The Leprosy Movement in Indonesia

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GPDLI (GERAKAN PEDULI DISABILITAS DAN LEPTA INDONESIA and FARHAN (Federasi ReINTEGRASI HANSEN INDONESIA))

www.pedulidisabilitas.org
GPDLI TEAM – Hermen and Abi + Nuah
FARHAN – Federasi ReIntegrasi HANSEN INDONESIA Team

An UMBRELLA Organization for all LOCAL and NATIONAL Leprosy grass root/DPO, CSO, NGO in INDONESIA developed in 9th December 2015 by Indonesia Human Rights Commissioners and GPDLI + people affected by leprosy in INDONESIA

http://www.pedulidisabilitas.org/?p=1401
Leprosy Movement Start with a very humble and modest situation and condition since 2007 (PerMaTa) and then GPDLI and FARHAN etc
SELAMAT TAHUL BARI 2007 kami ucapkan terlebih dahulu kepada pembaca setia BULLETIN ESAHABAT YTL, sukacita menyambut tahun 2007 ini.

Perkara yang terus berlaku pada tahun 2006 disempurnakan sementara ini, dengan kebijakan yang diterapkan. Perkara ini adalah bagian dari program yang telah dikuatkuatkan oleh Pemerintah yang akan diterapkan dalam pembinaan mesyuarat yang akan berlangsung pada bulan Januari 2007.

Huraian ini bukanlah komunikasi yang akan diterapkan dalam mesyuarat, tetapi sebagai pengisyah pendekai yang akan diambil pengetahuan dan inisiatif dalam membentuk rekaan perubahan yang akan diterapkan untuk tahun 2007.

Sebagai pelaksana program dan staf pelaksanaan, kami sangat menghargai peran serta kemampuan dalam mengoperasikan program ini. Kami berharap program ini dapat dijalankan dengan baik dalam menjalankan program ini.

Salam hangat,

Dari

Jakarta, 1 Januari 2007.
This is the FIRST WORLD LEPROSY DAY developed by People Affected by Leprosy ORGANIZATION – started since 2007.
Meet with President JOKO WIDODO

Together with People With Disability In International Day of People with Disability in State Palace (3rd Dec 2015)

And in early 2016 – Disability Law (based on CRPD) was signed and accepted by The Parliament (GPDLI is the part of the team) the only one Leprosy grass root Organization involved since early 2012.

http://www.dpr.go.id/prolegnas/index/id/26
INDONESIA AS THE LARGEST ARCHIPELAGO
(Indonesia as a Country)

Indonesia is the world’s largest archipelago with the population around 220 million in 2005 where more than 85% of its inhabitants professing the Islamic religion, making it the largest Islamic country in the world (but Indonesia is not ISLAMIC ideology State – we BELIEVE in PANCASILA – Spirituality, Humanity, Unity, Democracy and Justice/ Equality/ based on Dr Ir Soekarno thoughts our first President of Indonesia.

The country consists of a lot of ethnic groups who have different culture and languages (thousands). In 1997/8, the country was shocked by monetary and economic crisis that suffered majority of its population. But now is getting better, because of our 7\textsuperscript{th} President: JOKO WIDODO (Jokowi).
Advocacy for Disability Law with PPDI, HWDI, Gerkatin etc
LEPROSY ISSUES in Indonesia

Indonesia is a big country and has the fourth largest population in the world. Until now, Indonesia ranks third in the world the number of leprosy patients as many as 20 022 cases of leprosy (leprosy National Statistics in 2011).

Sequence 5 cities in Indonesia with a number of cases are East Java, Jakarta, West Java, Papua and South Sulawesi.
Basic Public Health Service still struggling including Education and

GPDLI focused on CRPD Article 28 and will focusing the others:

The description of the project is as follows:

To increase understanding and realization of CRPD Article 28 (Adequate Standard of Living and Social Protection) in relation to people with leprosy in Indonesia. This project will build the capacity of persons with leprosy to conduct advocacy on Article 28 at provincial, district, and city levels in Medan, Surabaya, Bali, and Jakarta; and work in these large cities to raise awareness amongst authorities and the broader community on people with leprosy as people with disabilities.
5,000 people involved in this
The national socio-economic survey 2004 conducted by BPS indicated that about 27.86% of its population have been categorised as poor with level of expenditure for consumption less than poverty line of Rp.102,635 (about US$11.5) per capita per month (BPS, 2005).

