program to help empower the marginalized sectors of society starts with an exploration of one's 'being,' that determines one's 'doing,' that determines one's 'having.'

Being.

This is about "Who I am."

This is about character development.

This is about determining the bases of my identity: Who am I? Where did I come from? Where am I going?

Doing.

This is about what I can do — my spiritual gifts, my natural talents, my acquired skills.

This is about my career, my accomplishments, my occupation.

Having.

This is about the products of what I do.

This is the sum total of all the resources that have been entrusted to me as a steward-manager of my time, talents, and treasures.

This is about building regenerative resources to sustain what I want to accomplish further.

FOUR HARMONIES: A HOLISTIC-INCLUSIVE FRAMEWORK FOR SELF-EMPOWERMENT

Like many marginalized sectors of society, a PAL needs a framework that would help see herself/himself as a whole person — that is, as an inherently good spiritual-ethical being, as a healthy psycho-social individual, as a significant socio-political participant, and as a responsible economic-ecological steward. This framework is best described as "Four Harmonies":

Harmony with the Cosmos. This is a people's or a person's view of Final Reality that provides a sense of spiritual connectedness and bases for ethical practices.

Harmony with One's Being. This is a people's or a person's view of psychological and social transformation. A growing person is one who is in the process of realization that 'being' is always 'becoming.'

Harmony with Others. This is a people's or a person's view of social relationships that determine a community's or country's political condition and transformation.

Harmony with Creation. This is a people's or a person's view of economic development and ecological stewardship based on what they envision of what is 'good' for the future of their perceived world and their view of humanity.

ENCOURAGING STORIES

At this part of the session, the resource person asked Ariel and Jenny from CLAP, to share their life story to the participants.

The Story of Ariel

Ariel felt that his loved ones started distancing themselves from him when they learned that he has leprosy. They have a very hard life that even buying medicine for him would signify that no food will be served on their table. Due to this experience, he started believing in himself and promised that one day, he would also be able to help leprosy patients one day. When he started to recover from leprosy, Ariel began his own business with 1,800 pesos as capital. He sold short pants and magic pillows to tricycle drivers and eventually, with enough savings bought one tricycle--until it became 7. The business grew and he bought 12 jeepneys. The profit from the business was used to buy land where he built a home for people affected by leprosy. This is a home for people taking medication near the treatment. They also have sustainable initiatives inside the home where they raise poultry and plant for food.

The Story of Jenny

When Jenny started to notice red spots in her skin, she knew there is something wrong. Growing up with suspected leprosy, her mother would bring her to traditional doctors, who only tried to take advantage of her. His father also had the same disease as and his brother also died when he was 11 years old due to the complications of leprosy. Her mother vehemently denied that her family is affected by leprosy.

She had to bring herself to the health center for proper medication. She and her best friend were the only ones who knew her disease. They kept it a secret because they do not want their classmates to know since she is in a private

It is true that I started with idealism. You call it idealism I call it a framework. A framework is something that is transcending the actual crisis but at the same time, with both feet on the ground.

school. With the initiative to top the class, she joined extracurricular activities to boost her academic rank. She joined the Citizen's Army Training at that time. Because it is summer training, all of the red spots erupted all over her body that it made her quit.

Meanwhile, her parents' relationship was also challenged. This was due to the fact that the disease made her father weak. Her mother left them and ran away with another man--and only the two of them were left at home. They decided to sell the house and some other properties. This made her think of taking her own life.

With a new start in mind, they went to Cebu and started their life anew. They have experienced the harsh reality of life from having no food to eat, and nothing to sustain their medication. This made them decide to admit themselves to a treatment facility. At this time, Jenny had a boyfriend back home who came to Cebu to see her. At that moment, the man took care of her and even proposed to her.

Eventually, she gained a scholarship and finished college with the help of a priest. She graduated Bachelor of Science in Accountancy and is now working with the Department of Social Welfare and Development based in Cebu as a Provincial Coordinator who handles 63 staff members.

GUIDING PRINCIPLES ON WORKING WITH THE GOVERNMENT

Basic Safety and Security. This is our most fundamental concern. Protection of Human Rights. Preserve dignity. Food. Water. Hygiene Facilities. Medical Needs. Adequate Shelter.

Integrated Psychosocial Support Systems.

We encourage our fellow religious organization leaders to link with the local government units. In the context of the Philippines, for example, it's best to facilitate the integrated services of the Department of Health, Department of Social Work and Development, Department of Education, Philippine National Police, along with the academe. We encourage our teams to be part of the Mental Health and Psychosocial Cluster led by the Department of Health.

Community-Based Resourcing. The affected people are the best resource. Our assumption is that the community, not the government or non-government organization, knows best on the psychosocial needs assessment and activities. We



Rev. Luis Daniel Pantoja (left) discusses with Kiyomi Takahashi (right) of Nippon Foundation.

emphasize being very sensitive to the culture of the community we're serving.

Long-Term Development Orientation. We look at our immediate intervention within the framework of the community's long term vision of inclusive development. We look at being inclusive based on three pillars: (a) high, sustainable development to create and expand spiritual, psycho-social, political, and economic growth of both individuals and communities; (b) broader access to opportunities to ensure that members of society can participate and benefit from holistic development; and, (c) social safety nets to prevent extreme deprivation.

CHALLENGES

For Religious Groups. We have to design new self-empowering counseling processes and training programs for stigmatized and discriminated sectors of society that are holistic, inclusive, and contextually-relevant. We have to multiply 'inherent power discovery' facilitators among religious leaders.

For Government Agencies. To listen to, and dialogue with, religious and other civil society leaders involved in PAL intervention to establish inter-operability structures toward —

- basic safety and security;
- integrated psychosocial support system;
- community-based resourcing; and,
- long-term development-oriented strategies and projects.

QUESTION AND ANSWER

Q: I would like to congratulate Coffee for Peace. It is an eye-opener for us. There are some issues on my mind. One is the issue of idealism. How person affected by leprosy on the other side, where there is an institutionalized stigma from the church, develop his goodness in him when in the first place when people think leprosy is caused by something bad, or a punishment?

A: *It is true that I started with idealism. You call it idealism I call it a framework. A framework is something that is transcending the actual crisis but at the same time, with both feet on the ground. That is why I am proposing an integrated thing. Religious, the idealistic, the person experiencing, the government, the health sector, the police sector*



Rev. Pantoja discusses with Filipino participants during the workshop on Religious and Government Partnership.

In solidarity economy, it says “I believe in you, I will help your people. I want peace so I will buy your product. Ask them how much the Mennonites are buying their coffee, because it is their price for human rights.”

should work together. If we don't have this hope in any crisis intervention, the meaning of reality can be depressing. We need that. The religious can't do it alone.

Q: You are a very brave man with a great heart and passion. We saw in the presentation that you go to areas that are dangerous. Our question is about coffee. How do you explore your market channels? How do you solve transportation?

A: *We came from a religious church background. Somehow, when they start their religious activities they drink coffee. We tell them “Please don't buy coffee from the supermarket, buy coffee from us so we will not ask too much religious donation and we do the rest.*

There is also this phenomenon about the solidarity economy that when I saw you helping the indigenous people with your product, I will buy your product at a fair-trade price. Because if we compete with the neo-colonial economy, the law of demand and supply is greed dictated. In solidarity economy, it says “I believe in you, I will help your people. I want peace so I will buy your product. Ask them how much the Mennonites are buying their coffee because it is their price for human rights.

The United Nations Development Program gave us this seal of impact on investment exchange. Meaning those who buy our coffee does not buy it, not for the product alone, although we compete in terms of coffee quality. We compete with the quality and we say “You like our coffee? Do you like what we are doing with the farmers? Then compare Nestle with us.

Comment: IDEA Korea is doing poultry farming with an agreement to the government of Korea

where products are sold to the army and police. The IDEA is so rich that whenever we need money in times of flood, they will help us. I appreciate your ideas.

QUESTION AND ANSWER

Q: The ones producing coffee have no stigma but are deprived of security. Would Canada, your market, buy coffee produced by people affected by leprosy? This is because we have experience in Culion when somebody produces food or raises crops and says this is from Culion, nobody will buy it because Culion is synonymous with leprosy. If they produce food and put it in the market and say products by HANDA, product by CLAP will the market with less information buy these products?

A: *When we started selling Bangsamoro coffee, they said they won't buy terrorist coffee. That is stigmatization too. It may not be a healthy and different comparison but still, it is hard on the market. When we were selling from NPA area, they did not receive it in the USA because NPA is branded as terrorists. I know these are different comparisons but the same market difficulty. A direct answer to your question is I would say “Let's try it!” Let us try the Christianity of people who go to church and say they love people. Let's see how they follow Jesus Christ or Issah. That is my answer to you.*

The importance of the roles of religious organizations as mediators to fight stigma and discrimination. For affected people, they can't fight alone. I want to ask this question to all of the organizations. Do you have someone, who can play as a mediator to fight stigma and discrimination? (This question is posted to all organizations present as the session ended.)

WORKSHOP 02 RESULTS

A chart is provided for each country, with a table divided into two categories: being and doing.

The participants are tasked to do the following: In your country and your culture, the role of the religious institution is to bring about being. Make a drawing a representation so we can advocate the awakening of people to move.

In the doing, what must we do if you have problems with the government providing basic safety and security, protection of human rights, preserve dignity, food water, hygiene, facilities, and medical needs?

KIRIBATI

- Kiribati always has a flood forecast announcing on the radio because of the rising sea levels.
- Disaster preparedness on floods should be raised. The government does not assist cripple residents.
- The first vision is to not get drowned on rising sea levels.
- The illustration shows that the cripple will not get drowned in the water.
- There is an initiative to create a house that will house cripple people.

NEPAL

- Nepal has the initiative to invite religious leaders to raise awareness on leprosy stigma among the religious.
- Education and economic empowerment are necessary to show the government a profound impact.
- Push the government the issues of people affected by leprosy but having respect and dignity. Sharing successful stories to the government.

PHILIPPINES

- The different stakeholders of CLAP have a shared vision to achieve.
- Intensify the government agencies about CLAP.
- Invite resource persons from the government for connection.
- Know and learn the services offered by the government.
- Submit request proposals for funding assistance to the government.
- Educate the family about ending the stigma on leprosy.
- Create awareness of leprosy through programs like SPP.

INDONESIA

- In the picture are people diagnosed with leprosy. They have thought of committing suicide and are separated from their family.
- Because of support from the government they can now have a smile on their faces.
- They want to be legal as an organization in the country to also connect properly with the government.
- They have health insurance from the government but people affected with leprosy are still discriminated in some hospitals and are not even accepted for the health insurance of the government.

CHINA

- The government lacks respect towards the human rights of people affected by leprosy.
- No actual actions were taken in the implementation of the principle and guidelines in the elimination of discrimination of people affected by leprosy and their families.
- There are too many restrictions on NGOs like HANDA.
- People affected by leprosy must have the power and courage to work for unity.
- There is a push among international organizations to have a dialogue with the national government to implement the guidelines with a monitoring system.
- Build own accountability and credibility that they are not doing anything against the government.
- HANDA and government and public partners taking the lead role.

COMMENTS FROM THE RESOURCE PERSON

- He commended one illustration that PAL is the nerve-center of the movement that defines the being. The being is not the individual being but the community.
- He also pointed out the connection of leprosy on the disaster preparedness of Kiribati. He emphasized that leprosy has

a connection on the government response which is a justice issue.

- Faith-based leaders tend to talk too much and not do much.
- The journey to end stigma is hard to get out when the values system, the social system is challenging. We have to have a dialogue on cross-cultural education and dialogue.
- The religious institutions have to learn a lot and unlearn about the topic of leprosy.

COMMENTS FROM DR. ARTURO CUNANAN JR.

- Partnership with the government is also asking the government what we can do to help the government, and develop social integration, economic empowerment.
- Media is also a powerful tool to help reduce stigma and discrimination.
- We have to partner with civil societies and the academe, also to know the platforms and avenues of the government where we can integrate organizations with.

COMMENTS FROM PROF. TAKAHIRO NANRI

- Media is indeed a strong partner for an organization to pursue.
- Programs of the organizations, when exposed by the media, might imply sustainability.

COMMENT FROM the Workshop Master

- Social integration is not about having our own agenda if we want to have partnership it is not always about the leprosy agenda, but the agenda of the society. Let us approach them with the agenda of the environment, for example. Let us be concerned with the concern of others. And in the process of doing that, model to them what it means to love our country, to love our society despite our situation.

Partnership and Sustainability of Organizations

Dr. Marie Lisa M. Dacanay, President Institute of Social Entrepreneurship in Asia



Dr. Marie Lisa Dacanay

In the case of the persons affected by leprosy, social enterprise is relevant to sustainability.

As a simple way to understand social enterprise, Dr. Marie Lisa Dacanay revealed the definition of the concept with the following.

- Deals with efforts to remedy/alleviate unfavorable conditions in life especially among the poor/marginalized
- Deals with important projects that require boldness, energy, considerable initiative, risk
- Deals with economic wealth creation

In the case of the persons affected by leprosy, social enterprise is relevant to sustainability. Moreover, she cited different cases studies of marginalized groups in contexts similar to persons affected by leprosy.

CASE ONE: Children are Us Social Welfare Foundation (Taiwan)

The mission of Children Are Us Social Welfare Foundation to inspire and promote the potential talent of people with intellectual disability (PID) to assist their return to social mainstream to enjoy the dignity and happiness of life.

The foundation has social welfare and business departments serving at least 300 PIDs. The social welfare department. The business department is running a world-class bakery and restaurant where the PID's are the actual employees and also being served with benefits from the social welfare department. The restaurant and bakery are world-class that one will be surprised to know that the people working behind are actual PIDs.

The business department generates 51% of income from world-class bakery and restaurant

which also employ their primary stakeholders (PID) and 49% of the funds are from grants.

CASE TWO: Sunshine Social Welfare Foundation (Taiwan)

The mission of Sunshine Social Welfare Foundation is to uphold the human rights and dignity of burn survivors and facially disfigured people and assist them in their physical, psychological and social rehabilitation. They used to own and manage the second largest gasoline station in Taipei. 75% of the employees (58) are physically or mentally challenged. They have a 50% net profit (about US\$600T/year) supports the welfare of employees.

CASE THREE: PARTNERS FOR HEALTH (Thailand)

It is a public-private-community partnership project with the objective to increase outreach and effectiveness of government programs for persons living with HIV-AIDS. The partners who made this possible are Thai Business Coalition on AIDS (TBCA), Center for People's Families Affected by AIDS (CPA), UNESCAP, Ministry of Public Health and Bangkok Metropolitan Authority.

The organization has a health component with outreach care and psycho-social support beyond hospitals in the homes of persons living with AIDS. Moreover, they also have marketing and retail support for PLWHA-made textile and handicrafts. They also set up a marketing and retailing arm which is the CPA-Positive Marketing Co. Ltd. The main customers are all the international organizations having conferences in Bangkok. Bags, conference kits, and souvenirs

This example shows you that PALs can also become managers and owners of a social enterprise. This is because if they set up the social enterprise only for the benefit of PAL, it will not go far.



Dr. Marie Lisa Dacanay presented different models of social enterprise that organizations of people affected by leprosy can adapt for organizational sustainability.

were the primary products of the project. The project cost USD 117,000. In 2004, they gained around USD 203,000 where 35% of profits are used to finance the health component of the organization.

Partners for Health started 2003 and became self-sustaining by 2008 giving profits for the health programs.

CASE FOUR: Tahanang Walang Hagdanan (Philippines)

The mission of Tahanang Walang Hagdanan is the rehabilitation of physically handicapped people to have gainful and productive lives. In order to do this, they have sheltered workshops which includes metalcraft, woodcraft, needlecraft, packaging and fish hooks.

They already had 309 workers (including 90 office-based workers) that do the sheltered workshops by 2009. They have a business center that assists them in the development and marketing of PWD-made products and to develop PWD micro-entrepreneurs.

What is interesting about Tahanang Walang Hagdanan is that they have a Board of Directors who are mainly from the religious sector with some from the private sector. In terms of management, there is a shift in composition from an earlier period where management dominated by non-PWDs.

There was a time where the management went through a mission rift where they wanted so much to give jobs to PWDs that they actually worked with exporters who did not care about PWDs, it came to a point where the PWDs are working so hard for a little pay. During that period they had a reflection that only when the PWDs would run the sheltered workshops that their aspirations would realize. Now, PWDs are the majority of people in Tahanang Walang Hagdanan. The board is also conscious of spotting and honing people for leadership positions. There is also a shift in orientation from PWDs as worker-beneficiaries for subcontracted jobs rehab/service-orientation towards fellow PWDs/more participatory planning and problem-solving processes.

This example shows you that PALs can also become managers and owners of a social enterprise. This is because if they set up the social enterprise only for the benefit of PAL, it will not go far.

CASE FIVE: National Federation of Cooperatives of Persons with Disability (Philippines)

They set up a PWD enterprise (school chairs) providing employment to PWDs, nominally organized in coops (1998-2003). Over-time they became a federation of self-propelling primary cooperatives collectively owned, directed and managed by a critical mass of PWDs from 2004 to present. The enterprise shifted from '1-person shows' significant number of pro-active members estimated a ratio of members with worker mentality to proactive owner-workers of the cooperative. The key for the transformation is the primary level coop leadership and capacity development program initiated by the federation in 2003-2004 that set up value formation, leadership development, and empowerment to best form the core of leaders and managers to lead the cooperative. PWDs develop at different paces that the advanced members could be able to take charge as soon as trained. The enabling partners including CBMI, CCA, Rabo Bank, Foundation for TheseAble. Impact of school chair project (2003-2007)

The 398 PWDs from 12 coops nationwide involved (out of 1,250 PWDs in 15 coops) and the 66 PWD members interviewed, 91% of them said that there is increased socialization and self-esteem; 64% earned more; 23% able to send children to school and provide school allowance. Their average annual income increased from P30,323 per year to P54,467 per year. A study on Social Return of Investment (2003-2007) showed that for every - PhP1 spent by the cooperative, PhP22 was realized. On one hand, there was a problem discovered in the study that most of the benefits did not actually go to the PWDs but there is a disproportionate share of government (about 50%) in social return generated.

PWDs were given very low prices that the government saved a lot of money from buying chairs. In engaging with the government, there was a corruption in the transaction with the



Dr. Dacanay emphasized the value of re-imagining the economy to support social enterprises serving persons affected by leprosy.

The government has the potential to play a big role in the social enterprise. That is why we need to lobby governments to provide an enabling environment for social enterprises serving poor and marginalized sectors including persons with leprosy.

government. This propels us to believe that problems of social enterprises need to be addressed squarely.

Social enterprises are different from private enterprises in three different ways. First, the traditional business or private enterprise has primary stakeholders and beneficiaries of stockholders and proprietors. On the other hand in the social enterprise we have the marginalized sectors. The second difference is the primary objectives. In the traditional business, the primary objective is to gain profit but in a social enterprise is the social objective. This is what largely makes the social enterprise different. The enterprise philosophy of traditional businesses is accumulative for themselves but for a social enterprise, it is distributive. Social enterprises create wealth and distribute the wealth to the poor and marginalized. A social enterprise is different from a traditional business because of these three factors.

When we talk about a social enterprise, we call it a hybrid organization. It is like an NGO because it is socially driven but it is also like a business because it makes money. But unlike a traditional business, the way it earns profit is very different. We are trying to promote social enterprises as a means for helping the poor and marginalized to be self-sustaining, there are many ways of wealth creation and distribution.

Social Inclusion Models

Social Inclusion models primarily address the need for sectors marginalized or stigmatized by virtue of their physical, psychological, social or economic conditions to gain access to basic services and/or (re)gain their dignified place as productive members of mainstream society.

Exemplified by TWH Sheltered Workshops, Sunshine, Children Are Us, Partners for Health At the beginning, we can set up an enterprise that not necessarily run by PALs, like the Tahanang Walang Hagdan, we can create mechanisms to be able to give leadership positions to PALs who are ready and who have the capacity to take over management positions.

Intermediation Models

This model provides primary stakeholders access to critical economic services (financial,

product development, trading and marketing, technological services) to enable them to become effective market players.

Empowerment Models

This model primarily addresses the need for the poor or marginalized to reap maximum benefits from owning and controlling the social enterprise themselves. At their best, social enterprises become catalysts for broader change in the community and society. This is exemplified by the NCPWD.

Resource Mobilization Models

The primary objective of this model is to generate income from the sale of products or services to finance/sustain organizational programs for the poor/marginalized in part exemplified by Partners for Health, Sunshine and Children Are Us.

Concluding Remarks

The different segments and needs of persons affected by leprosy may need a combination of social inclusion, intermediation, empowerment, and resource mobilization models. Whatever the model is, financial sustainability must still be partly or fully achieved through revenues made from the sale of products and services. Whatever the model, it needs to enable persons affected by leprosy as pro-active partners/empowered stakeholders, not as passive beneficiaries. There is a need for transactional and transformational services and hybrid financing. We need to provide services in the social enterprises to assist them to set up financial management systems. Hybrid financing means there is a grant component and enterprise component. PALs need to be assisted to be fully empowered to be actors in their own development.

The government has the potential to play a big role in the social enterprise. That is why we need to lobby governments to provide an enabling environment for social enterprises serving poor and marginalized sectors including persons with leprosy. It is a good opportunity to use the 2030 Agenda for Sustainable Development (SDGs) that says "Leave no one behind!" There is a need to push the government not to leave the PALs behind. Furthermore, to effectively lobby government we need to work with other SEs

Social enterprises, therefore, have a very important role to play in changing how our economy works.



Dr. Dacanay (left) answers the questions of the participants and Boyet Ongkiko (right) facilitated the workshop on Partnership and Sustainability of Organizations

and SE resource institutions and networks. In the Philippines, NCPWD and Tahanang Walang Hagdanan is part of a coalition called Poverty Reduction through Social Entrepreneurship Coalition. There is a call to work together with similarly situated organizations to make social enterprises as a vehicle for development for marginalized people.

To effectively develop and support SEs serving persons affected by leprosy: we need to re-imagine our economy. We need to have an economy that is not just the market economy but plural economy. When a cooperative is formed, the members say we want to help ourselves. The principle in cooperative is the principle of reciprocity. Fair-trade talks about not only serving market but serving the producers. These principles are not governed by market principles but by solidarity. In order for us to help ourselves, we need to re-imagine the kind of economy we have. This is sometimes called the social economy. There are two principles of social economy: redistribution (redress of inequalities) and reciprocity (collective action by equal citizens). Social Enterprise has to push the market economy to be more humane, to incorporate social objectives.

Social enterprises, therefore, have a very important role to play in changing how our economy works. And unless we start thinking about ourselves as actors in rebuilding an economy that is not just based on market principles, SE initiatives will just be small initiatives. SE should be a major part of the economy to change how our economy works.

Question and Answer

Q: If I start an SE, what is the most common challenge that I may face?

A: It depends on your context. Many SEs are born because someone has the vision to set something up for a marginalized sector. The assurance of this is that the people whom this social enterprise is made should benefit. You are not there for profit, but with a social objective how do you do that in a sustainable way? There are difficulties in financing and SEs should assert that we need two types of financing, for the enterprise and enable the marginalized group we serve. We push organizations and the government to give grants for our objective.

Q: What is the profit percentage would you impose on?

A: As social enterprise would need to define the level of profits depending on the context. For some, breakeven is enough because they are able to give jobs to people. And that is alright. But if a social enterprise is involved in marketing, they need to make money in order for them to serve more social enterprise or needs money for expansion. I think I have to go to different models. In the social inclusion model, breakeven is enough, but in the intermediation model, you need more money because you need to expand and grow. In the resource mobilization model, you need to make money is what will make your social mission to be pursued. The empowerment model, if you are a cooperative, even if you are just breaking even it is okay. There is no one way to say that you need to have this percentage of profit. For resource mobilization and intermediation, they have higher pressure. A social enterprise does not depend fully on income. For example, Tahanang Walang Hagdanan is a foundation and a lot of revenues come from the things that they sell but it also gets grants. If you are a social enterprise, you can have different legal forms because right now, there is a no form prescribed for the SE. Even the corporate form of social enterprises they have started to set up foundations because they need to get grants on training, capacity building and all.

Q: Before we started a social enterprise where people affected by leprosy produce honey, our challenge is when we are starting that projects, we get funds, we get grants. So without grants when we computed all the costs like fixed costs, it is far to reach breakeven points. We are happy to see income people who produce honey increase but as an organization, as HANDA

A: In order for us to be profitable we need to do better than businesses because we have a social mission and an enterprise to run. And most of the time what is useful is for us to calculate the social return on investment, meaning to say it is the blended value created by the financial returns and the social returns. It is a challenge to monetize because the social value created you can never really fully monetize it. We have attempted to do that to some social enterprise and they have appreciated that even if their profit is small, even if they are not yet breaking even that they are creating a lot of social value and because you are creating a lot of social value, society should actually be paying you.



Ms. Marie Lisa Dacanay explains the rudiments of starting a social enterprise (left photo) and with Prof. Takahiro Nanri.

But when we talk about the plural economy, a social economy that really gives value to empowering people and gives value to providing decent jobs for all, all the marginalized groups.

That is the reason why we are pushing the Poverty Reduction through Social Entrepreneurship Law in the Philippines because we believe that the government should be compensating social enterprises for doing what the government should be doing.

It is not incentive but a recognition that you're creating social value. It is a different mind frame and I think we have to do a lot of advocacy to show that. In the Poverty Reduction through Social Entrepreneurship Coalition, we are starting to grapple with that because we are trying to push the government to give tax incentives and then the government says "oh we don't give tax incentives" and then we changed our tone. We said "We are not asking you for incentives, we are asking you to recognize what we're doing, that what we are doing is something you should be doing so you need to pay us. It is really a mind-shift and all of us should realize that the social returns we are creating for our society are something that society should be paying us for.