This figure will be even more increased significantly by using poverty line of US$1 a day as it is commonly used internationally. The poverty situation was not becoming better since monetary and economic crisis in 1997/8.
Neglected tropical diseases [NTDs] are a group of 17 diseases that are medically diverse, but form a group as all are strongly associated with poverty, all flourish in impoverished environments and all thrive in tropical areas (WHO, 2010).

The term “neglected” is used in the name of this group diseases, as the diseases received little or no public health attention, advocacy or funding, until recently (Kolaczinski, Kabatereine, & Onapa, 2007). Although several NTD-related programmes exist nowadays, still enormous progress is needed (UN, 2006; WHO, 2001, 2011).
PerMata and friends (active in a very limit areas)
From a Research developed by Netherlands in these couple months (including in our Leprosy Settlement)

As also occurred in many countries around the world, leprosy affected people in Indonesia remain facing great challenge to have an access to social and development programs.

Although the roots of the fact remain unclear to this date, it is believed that a mixture of discrimination and stigma over people affected by leprosy and low concern of civil society to leprosy issue contributed to it.
Leprosy and the challenge of organization development and its sustainability.

While discrimination and stigma have been a global issue, the particular aspect that clearly happened in Indonesia is the low concern of the state as well as civil society toward issue, especially in relation with number of organization who work in the field, budget/fund allocated and programs.

As for instance in 2007, YTLI (Yayasan Transformasi Lepra Indonesia) is the only national organization that operates across provinces, while the others were merely operates locally.

INTERNATIONAL organization which is active in Indonesia with Ministry of Health since 1969 until around 2009 are The Leprosy Mission (TLM) which coordinated from South East Asia Headquarter in Singapore (TLM Indonesia Representative for Indonesia until that time is Nuah Tarigan) and NLR (Netherlands Leprosy Relief).
From a Research developed by Netherlands in these couple months. (Additional and current situations) in 2016

NTDs exist in 149 countries in southeast Asia, east Asia, sub-Saharan Africa and Latin America, where at least 100 countries are endemic for 2 or more NTDs (WHO, 2010). For example, in Indonesia, soil-transmitted helminth infections, lymphatic filariasis, schistosomiasis, dengue, yaws and leprosy are coendemic.

in at least parts of the country (Tan, Kusriastuti, Savioli, & Hotez, 2014). Approximately 195 million Indonesian citizens, which is most of the population, live in areas where at least one NTD is endemic (Tan et al., 2014). Estimates are that NTDs cost the lives of around 500,000 people per year (Hotez, Ottesen, Fenwick, & Molyneux, 2006).
Although these numbers are already striking, the main impact of NTDs is not captured by mortality figures, but arises from chronic disability and morbidity1 (Hotez, Ottesen, et al., 2006).

Globally, an estimated 1 billion people are affected by NTDs, causing a global burden of 56.6 million DALYs2 (WHO, 2010, 2015). It is estimated that only lower respiratory infections, HIV/AIDS, and diarrheal diseases cause more DALYs globally (Hotez, Molyneux, Fenwick, & Ottesen, 2006).
THE FIRST VISION coming from LEPROSY INSIGHT (GRASS ROOT organization)

A more specific vision statement for this planning period is:

Our vision for Indonesia is that people affected by leprosy will live as normal (common) members of their communities, able to enjoy quality of life through freedom from discrimination and access to opportunities to care for and support themselves and their families.

Their communities will work together to limit the impact of leprosy through communal awareness of the disease and early diagnosis.

MUST BE Implemented and developed by PEOPLE AFFECTED BY LEPROSY THEMSELVES so that is why GPDLI developed with this below VISION”
The intent and purpose of this GPDLI are: (VISION Strategy)

1. RESTORING and SATURATING SELF CONFIDENCE FOR PEOPLE who have had leprosy and its disability / OTHER DISABILITIES.

2. REMOVING Negative stigma EXPERIENCED among PEOPLE WITH DISABILITIES AND LEPROSY / OTHER DISABILITIES.

3. EMPOWERING PEOPLE who have had leprosy (PEOPLE AFFECTED by LEPROSY) and their SURROUNDING COMMUNITIES IN BUILDING better FUTURE starting from their PERSONAL situation and then their FAMILY and COMMUNITY/ society.
Are you aware of the Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members adopted by the United Nations General Assembly in December 2010 (resolution 65/215)? If yes, how did it come to your attention?

GPDLI: Yes we know very clearly the Principles and Guidelines on this well, therefore in the vision of our mission very clearly include this as one part GPDLI, can be seen in http://www.pedulidisabilitas.org/?page_id=2

PerMaTa and friends in Makassar South Sulawesi
HRCAC Elimination of DISCRIMINATION against PERSONS AFFECTED BY LEPROSY

You could see these complete QUESTIONS and ANSWERS at
[Subject: HRCAC Elimination of discrimination against persons affected by leprosy]

or

Secretariat of the Human Rights Council Advisory Committee
Attn. Ms. Dina Rossbacher
Office of the United Nations High Commissioner for Human Rights
CH-1211 Geneva 10, Switzerland

Fax: +41 22 917 9011
Working together with Leprosy Community in 4 areas in North Sumatera and several areas in Jakarta and its Fringe Areas.
North Sumatera (Huta Salem – around 300 Kms from MEDAN and Lau Simomo around 80 kms – Capital City of North Sumatera) + Pulau Sicanang and Belidahan.
FARHAN – GPDLI and KOMNAS HAM + People
KUSTA DAN DISABILITAS
BUKAN HAMBATAN
UNTUK MERAHI MASSA DEPAN

Peduli Kusta lewat Lensa

SORAYA - Ingat saja itu pesan dari seorang kustastot... dan dilerik di lapak kopi di pusat kota. "Kustastot jangan sempat putus asa, jangan mencari kehidupan yang menyenangkan dari dunia ini, kita harus belajar untuk hidup paceklik, hidup dengan orang lain..." Tutur Suryadi, kustastot di Malang. Kustastot adalah orang yang berkebutuhan khusus, fisik atau mental, yang memerlukan perhatian khusus dan dukungan untuk hidup dengan kondisi tersebut.

Sosialisasikan Kusta lewat Foto


Mantan Penderita Kusta yang Tetap Eksis

SURABAYA, SURYA - Selasa, 13 Februari 2012, mantan penderita kusta kini tampil dengan ceria dan bahagia di sebuah festival unggai yang diadakan oleh Pemda Surabaya. Mantan penderita kusta ini memberikan pesan positif kepada masyarakat bahwa kusta bukan hanyalah penyakit yang menakutkan. Ia juga memberikan inspirasi kepada para penderita kusta lainnya untuk tidak menyerah menghadapi kondisi kesehatan yang sulit.

"Saya tahu bahwa kusta bisa menyebabkan rasa takut dan kecemasan, tapi saya percaya bahwa dengan kekuatan pikiran dan semangat, kita bisa mengatasi segala tantangan," ucap mantan penderita kusta ini. "Saya berharap dengan cerita saya, bisa memberikan semangat kepada para penderita kusta lainnya untuk tetap berdiri dengan bangga."
3 December
International Day of Persons with Disabilities

- take action
- disability-inclusion
- women with disabilities
- understanding disability
- mobilize action
- promote dignity
- plan events
- mainstream disability
- organize forums
- ensure equality
- develop social policies
- inclusive education
- advocate human rights
- social integration
- children with disabilities
- empowerment
- accessible healthcare
- data collection
- awareness-raising
- end stigma and stereotyping

Be informed! Get involved!
www.un.org/disabilities
enable@un.org
THE END

Contact us Via email or WAP/LINE perkumpulanGPDLI@gmail.com 08159045699.