On the other hand, we need to re-imagine our economy because our economy should not be just about the market economy because the market

economy monetizes everything and just talks about profits alone. But when we talk about the plural economy, it is a social economy that really gives value to empowering people and gives value to providing decent jobs for all, all the marginalized groups. Then we are able to appreciate better than what we are doing is the creation of value and it is not just the financial value that is given a value of the market.

Q: You mentioned about a certain law passed, what level in the passing of that law it is now? Does it already have a specific bill?

A: We started to push the law in 2012 unfortunately until now it is still a bill. The last count that we have there are less than 20 in the lower house and seven senators supporting it. Our consolation now is in the Philippine Development Plan, the government recognizes it as a priority bill. So we are using that as a way to push the legislative branch of the government to do something about that. But also, the DSWD is engaging us to try to help them develop models for social enterprise development for the 4Ps beneficiaries. There some initiatives on the government but not that advanced.



RE-IMAGINE THE ECONOMY. *The participants look at the different workshop output on Partnership and Sustainability of Organizations through a gallery walk facilitated by Boyet Ongkiko (farthest right).*

WORKSHOP 03 RESULTS

TASK 03: The participants are tasked to reimagine their economy.

Re-imagining our Economy. We have to re-imagine our economy to be able to provide goods and services later.

CHINA

- Tourism is a big market in China which PALs could also have the opportunity to go around the country.
- Access to nutritious and safe food, environmental issue and pollution are big in China. We would like to see clean and safe environment for all.

PHILIPPINES

- An image of a Philippine economy that considers first the environment. Our economy should be environmentally friendly.
- It should be focused on people and profit to improve quality of life.
- Build a partnership with civil societies and government.

- There will also be no economic progress when there is no peace.

- Ride an electric vehicle using ECO SOLAR instead of gasoline. Utilize renewable vehicle.

- To help unemployed people and environment especially those persons affected by leprosy,

- Less transportation fee.

- Prevent air pollution.

- What if the Philippines, instead of importing rice or other products came from other countries, develop our farm and empower our farmers so that we are the one who will export to them.

NEPAL

- Sharing the successful testimony of people affected by leprosy which can draw the attention of the wider community.
- Equipping people affected with skills and knowledge.
- Expansion of tourism.

- Expansion of hydropower.

INDONESIA

- Recycle garbage-clean environment
- Convection--clothing is a basic need that is needed anytime.
- Moringa tree
- Planting cotton

KIRIBATI

- Cement shipment from the Philippines
- The cost in Kiribati is AUS 21.5/Cost in the Philippines is AUS 7
- Profit after shipment - AUS 12.5
- Cost of coconut timber in Kiribati is AU\$ 4 per 6 meters by 5 cm.
- Cost of sawn timber (Philippines) AU\$3 a profit after shipment is .50c
- Replanting coconut (cut) value after 10 years = AU\$ 160 p/ annum
- Environmental Support



PLENARY MESSAGE

Networking of Organizations

*Dr. Maria Faina Diola, Director Center for Leadership
Citizenship and Democracy*



In social marketing, you must have a central idea which shows your message. You need also to explain your mission through symbols.

Dr. Maria Faina Diola

Dr. Maria Faina Diola started her talk by giving the necessary objectives which include the following:

- To have an appreciation and basic understanding of Social Marketing towards resource mobilization (Resource mobilization is people as resources).
- To discuss and reflect on how to identify, assess and develop strategic partnerships using stakeholder analyses (To have a strategy is to have a tactical plan)
- To review principles of communicating for change (Not just to communicate but also with change in mind)

Social Marketing in Resource Expansion and Mobilization

If one would conquer a challenge, one has to think about marketing. Marketing has always been equated with profit-earning initiatives. If one to imagine a world, one has to identify who is the public? Relationships matter in social marketing. Marketing involves any transaction between an organization and its public. If, one, we have a common world, who is the public? Who are with us? What kind of transaction must we have in that world?

Broadening the concept of marketing one has to include any transaction between an organization and its publics. Social marketing is creating awareness of relationships to advance a social

cause, idea, or pattern of behavior. What do you want to sell will change the mindset of the government, donor and direct to our attention and concern: Thinking ties that bind.

Our message to the government – give us quality public services. This is the demand the world wants.

Ideas, concepts, and philosophies of social change espoused by the following:

1. Museums – a showcase of victims of Human Rights Violation and extent and history of violence through art.
2. Colleges, universities – Indigenous People's Rights – integration with students in the classroom to talk about ancestral lands thru learning by doing; storytelling.
3. Government agencies -- hospitals, labor unions, charitable organizations, and community associations support for abandoned children thru student exposure tours in orphanages and home for the aged.

In social marketing, you must have a central idea which shows your message. You need also to explain your mission through symbols. By doing this is powerful, in order to explain your message to your audience. One can also write down the steps "supporters" can help. We have to clear what our supporters want to do with us or do for us. Another is painting a picture for everyone to have a role in your campaign. One more

We want to think that our supporters will care for us. Where we can say we belong to a Caring Society.

Dr. Diola discusses the value of stakeholders as a social companion in every organization.



example is creating a community mural. This initiative may show a strong message of our art. There are different avenues where we can easily communicate our idea or message to the world.

The issue that social marketing addresses especially to organizations is the need for sustainability and it is communicating for change. This helps organizations to be self-sustaining as it comes from our own picture of the world for the long-term viability of organizations. Furthermore, social marketing may also mean target to the audience to explain the interconnectivity of partners to our common future.

Counterpart funding or "sweat equity" and exit strategies have become necessary components in grant proposals. The counterpart program should have a clear goal, that matches for sustainability. What is each participant willing to give in a contribution to the program?

Planning for Social Marketing for People Affected by Leprosy, issues and concerns in the hope of expanding a support base for PAL's programs and activities may be guided by the following principles.

The first principle is to Assume a Marketing Mindset and Attitude. Imagine who the "donor" or "supporter" you want to convince. In your organization (your division or unit), who is your "customer" or your client, aside from the PAL communities you serve? What don't they know about your condition? What is it that they should know about us because this is what we can offer to them? What must they know about what you can offer?

To develop a marketing stance, for non-profits three propositions are involved. First is client-orientation/perspective "supporter" orientation. One has always to think who is the supporter? The second one is, coordination of all client-related activities and it is thinking about the ties, and the third is goal-orientation.

We want to think that our supporters will care for us. Where we can say we belong to a Caring Society. A nonprofit or public organization should remember that it exists to serve the needs of its clients. You need to know your organization's clients – their needs, attitudes and general "buying-in" or adoption behavior. E.g. (Phil.) if you are targeting government as a supporter, think about the government's goal of "Malasakit" – a caring society. This is what we do as marketers, we try to communicate the connection.

In another note, coordination as a marketing stance requires planning. Therefore, in coordination is acknowledging that we have a common world, we have common relationships

and a common future. What marketers need again, is to communicate the connection.

To get support from community associations of PALS, therefore, needs to clearly match the organization's' goals with those of PALS and their communities. One more thing, to get support from NGOs and other civil society groups who work on PALS issues and concerns, know the overall goal of such CSOs. (e.g. poverty reduction, urban resettlement, land reform, small enterprise development, peace, and development, etc.)

Stakeholders are our social companions. A stakeholder is someone who can affect or who will be affected by the activity of an organization. We should identify our companions to have power. They have the power to respond to our concerns, negotiate with them and change our world. Who are these companions? It's not just people who accompany us and they have power. Exploration of the relationships, associations, and interactions that influence the ability of people (individuals and teams) to accomplish the tasks comprising their work – that can be more effective, more satisfying, more reinforcing for those engaged in the work.

In developing a client-orientation, these are some pressing questions:

1. What is your goal?
2. What is your advocacy? What social change do you want to see? Who will be involved in your discussions on stakeholders?
3. If the decision is made to develop such a focus, how will it be implemented?

The next principle is Forging Strategic Partnerships (Network).

1. Conduct a situation analysis
2. Define your stakeholders or partners (scanning the common world in which we live).
3. Who has the same challenges as you?

The third is to Conduct Strategic Planning for Social Marketing. We have to design a Participation Planning Matrix. A Participation Planning Matrix is specifically designed for this purpose, highlighting the public participation for each management function of an organization. Here are some questions that we need ponder about:

1. What do we want from "supporters" and "partners" in society? – what is the common goal or social cause that we want to pursue in our community? In our country/society?



Dr. Diola points out the differences of social marketing for cause-oriented work like the NGOs.

Strategic targeting and consistency to one's key message play an important role in developing an effective communication strategy.

2. What would make us happiest in the world today?
3. What makes us sad about society?
4. What can we contribute to society?
5. What are our major challenges in dealing with the outside world?

The fourth and last principle is to Develop a Communication Plan for Change.

First is objective. What do you want to accomplish from your communications activity or activities? State it in a manner that is specific, measurable, achievable, realistic and timely.

Be mindful of the Social Change you want to see based on previous stakeholder analyses.

This could be classified as Knowledge, Attitudes, and Skills. Second is the target audience. To whom do you really want to talk? The general public is never the target audience of a strategic communication effort. We need to identify the audiences with whom you need to communicate to achieve your organizational objectives.

The third is the key message. Strategic targeting and consistency to one's key message play an important role in developing an effective communication strategy. The key is to have a well-developed key message in a case statement form and identify its various inflection points for different audiences. Be clear with the change you want to happen.

Media Channels are also important components of a Communication Plan. Identify channels through which messages will be delivered, either print, broadcast, the Internet (web, email), direct mail, etc. Remember that face-to-face dialogs, phone calls, plays, text messages, bulletin boards, etc. are also communication channels which may

only be more accessible, but more effective too, in reaching out to your target audience.

Last are resources, Timelines and Person/ Unit in Charge. Specifics on logistical, systems and staff requirements, the length of time needed before results may be expected and who is going to be responsible for managing the various process and achieving the goals.

Without these, the communication would most likely remain a mere intention.

QUESTION AND ANSWER

Q: Does social marketing need skills?

A: Yes.

Q: One of our limitations is capacity. Capacity has a big factor for sustainability in moving forward for an enterprise. You have presented a good picture of social marketing. How can we enrich ourselves further?

A: We have two exercises for tomorrow about stakeholders' analysis on identifying power and crafting a communication plan.

Comment from Prof. Takahiro Nanri: She made a very important point for all the organizations for sustainability. We have to partner with people and stakeholders. Stakeholders mean foundations, government, beneficiaries, members, media so for you to survive you have to develop relationships with all these stakeholders. She shared this idea dramatically. As an example, most of you here received a grant from Sasakawa Memorial Health Foundation and for us to decide to give you grants, you must do social marketing to us because we are one of your stakeholders. Tactics and strategies work. If you are an owner of a football team, in order for you to win today you need tactics, but in order for you to be a top team towards the whole year, you need a strategy.

WORKSHOP 04 RESULTS

When we do social marketing, we start with the audience. The task is to identify the stakeholder list and identify their interest and power. Interest is their agenda when it comes to leprosy. We are identifying the interests because we are identifying the common good. Power is control. When you have the power to have the ability to do something (e.g., funding). Rate this into high, medium and low.

The function of stakeholders' analysis. For example, we aim for social integration and identify the government as a stakeholder. Next is to identify power. Power allows the common good to become better. The reality of the dream is higher when power is higher. However, power is not just working for the dream. It also can work against. That is why we need to identify power. That is the purpose of stakeholder analysis to determine the common good. If it is high it is good but if it is low, it means engagement is just starting. That is why we need to identify the power level to help us identify the communication strategy.

Given your analysis, you must have a specific objective. When it comes to projects, what could be the objective?

You have to identify your audience. So who do you want to talk? Who are the key people? Make sure they are able to receive your organizational message. What can be your communication strategy? Identify the people and even the people you know who can bring you and your message to the person. IDENTIFY the PRIMARY PERSON and the SECONDARY PERSON.

In relation to your project, what now is your key message? The key is having a well-developed message and be clear with the change you want to happen. This is the elevator talk. What will be your key message to capture your audience's heart and mind? Also, find out their interest. Affirm their interest and engage with them. Connect interest and address the power issues with that interest.

WHAT IS YOUR KEY MESSAGE?

CHINA

Stakeholder: Leaders of university student volunteers

Key message: We know that you are looking for opportunities to participate in HANDA activities. We are going to organize a big event on March 11, Monday. We are in need of 20 volunteers to help us in organizing this event. Could you please help mobilize 20 volunteers and contact me as soon as possible?

NEPAL

Stakeholder: Leprosy Control Division of Nepal

Key Message: We would like to end stigma and discrimination and bring back the lost dignity of people affected by leprosy and mainstream them in the existing society. Dignity is inherent that is why people affected by leprosy should live a dignified life as any other citizen. For that first, please help us abolish the discriminatory laws which discriminate people affected by leprosy. Second, provide some fund and some staff so that we could lobby to the constituent assembly.

Suggestion: Ask them specifically what power do you recognize that they possess you can elicit with them.

PHILIPPINES

Stakeholder: Mayor

Key Message: CLAP is geared towards the improvement of the quality of life among the members through resource-based and market-based social enterprise for inclusive growth. I've heard mayor that in your development plan, you have funds for livelihood. Can we have access this fund so we can go ahead and work together to achieve economic growth here in your area.

Suggestion: Interest is the starting point and power will be recognized. It needs to be specific. This is because they are in the decision-making sphere, to decide whether they will yield power. You need to be specific for example, you need this year we have this economic program that would require a certain amount. Can our group be part of the committee? Key messages are specific. Our power analysis is important.

The important thing in strategic communication is to pinpoint.

TIP: What to do when the attitude of the stakeholder is negative or of low interest? The goal is to move from low interest to high interest. Believe your project will work and tell them important information. But if the stakeholder needs to be moved from low power to high power, the intervention is training and exposure. Capacitate the people and raise awareness. It is called a key message because it opens the door for them so they will have a peek. Do they like what they see? Hear? If they will be interested, then they will open the door. Small key is used to open the door to peek, and eventually opens the door wide and the stakeholder will decide to come in. That is why it should be short. As a tip of the iceberg, you see only small but the data is there and it should be ready. That is how you develop network and relationships.

Thoughts and Learnings

- Regular communication is important. We cannot just communicate when we need support. We need to establish a relationship.
- The inputs become an eye-opener to develop communication skills.
- We have to find a common agenda. Putting up bulls-eye on a stakeholder that could find an agenda interest is a challenge. You need to know and what kind of interventions you have.
- Knowing objective and goal, and then we will present it to our partner and we are very convincing because we knew everything and we lay our cards, we can be positive in dealing and we can get their attention and interest more. Because we knew that we have to express what we need.



The closing ceremony is led by the Workshop Master, Boyet Ongkiko giving emphasis on the community values as an organization.

A Review of the Assembly Objectives

At a rating scale of 1-5 with 5 as the highest (achieved), the following objectives of the Regional Assembly of Organizations of People Affected by Leprosy in Asia-Pacific were rated as:

1. To share the achievements and experiences and best practices as an organization and in partnering with various international, national and local agencies in ensuring the effective delivery of quality health services, reduction of stigma and discrimination, empowerment, improvement of the quality of life brought by socio-economic enterprise and in increasing sustainability of people's organizations;

This is rated 5 by the participants.

2. To present and highlight the roles and contributions that the people's organizations can provide at different levels of society and government;

This is rated 4 by the participants.

3. for coordination, consultation and joint learning towards elimination and fulfillment of the right to dignity as human beings and citizens.

This is rated 3.5 by the participants.

4. To discuss means to strengthen / increase sustainability for people's organizations;

This is rated 4 by the participants.

5. To discuss means how to develop a functional network and partnership between and among people affected by leprosy organization;

This is rated 4 by the participants.

6. To propose a recommendation for the World Assembly and other strategies and activities on a way forward.

NATIONAL AND REGIONAL INITIATIVES

SUGGESTIONS PER COUNTRY

Country	Priority Agenda	Regional Collaborative Agenda
Philippines	<ol style="list-style-type: none"> 1. Expand SPP to other regions 2. Initially start a social enterprise to address "sustainability" 3. Establish leprosy utilizing current technology and social media. 4. Legislation for the inclusion of persons affected by leprosy as persons with disabilities. 5. Leprosy helpline in the Philippines 6. Social marketing-expansion for partnership 7. Sustainability 	<ol style="list-style-type: none"> 1. Come-up with a regional roadmap to address stigma and discrimination and promote inclusion. 2. Come-up with a quantifiable indicator to measure stigma. 3. Come up with a strong regional network and assign thematic focal-in-charge. 4. Social enterprise for each organization.
China	<ol style="list-style-type: none"> 1. Develop a strategic plan for fundraising locally. 2. Improve staff's capacity on fundraising proposal writing (local foundation, corporates) 3. Build-up HANDA brand image. 4. Provide capacity building to PO's or the other NGOs. 	<ol style="list-style-type: none"> 1. Each organization must develop clear objectives with regards to its organization's future development. 2. The objective must have a timeline 3. Have designated person as a regional coordinator (person from PO's organization)
Nepal	<ol style="list-style-type: none"> 1. Think deeply about the sustainable development of the organization. 2. Equip our members of the organization with adequate knowledge and resources for social marketing. 3. Role of religious leaders to end the stigma and discrimination, religious leaders could play the role of ambassadors to spread the positive vibes. 	<ol style="list-style-type: none"> 1. Conduct expertise exchange program. 2. Continuous of conducting the conferences or organizations of people affected by leprosy and allocate the time to share. 3. Conduct high-level training for the Sustainable Development Strategy Workshop and strictly follow-up to see the changes in the concerned organizations.
Indonesia	<ol style="list-style-type: none"> 1. Networking 2. Sustainability 3. Programs that will confine government trust. 	<ol style="list-style-type: none"> 1. Networking 2. Sustainability of organization 3. Awareness raising about inherent power.
Kiribati	<ol style="list-style-type: none"> 1. Legal recognition process (identity, by-laws etc.) 2. Location and contact of board members. 3. Full vision for a social entrepreneurship. 4. Networking with current members (Regional Assembly of Organizations of People Affected by Leprosy) 	<ol style="list-style-type: none"> 1. Set out opportunity visions to sustain membership countries. 2. Address for current administrators who will be the center of action/contact/. 3. List of membership and contacts/



Recommendations were elicited from the participants for the world assembly on September to be held in Manila, Philippines.

DISCUSSION OF RESULTS

Priority Agenda	Regional Collaborative Agenda
<ol style="list-style-type: none"> 1. Addressing Sustainability through Social Entrepreneurship and Fund Raising 2. Networking with government and Legal Identity Initiatives with other organizations 3. Image Branding and Marketing 	<ol style="list-style-type: none"> 1. Create and strengthen Regional Link thru a secretariat 2. Sustainable Development Strategy (Social Enterprise) 3. Coordinate a Regional Capacity Building Plan

In coming together as one region during the assembly, the participants now reach the decision-making to identify pressing issues that concern them as a national representative and also, reflecting the agenda of the world assembly on September.

The participants have noted that they have a certain commonality regarding the issues and concerns. On the other hand, the suggestions which came about need more to be specific to be able to raise a point as an agenda. The Asia-Pacific Assembly has to come up with concrete recommending issues which each country has to do as an initiative in their country. These agenda can also be used as a recommendation for the world assembly. One point raised during the discussion by CLAP is the adaptation of the roadmap for the commonalities each country has.

Furthermore, an issue was raised on the linking of the nations together, HANDA has proposed a hub to be able to know the best practices, get an update to now best practices of each

country; thus, a regional secretariat. The regional secretariat is the team consolidating and distributing information to different countries. The regional secretariat might use social media channels and web-pages to acquire and disseminate information.

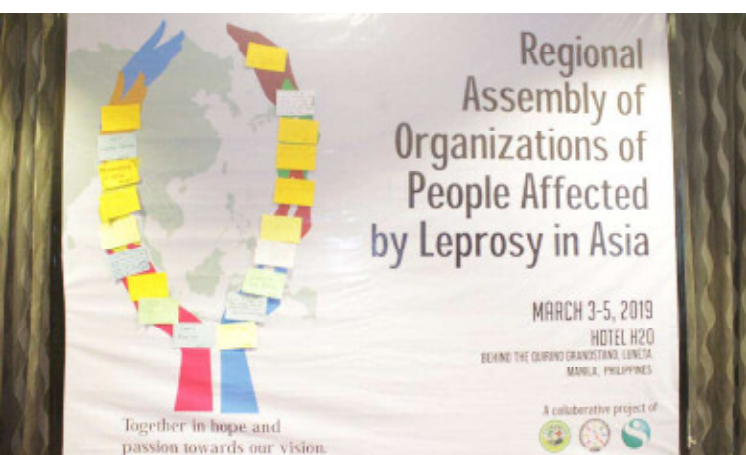
Accordingly, the participants and representatives present, have seen the validity of the recommendations--thus proposing the regional initiatives to the world agenda. The question now is who will take the lead?

Nepal, citing the "mechanisms" during the regional assembly has raised that the three collaborating bodies who made the assembly possible, would act as a regional secretariat. Frank Onde and chairman of CLAP accepted the secretariat. Furthermore, the collaborative agenda needs to have details. Specific ideas on planning, what kind of capacity building, through the secretariat, to be done by June. The regional secretariat will work to provide a more detailed agenda or points to be raised for the June preparation.



The participants articulate their commitment as a part of the closing ceremonies of the Asia-Pacific assembly.

IMPRESSIONS OF THE GATHERING



The participants posted their commitments in the hands of the assembly logo as a symbolic act of unity in the Asia-Pacific Region.

Closing

If one looks at the image, the participants started with hands. But now they have written there something with their hearts and minds. They are connected. The head, heart, and hands. For this hope to realize and for this vision to be true they need to bring their heart and hands together. So that every step of the way, the world becomes better.

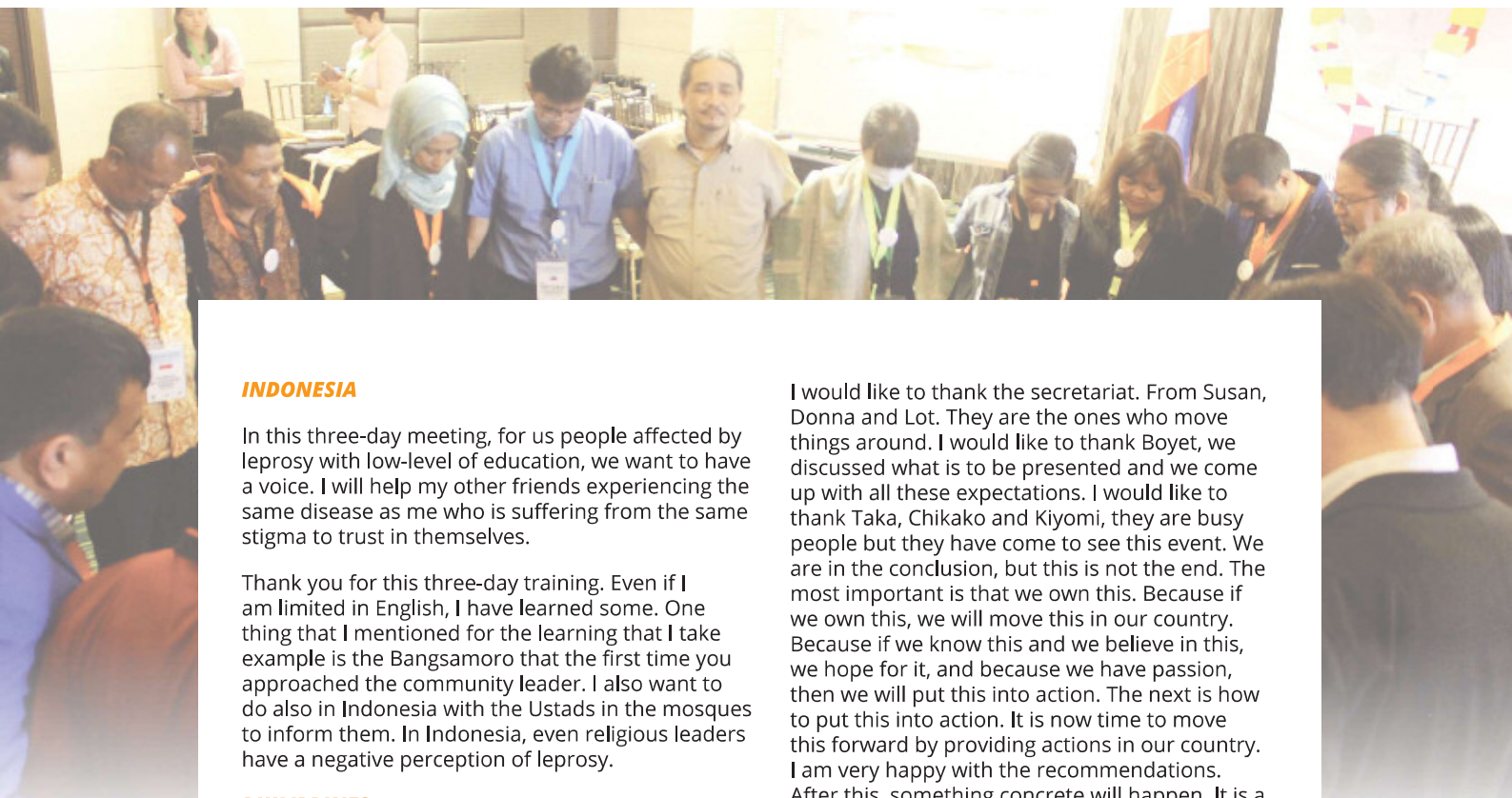
The participants joined in a circle, and shared the following wishes:

NEPAL

It has already been three days past but we still want some more days. The meeting was so impressive. Before I start my journey from Kathmandu to here, I did not think at that time that the meeting will be so powerful but now, this is really incredible. I have not attended such kind of meetings though I have been to many meetings before. The coming together of all the organizers of people affected by leprosy, who have gone through the same difficulties. We are here because we have suffered a lot and we are working so hard so that no one can suffer in the days ahead. That is very important. Sustainability, plan, a strategy we know the words but we went in the depth of the words and we internalize that and talking about home, I am very much impressed and definitely, this will reflect IDEA Nepal.

CHINA

During this three-day meeting, the stories shared by Ariel and Jennifer impressed him. He said the people affected by leprosy themselves must respect themselves and believe that they have power in themselves. That is a very good example for him to share as an example of living in villages. As the president of our organization HANDA, we realized the importance of the sustainable development of our organization. It is time for us to make a plan, develop a strategy and take action now. We will not just keep on talking, without real actions taken. When he gets back, he will start planning.



INDONESIA

In this three-day meeting, for us people affected by leprosy with low-level of education, we want to have a voice. I will help my other friends experiencing the same disease as me who is suffering from the same stigma to trust in themselves.

Thank you for this three-day training. Even if I am limited in English, I have learned some. One thing that I mentioned for the learning that I take example is the Bangsamoro that the first time you approached the community leader. I also want to do also in Indonesia with the Ustads in the mosques to inform them. In Indonesia, even religious leaders have a negative perception of leprosy.

PHILIPPINES

We are happy that we were able to be part of meeting other people. We have learned so much from you also in what we are doing here in the Philippines. And we are thankful for everything.

Thank you for the chance of holding the assembly in the Philippines. For the three days I have learned so much and I have gained a lot from these activities. We have more to do and we will apply this to improve and develop.

Sasakawa

It seems that now, you can feel the ownership of this conference because this conference is yours. Not ours as a foundation because that is what we expected.

Thank you for CLAP members for organizing this wonderful assembly. Thank you for the hard work

Rev. Dann Pantoja

Thank you for the CLAP members who have shared their stories when we ate with you on the table. I have now a glimpse on what it means from your perspective, what is self-stigma and social stigma. I will never be able to understand that existentially the way you experienced it. Thank you for giving me a glimpse of how painful it is. I pray that I would be able to practice compassion, meaning to suffer with you.

Dr. Arturo Cunanan Jr.

Thank you for accepting the invitation. Thank you for the media, for the past three days, you can see on the internet what they are publishing and they are a powerful partner. It is good learning that media can also be our partners and providing a common agenda with us, they can affect change.

I would like to thank the secretariat. From Susan, Donna and Lot. They are the ones who move things around. I would like to thank Boyet, we discussed what is to be presented and we come up with all these expectations. I would like to thank Taka, Chikako and Kiyomi, they are busy people but they have come to see this event. We are in the conclusion, but this is not the end. The most important is that we own this. Because if we own this, we will move this in our country. Because if we know this and we believe in this, we hope for it, and because we have passion, then we will put this into action. The next is how to put this into action. It is now time to move this forward by providing actions in our country. I am very happy with the recommendations. After this, something concrete will happen. It is a challenge for the Asia-Pacific Region to lead the world assembly, let's be on the lead. Asians will be on the lead with the fight on social stigma, discrimination, and we are doing something. I also like the widening of horizons and because we are working with media, with entrepreneurs, the grassroots, with the academe, our resource persons, we have expanded talking and advocating and widening our agenda to different partners. There are still partners around that might help. It is a big challenge for CLAP and Culion for having taken the lead role to be the regional secretariat. Rest assured that we will work together and bring out the specifics of this in June. But please respond to our emails because this will be a collective effort as a region. So we will expand this in putting this in a newsletter, and in our own website or social media of different organization. In that way, we share.

Boyet Ongkiko

I just want to affirm Sasakawa. In my work in the development world, there are not many funding organizations who would take your servant attitude of really not imposing but allowing and journeying with us. I am so humbled by your attitude.

The conclusion of the event left a strong mark to the hearts of the participants as they will continue the journey in their country. The assembly has strengthened the links and network of the Asia-Pacific Region in continuing the fight for human rights, preservation of leprosy history, sustainability and improvement of public health. The activity ended with a prayer by Rev. Luis Daniel Pantoja.

Role of Media in Ending Stigma and Discrimination of People Affected by Leprosy

One of the important discussions that emerged during the Regional Assembly is the role of media in the integration of the society of persons affected by leprosy. During the discussion on Partnership with the Religious and Government, Dr. Cunanan, and Dr. Nanri pointed out the importance of the role of media as partners in the journey to end the stigma and discrimination of PALs. Dr. Cunanan pointed out that there is a need to partner with media for it to be able to campaign to the masses correct information on leprosy.

Moreover, the reach of media has already been part of the work as it has proven effective by IDEA Nepal and PerMata Indonesia as they have utilized different media channels like radio and television to communicate their stories. Nalisha Adams, a reporter of the IPS News, pointed out that collaboration is much needed for media platforms like IPS to be able to capture grassroots stories that can impact their readers. IPS News is an international NGO which works primarily in covering stories aligned to the Sustainable Development Goals of the United Nations. IPS News has a headquarter in New York. They are the main media partner which covered the three-day Asia-Pacific Assembly.

The agenda of IPS and other media organization related to UN is directed to its SDGs development agenda. In this way, the media has the power to give voice to communities. Moreover, Adams also added that the stories empower the people, that they are aware of what is currently happening to them. This provides a voice to the voiceless.

Ben Kritz, a reporter of Manila Times emphasized that in order for the media to give attention to the PAL community, there must a collaboration or a partnership at work to be able to communicate clearly to the non-leprosy audience the significance of the cause. It must be told as if it is also important to other people. This is being relevant to the communities.

She encouraged the participants to use social media to create a positive impact in their communities.

Stella Paul, editor of IPS News told that we are already living in the age of social media. Social media is used in different ways. In creating a negative or positive impact. She encouraged the participants to use social media like Facebook and Twitter to create positive impact on their communities.

“...there must a collaboration or a partnership at work to be able to communicate clearly to the non-leprosy audience the significance of the cause”

Acknowledgment

The Regional Assembly of Organizations of People Affected by Leprosy in Asia-Pacific is made possible through:

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For the participating organizations for coming and actively participating and sharing their experiences and best practices.



Culion Sanitarium and General Hospital
Sasakawa Memorial Health Foundation
Coalition of Leprosy Advocates of the Philippines

The following section of this documentation are significant stories by IPS News during the Asia-Pacific Assembly.

First Asian Leprosy Assembly Calls for Greater Social Inclusion for the Affected

by Stella Paul
ips.news.net

“Integration is very important and we as a foundation, hope, we can contribute to the integration [of people affected by leprosy] with the society,”

MANILA, Mar 3 2019 (IPS) - Growing up in Kathmandu, Nepal, Amar Bahadur Timalisina was not allowed to attend school as a young boy because he was affected by leprosy. But decades later, after treatment and being able to re-integrate into his community, the boy who was once denied an education is now inspiring the principal of a school of 400 students.

“I suffered from leprosy when I was 12 years old. At that time I was forced to leave my village and my community,” Timalisina told IPS.

But after that Leprosy Mission Nepal supported me with a recommendation letter, he was subsequently able to attend an orphanage “where I got an opportunity to continue my studies.”

“At my school there are 400 students and 30 staff. Now if I go to my village, there is no discrimination, no stigma and everyone welcomes me like any other person,” he said.

Timalisina, who is president from the International Association for the Integration, Dignity and Economic Advancement (IDEA), Nepal, a group founded by people with leprosy to support others with

the disease, is in agreement that there needs to be greater inclusion for those affected by it.

Participants at the Regional Assembly of Organisations of People Affected by Leprosy in Asia kicked off today, Mar. 3 in Manila, Philippines, made a vocal appeal to adopt and embrace greater social inclusion and build a stigma-free society for those affected by leprosy

The three-day regional event, which is the first of its kind to be held, was organised by the Philippine government-run Culion Sanitarium and General Hospital (CSGH), the Coalition of Leprosy Advocate of the Philippines, and the Nippon Foundation (TNF) and its sister organisation, the Sasakawa Memorial Health Foundation (SMHF). Since the late 1960s TNF has been actively supporting the fight to eradicate leprosy worldwide including providing free multidrug therapy through the World Health Organisation. “The biggest challenge before us today is stigma,” said Dr. Maria Francia Laxamana, Assistant Secretary in the Philippines Department of Health and one of the key speakers at the conference.



Participants at the Regional Assembly of Organisations of People Affected by Leprosy in Asia kicked off today, Mar. 3 in Manila, Philippines, made a vocal appeal to adopt and embrace greater social inclusion and build a stigma-free society for those affected by leprosy. Credit: Stella Paul/IPS

According to Laxamana, only one in every four in the Philippines seek out medical treatment for the disease and social stigma is one of the main reasons why they hide their condition. So, for the Philippines to achieve the global target of reducing leprosy cases by 2020, it would be crucial to have policies that could look at the disease in the local context and can provide solutions that are locally applicable.

For example, we should not be looking at leprosy just as a disease, but take a holistic approach and provide the affected people with a package of support that includes not only drugs, but also education, vocational skill trainings and employment. Such a package will not only help improve their quality of life, but also pave the way for greater social inclusion, resulting in removal of social stigma, she said.

“Integration is very important and we as a foundation, hope, we can contribute to the integration [of people affected by leprosy] with the society,” said Dr. Takahiro Nanri, Executive Director of SMHF and the second key speaker of the day. Reiterating the dedicated and continuous support of the foundation to eradication of leprosy, Nanri informed that SMHF has been organising regional assemblies across the world, including Africa, Latin America and the current one in Asia, to facilitate greater engagement and participation of all experts and leaders working on the disease.

Alice Cruz, United Nations

Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, pointed out that social exclusion and stigma was having a devastating effect particularly on the children of those affected by Hansen’s disease. Addressing the assembly virtually, Cruz emphasised the need for sensitisation of school teachers because in many countries children with leprosy were expelled from schools by the teachers themselves.

“Teachers in endemic areas should be trained on leprosy and the schools should be one of the first places to raise awareness on leprosy’s signs and symptoms, but also on the human dignity and rights of the persons affected,” she said.

Dr Arturo Cunanan, chief of CSGH, said that while those working in the field always talk about the social stigma and discrimination that people with leprosy face, the question is how to measure this. “Usually, government will not address issues of human rights, not unless they know about the issue of burden.”

There are representatives from six nations in the region attending the assembly: Philippines, Japan, Indonesia, China, Nepal and Kiribati. While some are working with the government at the policy level, others are working directly with the affected communities and are expected to share their respective experiences and impacts to find a common, collective way to fight leprosy more effectively in the future.



Coalition of Leprosy Associations of the Philippines (CLAP) community outreach organisers Jennifer Quimno (left) and Michelle Ann Ore (right). Credit: Ben Kritiz/IPS

Leprosy Detection With a Personal Touch

by Ben Kritiz
ips.news.net

MANILA, Mar 3 2019 (IPS)

Jennifer Quimno can put anyone at ease. So when she travels across the Philippines as part of peer to peer programme that helps identify new leprosy cases, people generally allow her to examine them.

"We met a young boy, about 16 years of age, who had symptoms of leprosy, and we needed to examine and send pictures of his skin rashes to the doctors for diagnosis," Quimno told IPS. Quimno, herself a former leprosy patient, was able to put the teenager at ease. "One of his rashes was on his buttocks. He was a little embarrassed to show it at first, but when I asked him nicely, he let us take a look."

That unique sensitivity toward persons affected by leprosy is a valuable resource in identifying new cases and encouraging patients to seek treatment, Frank Onde, the president of the Coalition of Leprosy Advocates of the Philippines (CLAP) explained.

"Strengthening the participation of persons affected by leprosy is the most effective way to reduce the burden on government health departments," explained Onde, one of the keynote speakers

at the Regional Assembly of Organisations of People Affected by Leprosy in Asia. The assembly is being held in Manila, Philippines, Mar. 3 to 5.

Helping their own

Under the programme organised by CLAP, former patients are trained in community outreach and help to identify potential cases for diagnosis and treatment. Using people who have personal experience with the disease helps to reduce the reluctance of leprosy sufferers to seek treatment, Onde said. Not only can the outreach workers relate on a personal level with others affected by leprosy, also known as Hansen Disease, their own experience also helps healthcare personnel make accurate diagnoses, he added.

Launched in the cities of Manila and Cebu in November 2018, the programme, 'Strengthening Participation of People Affected by Leprosy in Leprosy Service', known as SPP, is currently working among known affected communities. It pursues the twin objectives of gathering demographic information to update the Philippine Department of Health database and identifying relapse or new leprosy cases.

Financial sustainability is a common worry for leprosy advocacy groups throughout the region, but in the Philippines, Onde explained, CLAP and other organisations face a unique challenge.

Quimno, who is a field health officer with the regional Department of Health office in Cebu, said that personal experience helps to build trust. "We know what they are experiencing," she explained. "We can also tell them exactly what the consequences of not seeking timely treatment will be."

Grassroots connections

While CLAP's activities are officially supported at the national government level—the coalition is represented on the Department of Health's National Leprosy Advisory Board—it is at the smallest level of government where the initiatives of the coalition's individual organisations are substantially embraced.

"We coordinate with local government units at the municipal and barangay [village] level, including the mayor's office and the city or municipal health official's office," Quimno explained. "Since our individual member groups are the ones doing most of the work right in their own communities, they are really embraced by their local officials."

Mark Anthony "Macoy" Esparas, a CLAP outreach volunteer in Manila, agreed. "We do receive a lot of help from the local governments," he told IPS. "What we do is helping them as well."

CLAP advisor Joseph "Boyot" Ongkiko highlighted the success of one CLAP member group in Cotabato, Mindanao, southern Philippines, which formed a cooperative of motorcycle taxi drivers to provide livelihoods for people affected by leprosy. "At first, the community was reluctant to patronise the drivers," Ongkiko told the conference attendees. "Now, they have been accepted so well, that the cooperative even has non-Hansenite members."

Other livelihood activities pursued by the member groups of CLAP—the coalition represents a total of 19 local organisations across the Philippines—include production and marketing of various household products, clothing, and small-scale farming.

Financial sustainability challenge

While CLAP's initiatives are steadily gaining traction among people affected by leprosy and local communities alike, the organisation is concerned about its prospects for sustainability.

"That is our biggest challenge right now," Onde said. "At the moment, our financial support is really only coming from the Sasakawa [Memorial Health] Foundation (SMHF), and we would like to better secure our future." SMHF, along with its parent body the Nippon Foundation (TNF) are co-sponsors of the assembly along with the Philippine government-run Culion Sanitarium and General Hospital (CSGH) and the Coalition of Leprosy Advocate of the Philippines (CLAP).

Financial sustainability is a common worry for leprosy advocacy groups throughout the region, but in the Philippines, Onde explained, CLAP and other organisations face a unique challenge. In 2013, a large-scale conspiracy dubbed the "Pork Barrel" scam and involving the misappropriation of billions in legislators' development funds was exposed. Funds intended for local projects were diverted to fabricated non-government organisations and then pocketed by the scam perpetrators, including a number of lawmakers.

"Since the Pork Barrel scam, it has become difficult for a lot of civil society groups, not only us, to attract donors," Onde said. "So one of our important tasks is to try to share information about what we're doing to convince potential financial supporters that we are a legitimate, sustainable organisation."

One advantage for CLAP is its close connection to the government's own leprosy control efforts. "We have a consultative role in the government's National Leprosy Control Programme and the Leprosy Roadmap 2016-2022," Onde said. "That does help give us some credibility, and of course, we strive to do good work to match that."

Capacity Building the Key to Fighting Leprosy

by Ben Kritz
ips.news.net

Beyond the day-to-day goal of carrying out programmes and managing organisations in an efficient way, capacity-building is key to helping the various organisations secure financial sustainability.

MANILA, Mar 3 2019 (IPS) - Strengthening the participation of persons affected by leprosy, or SPP, has proven to be an effective strategy in reaching out to often isolated sufferers in local communities throughout Asia. A significant challenge to civil society organisations, however, is finding enough management talent to maintain and expand the programmes.

Capacity building, providing organisational and management training to SPP participants doing the heavy lifting for leprosy advocacy groups in their work in individual countries, was highlighted as a significant priority by the participants at the Regional Assembly of Organisations of People Affected by Leprosy in Asia in Manila on Mar. 3.

Starting from scratch

The challenge is made even more difficult because many programme volunteers come from marginalised communities, or have had their own education interrupted by complications or social ostracism associated with leprosy.

Amar Bahadur Timalisina, president of International Association for the Integration, Dignity and Economic Advancement (IDEA), Nepal, told IPS that capacity-building is likely the biggest problem facing his organisation. "Many of the people working with us are completely uneducated, and some are even illiterate," Timalisina said. Many of Nepal's leprosy patients are found in poor communities, and face significant discrimination.

"Right now, we are focusing on building the capacity of our board members and

programme managers," Timalisina said. "Fortunately, we are able to work with the Leprosy Mission Nepal, who are able to provide us with expertise in business management, finance, and social programme management."

The discrimination that prevents leprosy sufferers from accessing education and seeking out medical and social assistance in Nepal is perhaps a bit stronger than in some other countries, as it is still part of the law in one respect. In his presentation to conference delegates, Timalisina highlighted IDEA Nepal's efforts to amend a constitutional prohibition of marriage between leprosy sufferers and unaffected persons, and to include information on leprosy in the country's health education curriculum.

Differing approaches

While the capacity-building challenge is a common priority, organisations in different countries have adopted different approaches to addressing it. For example, the focus of PerMaTa Indonesia, which means Gem in Bahasa, places heavy emphasis on emotional and social support for persons affected by leprosy. The organisation also directs much of its attention to youth. PerMaTa's Yuliati explained that the social focus helped leprosy patients gain acceptance, which is particularly important for young people to have continued access to education. Over the long term, it will help the skills capacity of the organisation; in the short term, however, PerMaTa must still rely on some degree of outside expertise.

China's Handa faces a similar challenge, but has actually been

able to quantify its need for expertise. The organisation, which has about 3,500 members across 14 provinces and serves nearly 9,500 beneficiaries, has structured its board so that one-third of its members are private-sector professionals, Handa representative Qi Xiuli told the conference delegates. With this arrangement, overall policy objectives are generated by persons affected by leprosy who make up two-thirds of the board, while the professional board members take charge of practical implementation of the organisation's initiatives.

Capacity tied to financial sustainability

Beyond the day-to-day goal of carrying out programmes and managing organisations in an efficient way, capacity-building is key to helping the various organisations secure financial sustainability.

In a group discussion, Dr. Arturo Cunanan, Director of the Philippines' Culion Sanitarium and General Hospital and the country's foremost leprosy advocate, pointed out the need for organisations to secure a substantial initial investment in order to be able to work on sustainability. Cunanan suggested that this might be one way organisations could address their capacity gaps.

"That initial investment may be in the form of a financial investment, but it could also be a technical or capacity investment," Cunanan told the conference delegates.

Sasakawa Memorial Health Foundation (SMHF) Executive Director Dr. Takahiro Nanri pointed out, however, that a financial investment would inevitably be limited. "You

can start off with grants from government or non-government sources, you can gather some financial resources in the form of membership fees, but these are limited," Nanri said. "In order to be truly sustainable, the organisation has to create an income-generating programme," and for that, the organisation would need sufficient expertise. SMHF is a sister organisation of the Nippon Foundation (TNF), one of Japan's largest foundations. Since the early 1960s, TNF has been actively working to eradicate leprosy across the globe and this has included providing free multidrug therapy through the World Health Organisation.

Having that capacity, however, would make achieving sustainability much easier, boosting the organisation's credibility to potential donors. "We know you probably couldn't generate real income to sustain your organisation for quite some time," Nanri told the delegates. "But we [Sasakawa Foundation] could justify supporting you for, say, three years, if we could see that you were able to develop a business plan that would be viable in that amount of time." Expertise in business and management is needed to be able to develop such plans.

Fortunately, most organisations seem to be successfully balancing the goals of becoming self-reliant and accessing enough expert help in planning and carrying out financial and operational strategies. In the group discussions, however, all the conference participants agreed that greater public awareness of their work would greatly benefit their respective organisations' goals.



Dr. Takahiro Nanri, Executive Director of the Sasakawa Memorial Health Foundation, explained the need for leprosy CSOs to develop income-generating plans to cover gaps in sustainable funding. The Sasakawa Foundation is a major supporter of organisations for people affected by leprosy throughout Asia. Credit: Ben Kritz/IPS

Living with Leprosy on the Climate-Vulnerable Kiribati Island Atolls

by Stella Paul
ips.news.net

MANILA, Mar 4 2019 (IPS) — Kurarenga Kaitire lives in Kiribati—one of the world's most climate-vulnerable nations. Already vulnerable to nature, the 29-year-old mother of five has faced a series of vulnerabilities over the past decade, including facing social stigma and domestic abuse.

The reason: she has leprosy—a disease still dreaded by many in the world.

Currently in Manila to attend the ongoing 3-day Regional Assembly of Organisations of People Affected by Leprosy in Asia, Kaitire tells her story of personal loss and triumph with IPS.

A 2010 medical test confirmed that Kaitire had leprosy, news she quickly shared with her husband of two years. What happened next was unexpected.

"He went cold. He stopped coming near me or our child. From next day he would not come home in time. He would not touch me and when I questioned him on why he was behaving like that, he beat me up and cut off my hair," she tells IPS.

When she could not take the beatings any longer, Kaitire threw her husband out of the house. He then stripped the home of its roofing, making the house uninhabitable.

It was around this time that she was introduced to Itinnenga Uan—country head of Pacific Leprosy Foundation in Kiribati. The foundation runs a welfare programme for leprosy affected people and Kaitire's conditions qualified her for it.

"She was single [divorced], she had physical deformity and she faced discrimination too. So we helped her [boost her income to rebuild] the house. She is very hard working and had tried many things to have an income, but now she sells vegetables

and potable plants. Now she has a better way to support herself and her children," Uan tells IPS.

Kiribati has only 118,000 people. But for such a small population, the number of people affected with leprosy is quite large as each year over 200 new cases are reported. The low-lying and sinking Pacific island nation has the highest percentage of people affected by leprosy compared to the total population.

And despite being a tiny country, the level of discrimination and stigma is just as high as everywhere else in the world, Uan reveals.

For a country which is considered lost to rising sea levels, this stigma is an added burden and one that is difficult to cope with. The government of Kiribati, which heavily relies on international aid for running welfare programmes, has just started to provide financial support to the people affected by leprosy. This is aside from providing free basic medication.

But to access the support packages, one must first be graded by the government. Grading is a clinical system of classifying stages of the disease for treatment purposes. According to the World Health Organisation (WHO), Grade 0 means no impairment, with Grade 2 meaning visible impairment. Scores are added also by combining indicators on six body sites and a final grades range from 0 to 12.

Those with the highest grade receive 50 Australian dollars a month.

There is no magic wand that either Uan or Kaitire know of. However, they are in Manila with the belief that there will be new ideas and connections that they can make to help themselves in the future.

However, the government has made significant progress in creating public awareness.

"People are highly aware of leprosy because there are regular programmes on public radio which give a lot of information. In fact Kurarenga Kaitire went to a doctor for a medical check up only after she had listened to a radio

programme on leprosy," Uan says.

But there is still a lot left to be done.

Programmes and policies that can address the vulnerabilities of leprosy affected people who are also climate

vulnerable is one of them.

For example, many of the people in Kiribati are severely crippled by leprosy. Many others are living with physical disabilities, which include loss of eye sight. There is still no climate policy that particularly designed for these people with special need.

"Because of the sea level rise, we are sinking. There is constant heavy rain, wind and flooding. So our government recently has announced that we all can elevate our houses to a higher level. If I want, I can build 4-5 stories on my house. But those who are immobile (with leprosy), how will they climb to such heights? What is the alternative for them?" Uan asks.

Kaitire who travelled for almost 24 hours to reach Manila,

the capital of the Philippines, admits that she is experiencing stiffness in her legs already. She also has just spoken to her daughter in Kiribati over the phone and learnt that its raining heavily there. The thought of another 24-hour journey and multiple flights and walking in the middle of a flood is intimidating for her. "I will come to your home," she tells Uan, trying to humour herself. Uan's home is closer to the country's airport and not affected by the flooding.

There is no magic wand that either Uan or Kaitire know of. However, they are in Manila with the belief that there will be new ideas and connections that they can make to help themselves in the future. The Sasakawa Memorial Health Foundation/ the Nippon Foundation (TNF) which supports leprosy projects across the world, is yet to work in Kiribati. If they enter the country and partner with the government, there can be better support for the leprosy affected people, Uan hopes. TNF has been supporting leprosy eradication across the globe since the late 1960s, even supplying free multidrug therapy through the WHO.

Kaitire, on the other hand, is more focused on helping her children obtain an education and making herself strong enough to deal with all the challenges she may still face—be it social, physical or financial.

Recently, her ex-husband returned to her, asking for forgiveness but she didn't take him back. "I need medication, financial stability and above all, dignity. I don't want a man who can't give me that."



Itinnenga Uan—country head of Pacific Leprosy Foundation in Kiribati (left) and Kurarenga Kaitire, travelled for almost 24 hours to reach Manila, the capital of the Philippines, to attend the Regional Assembly of Organisations of People Affected by Leprosy in Asia. Credit: Stella Paul/IPS

Individual Empowerment Still Important in Leprosy Groups' Strategies

by Ben Kritz
ips.news.net

The approach is as much practical as it is aspirational. A common theme that emerged in the conference's first day was the challenge faced by organisations in achieving and maintaining financial sustainability.

MANILA, Mar 4 2019 (IPS) - The tragic tale of Thobias Alexander Manas's personal experience with leprosy is all too typical.

Manas, who is now 52, is from West Timor, Indonesia, and was afflicted with leprosy as a grade 10 student. The reaction to his illness as soon as he exhibited signs of the disease was predictable. Shunned by his friends and forced to leave school, Manas was eventually driven out of his family's home by his sisters and exiled from his village. He was eventually reduced to an isolated existence in a shanty he cobbled together from discarded materials, he told IPS through an interpreter.

Related IPS Articles

Living with Leprosy on the Climate-Vulnerable Kiribati Island Atolls

Q&A: We Need a Holistic Approach to Eradicate Leprosy Capacity Building the Key to Fighting Leprosy
FEATURED TRANSLATION – FRENCH

When his disease became too painful—it had progressed to the point where Manas suffered permanent deformity of his hands—he made his way to a government health clinic where he was finally properly diagnosed and prescribed treatment. Fortunately for Manas, the clinic had a referral arrangement with UK-based Leprosy Mission International, which offered assistance to Manas.

"Thoby had to end his schooling because of his sickness, and so the most important thing

was to offer him some kind of skills training," explained Kalep Manikari, a former field worker for Leprosy Mission International and now a youth minister. Manas received training in tailoring, and was able to return to his village and set up a small shop.

His talent in spite of his disability helped to overcome the stigma he had experienced earlier, and it helped that Manas had been shrewd in his choice of vocation: His village only had one other clothing maker – who has now been his wife for 19 years. "Still, my family was against the marriage, because I had been sick," Manas tells IPS through his interpreter. "But I said, it's up to us to manage our lives, so we went off and married without their consent."

Facing the prospect of losing not just one but both of the only people who could provide well-made clothing in the village, Manas family eventually accepted his marriage and his business thrived; he explained that he had recently diversified into poultry and rice farming, and had been able to send his daughter to college. Is was not without some pride that Manas described how he is now considered "well-off," and has been transformed from a once-shunned leprosy sufferer to one of his village's leaders. Practical social entrepreneurship

Skills and livelihood training has always been a key objective of organisations supporting people affected by leprosy,



Thobias Alexander Manas (R), here with his former social worker Kalep Manikari (L), was shunned and driven from his school, home, and village in West Timor when he contracted leprosy as a teenager. Thanks to individual intervention and skills training, Thobias, now age 52, owns a sewing shop and a rice and poultry farm, and is a community leader in the village that once rejected him. Credit: Ben Kritz/IPS

and the three-day conference was filled with success stories much like Manas's. While this remains a priority strategy, leprosy advocacy groups are shifting more of their focus toward organisation-level social entrepreneurship.

In a workshop session at the Regional Assembly of Organisations of People Affected by Leprosy in Asia in Manila on Monday afternoon, conference participants discussed various ways their groups could generate revenue through social entrepreneurship.

The approach is as much practical as it is aspirational. A common theme that emerged in the conference's first day was the challenge faced by organisations in achieving and maintaining financial sustainability. Government and other donor grants are variable, and unavoidably limited. As Dr. Takahiro Nanri, the executive director of the Sasakawa Memorial Health Fund (SMHF), commented, "We are willing to give a great deal of support to these organisations, but whether we wish it or not, sometime it will have to end. Hopefully that does not happen before the organisations are able to stand on their own, so that is what we are trying to help them achieve." SMHF is a sister body of the Nippon Foundation (TNF), one of Japan's largest foundations.

Social entrepreneurship, the conference participants agreed, was a practical approach to meeting financial and social

needs. Revenues from products created by organisations of people affected by leprosy fund the organisations' activities, while providing livelihoods for their beneficiaries.

Even though there is a great deal of enthusiasm for the idea of organisation-level social entrepreneurship, there was a sense among the conference participants that in some circumstances success might be more easily described than achieved. Differences in resources and capabilities may narrow options for some organisations and expand them for others.

That reality makes it important for organisations to give equal attention to both collective and individual entrepreneurial opportunities, Manas suggested. "I just needed a chance. It's important that organisations help people who can help themselves."

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New Regional Secretariat to Advance Leprosy Advocacy in Asia

by Ben Kritz
ips.news.net

Culion Sanitarium and General Hospital Medical Director Dr. Arturo Cunanan (left) urged delegates to the Regional Assembly of Organizations of People Affected by Leprosy in Asia to "put our partnership beyond these walls" and act on the strategies discussed at the three-day conference.
Credit: Ben Kritz/IPS

The consensus among the participating organisations was that sustainability was indeed a critical priority, and perhaps the most significant challenge faced by leprosy advocacies at the national level.

MANILA, Mar 5 2019 (IPS) -

Organisations of people affected by leprosy in Asia have agreed to form a regional-level secretariat to support national advocacies and represent their collective agenda at a world conference to be held later this year.

This was the most significant development to emerge from the Regional Assembly of Organisations of People Affected by Leprosy in Asia held in Manila from Mar. 3 to 5. The Coalition of Leprosy Advocates of the Philippines (CLAP) was selected by the delegates to serve as the first regional secretariat.

Sasakawa Memorial Health Foundation (SMHF) Executive Director Dr. Takahiro Nanri requested that the first major initiative of the secretariat be the formulation by June of a "road map" encompassing the Assembly's consensus agenda, which would then be used by the SMHF and its parent body the Nippon Foundation (TNF) to help develop the programme for the world leprosy conference to be held in September.

SMHF and TNF convened the regional assembly in partnership with CLAP and the Culion Sanitarium and General Hospital (CSGH).

From theory to practise

CSGH chief Dr. Arturo C. Cunanan told the delegates assembled for the final day of the conference that, "putting our partnerships beyond these walls, putting it into action, is the big challenge" faced by the national organisations, who represented the Philippines, Indonesia, Nepal, China, and Kiribati.

Cunanan, who is considered the Philippines' foremost leprosy

expert, was particularly upbeat about the conference's focus on improving communications to stakeholders.

"One of the most valuable things to come out of this conference is the learning about social marketing, and what interventions we can use," Cunanan stressed to the attendees.

Another key takeaway from the conference, Cunanan said, was the recognition of economic opportunity as a vital component of social inclusion strategies for people affected by leprosy.

"I think an important thing that has emerged here is the idea that poverty is really the root of stigmatisation and prejudice," Cunanan told IPS. "When people have financial resources, the discrimination goes away. Obviously, providing economic opportunity should be a priority for the various national organisations."

Cunanan pointed out that priority complemented the focus on organisational sustainability, which was an emergent theme at the conference. "It is very similar to the same thinking that organisations need to find income-generating programmes to be sustainable," Cunanan said. Reiterating the point he made to the assembly, he added that the goal for the organisations should be to put "theory into practise" and develop practical actions from what they learned.

Clear consensus

Starting with an overall theme of "improving social inclusion," the Regional Assembly of Organisations of People Affected by Leprosy in Asia at the outset identified four areas for discussion: Preserving the history of leprosy and its treatment; defending human rights and eliminating the stigma associated

with leprosy; improving the delivery of public health services; and sustainability of the organisations.

The consensus among the participating organisations was that sustainability was indeed a critical priority, and perhaps the most significant challenge faced by leprosy advocacies at the national level.

Another key national-level agenda item agreed by the conference attendees was the need to improve networking with their respective governments, as well as other key organisations. In line with this, developing strategies to improve organisations' public image, branding, and their marketing efforts was also acknowledged as an important objective for national organisations. During the conference, the importance of understanding and developing effective social marketing was stressed, both through the use of social media and more conventional practises.

The development of a regional secretariat was considered the most important objective at a collective level. The conference participants echoed the sentiments of CSGH's Cunanan that the shared ideas developed over the three days of talks should not be allowed to "dissolve" when the organisations return to their home countries.

Conference attendees also agreed that creating a "sustainable development strategy" on a regional basis should be prioritised going forward, taking into account the need to strengthen national organisations as well as the regional group. Just what that strategy would entail, however, is still subject to discussion among the various groups.

Capacity building, improving the organisational and managerial capabilities of national organisations, also emerged as a regional agenda. During the conference, capacity building was expressed as a significant concern for many organisations, since many of their members lack relevant work experience or education. A regional strategy could help pool talent resources among the Asian organisations, at least until some of their own people could gain more experience.

The development of a regional framework and individual national agendas made the first Regional Assembly of Organisations of People Affected by Leprosy in Asia a success, conference facilitator Joseph "Boyot" Ongkiko told IPS.

"What excites me is to see the coming together of different groups, and their coming away with unity of heart and purpose," Ongkiko said. "With leprosy, there is a commonality in the stories, but what we saw and heard are people moving from victims to victors."

Nanri told IPS that much still needs to be done.

"There's a big difference between elimination and eradication. As of today, most countries have eliminated leprosy, but it has not been eradicated yet as new cases continue to appear. To eradicate, what we need is one last big push – or re-activate public attention to leprosy," he said, adding that until now the information around leprosy has not been well presented.

"If we can better package it, forge better partnership with media and if we can get greater political commitment, we can make that reactivation of people's attention can happen."

Leprosy Survivor Creates Hope and Support for Others Affected by Disease

by Nalisha Adams
ips.news.net

"The doctor promised me I would be helped. And I promised that I would help those with leprosy"

MANILA, Mar 4 2019 (IPS)

- When Ariel Lazarte from Quezon City, Philippines, was first diagnosed with leprosy in 2014, his life seemed as if it was falling apart. But now more than four years later Lazarte's life is a huge contrast from the poverty and isolation he experienced as a person affected by leprosy.

Now the owner of multiple businesses, including ones in transport and construction, and the owner of a large family home as well as an in-patient home for persons receiving treatment for leprosy, Lazarte was driven to become a success by his strong desire to help others.

"I didn't get any help from my family, my friends, my relatives. I only trusted the doctor," Lazarte tells IPS of the year he spent receiving treatment for leprosy, which is also known as Hansen's Disease. "I was very thirsty for the help from others. I was in need."

He was one of the participants of the Regional Assembly

of Organisations of People Affected by Leprosy in Asia. The assembly is being held in Manila, Philippines, Mar. 3 to 5 and is supported by the Nippon Foundation (TNF)-one of the biggest private foundations in Japan that has been working to provide assistance to people with leprosy since the late 1960s.

At the time of the diagnosis, the then 32-year-old who worked as a manager in a fast food store, was able to afford treatment at a private hospital. But instead of being cured, his condition worsened.

Eventually, he lost his job and felt more and more alone as his wife stopped sharing a bed with him and his friends stopped visiting. His wife's dried fish kiosk business become their sole support of income and much of the money was spent on survival and not medicine.

And while he kept receiving treatment, he kept thinking: "I'm dying." Eventually Lazarte's doctor told him he couldn't cure him and



Filipino businessman Ariel Lazarte was diagnosed with Hansen's Disease in 2014. Since his treatment he has built a successful business and has become a patron for those affected by the disease. Credit: Nalisha Adams/IPS

referred him to the Jose Reyes Memorial Hospital. He began an 8-month treatment course that eventually cured him.

"The doctor promised me I would be helped. And I promised that I would help those with leprosy," Lazarte says, explaining that it didn't want others who were affected by the disease to experience what he did.

According to a World Health Organisation report, the country has 2,000 new leprosy patients a year. Dr Maria Francia Laxamana, assistant secretary of Health in the Department of Health, says only one in four receive treatment because many fear the social stigma.

But after a year of treatment that cured him of Hansen's Disease, Lazarte started fulfilling his promise.

Lazarte started small. With 15 dollars, he bought some shorts and pillows and began selling them. Soon he bought a tricycle - a Filipino transport bicycle with a small cab. And soon he owned seven of these.

And then later he was able to afford a jeepney. Unique to the Philippines, jeepneys are long wheel based taxis, converted from American jeeps left in the

country after World War II.

He is now the owner of 12 jeepneys.

With the money from the businesses he built a 4-bedroom in-patient home for those receiving treatment for Hansen's disease. Situated just outside the capital, it houses people receiving treatment at the Jose Reyes Memorial Hospital. The property also has a car so the patients can drive to the hospital, which is some 45 minutes away, for their check ups.

He's very clear about what he spent the income from these business on in the early days. "I knew that my wife was able to support my children ...so I kept on dreaming of having enough money to buy my afford to the house [for the leprosy patients]."

While they now have a large home and not all Lazarte's income goes into the in-patient home, Lazarte says that he wants the Hansen's Disease patients to learn to self-sufficient. They have a garden to plant vegetables for resale and recently received funding for a poultry project.

"I started my own pathway for my own direction," he tells IPS.



Unique to the Philippines, jeepneys are long wheel based taxis, converted from American jeeps left in the country after World War II. Credit: Nalisha Adams/IPS

Q&A: Why Treating Leprosy as a Special Disease Violates the Rights of the Person Affected by It

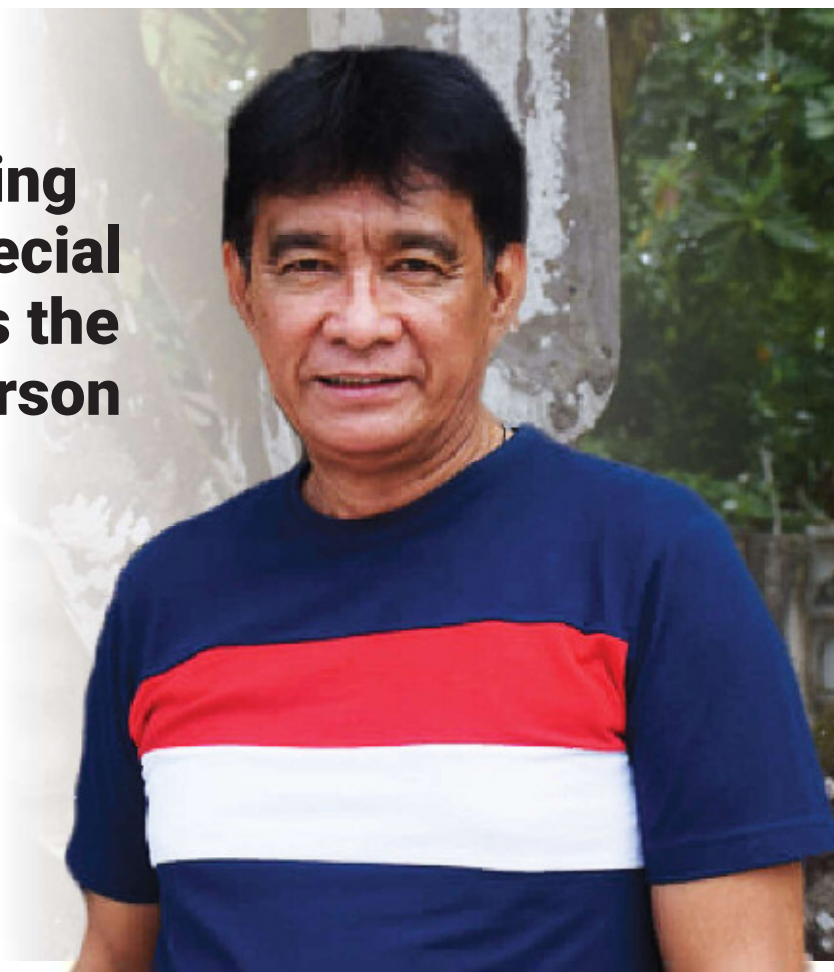
IPS Correspondent Stella Paul interviews DR ARTURO CUNANAN Jr., one of the world's leading experts on leprosy and Medical Centre Chief of Culion Sanitarium and General Hospital in the Philippines.

MAJURO, Mar 25 2019 (IPS) – His multiple awards and degrees aside, Dr. Arturo Cunanan is known as a people's doctor; one who has profound belief in the human rights of every person affected by Hansen's disease, commonly known as leprosy. Considered one of the most experienced experts on the disease in the world today, Cunanan is currently the Medical Centre Chief of Culion Sanitarium and General Hospital in the Philippines. He is the first director of the hospital who is a direct descendant of people affected by Hansen's disease who were isolated and segregated in Culion. The island of Culion, where the hospital is based, was originally set up as a leper colony at the turn of the 20th century, with the hospital been founded to solely treat patients with Hansen's disease. However, from 1994, the Culion Sanitarium and General Hospital began general hospital services.

Currently in the Marshall Islands, in the northern Pacific, to review the national leprosy programme for the atoll nation, Cunanan tells IPS about the importance of viewing leprosy as an ordinary disease and how the failure to do so leads to continuous stigma.

"Integration of leprosy in the mainstream is important and it is also important to see that leprosy is treated as an ordinary disease and not as a special disease. Leprosy then becomes an ordinary disease. But if you treat leprosy as a special disease, then those with leprosy can become more stigmatised. People who have leprosy, can live a normal life. This is the message," he tells IPS.

Recipient of several national and international awards, including the 2015



Gandhi Peace Prize, Cunanan earned his Masters in Public Health and Hospital Administration at the University of the Philippines and a Doctorate (PhD) in Health Systems and Policy at the National Institute of Health, University of Leeds as an International Ford Foundation Scholar.

He is also a consultant with the World Health Organisation and has provided his leadership in reviewing the National Leprosy programmes across the Micronesia region.

Cunanan is also the implementer of Sasakawa Health Foundation/Nippon Foundation's projects in Culion and the Philippines that are related to leprosy and human rights, preservation of leprosy history, and various socio-economic projects that improve quality of life of people affected by leprosy and their families. Excerpts of the interview follow:

Inter Press Service (IPS): Can you elaborate on how treating leprosy as a special disease leads to more stigmatisation and violates the rights of a person affected by it?

Arturo Cunanan (AC): Leprosy is one of the oldest known diseases in human history. It's a biblical disease; there are instances of Jesus meeting men suffering from leprosy—men who were described as unclean and who became clean after Jesus touched them. The fear of leprosy and the social reaction to leprosy—both are old.

This means that leprosy treatment can be made available at the local level. At every health centre, someone should be skilled enough to at least raise suspicion—if not fully detect—when he or she notices a possible case of leprosy.

In modern times, we have seen governments bring in laws that were built on the rule of detection and segregation. All of this only alienated a leprosy-affected person further.

But the truth of the day is: leprosy is curable. A person with leprosy can live a normal life. He can get treated—free of charge—for his disease. But, if we continue to treat leprosy as a special, extraordinary disease, it will perpetuate the alienation and it will also perpetuate the fear and stigma.

IPS: What happens when a leprosy-affected person faces stigma?

AC: First, they are socially, economically, and culturally isolated. People in their village, neighbourhood, society stop making contact with them and their families. But it ultimately violates their rights to respect and dignity. Let me give you an example. In Culion, we get visitors. Some of them ask me if they can visit some leprosy-affected people. I tell them, look around you—everyone here has been affected by leprosy. But they look around and they do not want to believe what they see: normal people, with a normal physical appearance.

What these visitors are expecting to see is a person who has severe physical deformity, because in their minds, they [the visitors] have the image of a leprosy-affected person like that—a demonised image.

So, I tell them, these are people, no matter how severely they are affected by the disease—they are people like you and me, they have a right to a life of respect and dignity. How would you feel if someone looked at you in shock and fear, maybe disgust and gasp? This is what stigma and isolation leads to—the total denial of dignity.

IPS: How does this affect the treatment of leprosy?

AC: There are several reasons why a person affected by leprosy doesn't seek treatment and social stigma is one of them. The person is afraid that once he has been confirmed as a person who has leprosy, the reaction of society will be severe towards him and his family.

They will not be included in any social or cultural events, nobody will visit them at their homes, and nobody will continue social relations with them. This will affect them economically also, they will not be employed like before. All of this discourages the person from going to the health centre and reporting his condition as he wants to avoid this social stigma.

IPS: You often say that Leprosy treatment needs to be integrated into the general health service system. What does that mean?

AC: This means that leprosy treatment can be made available at the local level. At every health centre, someone should be skilled enough to at least raise suspicion—if not fully detect—when he or she notices a possible case of leprosy.

For example, a person visits the health centre with a visible patch on his or her body which maybe numb. If a staff member at the health center can suspect that this could be a leprosy case, he could share this with the person and refer this person to a more skilled health worker to another clinic that specialises on leprosy. This way, a detection, confirmation and treatment could then begin. But if the staff member is not capable of this, then he could simply give him an ointment for a skin rash and send him back home.

Especially in the islands, where people live a simple life, in close contact with the sun, sand and salt water, small skin marks like a patch would not usually make a person suspicious of his body or make him go to a leprosy clinic straightaway. But if even one person at the health centre can think that this might be leprosy, it could be a big help.

The third point is, even when the treatment begins, the person affected by leprosy may not take his medicines regularly or may not monitor his health conditions such as a sign of reactions etc on a regular basis and this could affect him adversely. But, if the staff at his local health center can communicate with him that he must report back if there is a reaction, he will do so. So, it is key to have leprosy treatment integrated in the general health service, so there are skilled workers at every level of the health system.



The Philippines has the highest incidence of leprosy of any country in the region – about 1,700 new cases have been identified in each of the last three years. Credit: moyerphotos/CC by 2.0

“That also helps to reduce some of the social stigma patients face, by giving us a chance to educate their communities and eliminate some of the fear of the disease,”

Leprosy Remains a Stubborn, Unseen Problem in the Philippines

by Ben Kritz
ips.news.net

MANILA, Mar 2 2019 (IPS) - The stubborn challenge of diagnosis and treatment of leprosy among difficult to reach populations in the Philippines should soon become easier with the rollout of a mobile app connecting field health workers with physicians and clinics.

Officially launched at the end of January after years of testing, the app was created by Philippine developer MetaHelix in cooperation with the Department of Health (DOH) and pharmaceutical company Novartis. It will allow barangay (village) health workers to connect remotely with specialists to confirm diagnoses and plan treatment of isolated leprosy patients.

First launched as a pilot in 2014, the Leprosy Alert and Response Network System (LEARNS) app allows healthcare workers to “send images of suspect leprosy lesions and symptoms to a specialist”.

“LEARNS promotes early case finding and helps reduce delays in diagnosis and treatment,” Novartis said in a statement when the app was launched. “LEARNS also provides data for disease surveillance, patient education, and report generation.”

The new mobile application that was tested in the Philippines for more than a year highlights ongoing efforts against leprosy, or Hansen’s Disease, which is sometimes called “the world’s oldest diagnosed disease”.

In most of the world leprosy is largely considered a disease of the past. According to the World Health Organisation (WHO), leprosy was eliminated as a global public health problem in 2000 because it had a prevalence of less than one case per 10,000 people.

The treatment of leprosy in the Philippines throughout most of the country’s history has been typical of the way societies everywhere have handled it.

However, one of the few remaining places where the disease remains an elevated public concern is the Philippines, which makes the country an appropriate venue for the “Regional Assembly of Organisations of People Affected by Leprosy in Asia,” being held in Manila from Mar. 3 to 5.

The conference is a joint project of the Philippine government-run Culion Sanitarium and General Hospital (CSGH), the Coalition of Leprosy Advocate of the Philippines (CLAP), and the Sasakawa Memorial Health Foundation (SMHF)/the Nippon Foundation (TNF), and seeks to find ways to overcome the last stubborn obstacles to completely eradicating leprosy.

The issues faced by public health advocates and victims of the disease in the Philippines are emblematic of problems faced throughout the region: Difficult detection and treatment of often isolated sufferers, a lack of public awareness and understanding of leprosy, and low prioritisation of public health efforts to treat leprosy and its social impact on the part of governments.

Hidden in plain sight

The treatment of leprosy in the Philippines throughout most of the country’s history has been typical of the way societies everywhere have handled it. Largely ostracised by communities and even their own families, leprosy sufferers were isolated in dedicated facilities and kept out of sight. The two best-known facilities in the Philippines are the CSGH, once the largest facility of its kind in the world, located on Culion Island in the Western Philippines; and the Tala Sanitarium – officially known as the Dr. Jose N. Rodriguez Memorial Hospital – located in Calocan, a distant suburb of Manila.

Although both facilities are still technically operational, better understanding of the disease and its low communicability has allowed health officials to shift most of their efforts to community-based treatment. According to Dr. Mary Ann Navarro, a Department of Health administrator in Palawan, where a minor outbreak of leprosy among indigenous people was detected in late 2017, in situ treatment is often the only feasible approach.

“Better treatment options and the relatively low risk of transmission means that it’s not necessary to isolate patients,” Navarro told IPS. “Many cases, such as the ones discovered last year here [in Palawan] are among people with little access to healthcare, so our best option is to bring treatment to them.”

“That also helps to reduce some of the social stigma patients face, by giving us a chance to educate their communities and eliminate some of the fear of the disease,” she added. “Changing social attitudes still is a big challenge, however.”

Situations like the outbreak in Palawan, where eight cases were discovered among an indigenous community in the southern part of the island, are relatively rare. Most cases, according to a local government official, are individuals who remain in the community, but often struggle for acceptance.

“To our knowledge, we have about 10 people from this barangay who come to the health centre for treatment,” Alexander “Bong” Medina, chairman of a barangay in San Jose Del Monte in Bulacan Province north of Manila told IPS.

“The treatment is provided free, and we do our best to assist them socially, but it’s difficult,” Medina explained.

“These are poor, what you might call marginalised people to begin with, and they often don’t realise there is assistance available until it’s too late, or they are afraid to come in because of the shame. And we don’t really have resources to go seek them out.”

Persistent problem

The Western Pacific Regional Office of the WHO views the Philippines as somewhat of an outlier in terms of leprosy incidence. The Philippines has the highest incidence of leprosy of any country in the region – about 1,700 new cases have been identified in each of the last three years, although that rate is half what it was a decade ago – and is largely responsible for the region being behind the rest of the world in achieving the 1 in 10,000 benchmark.

According to data from the Philippines’ Department of Health, although the overall prevalence of leprosy is less than 0.4 cases per 10,000, 1,660 new cases were identified in 2017 alone, with about 6.7 percent of those being children under the age of 15. This Southeast Asian nation, which comprises some 7,000 islands, has a population of over 104 million.

To address the problem, the Philippine government in 2016 launched the National Leprosy Control Programme (NLCP), a multi-agency effort involving the DOH, WHO, and a number of private sector and NGO partners with the goal of “a leprosy-free Philippines by 2022.”

To better calibrate the programme’s response and identify pockets where leprosy is still prevalent, the first major initiative of the NLCP is the completion of a baseline population survey, being conducted in cooperation with the Regional Institute for Tropical Medicine and expected to be completed sometime this year.

The programme is also working on raising public awareness and understanding of the disease by promoting various activities, such as World Leprosy Day in January, a national-level Leprosy Control Week in February, and National Skin Disease Detection and Prevention Week, which is held the second week of November.