



# Perhimpunan Mandiri Kusta Indonesia (PerMaTa Indonesia)

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## 1 Leprosy Issues in Indonesia (PerMaTa Members Perspective)

**Methodology** Cross-sectional study with purposive sampling and data collecting method

**Method 1 – questionnaire:** targeted willing individuals to interview with informed written consent and diagnosed 2020 – 2025. Facilitated by PerMaTa member and 5 enumerator PerMaTa members. Enumerators used g-form to send the data.

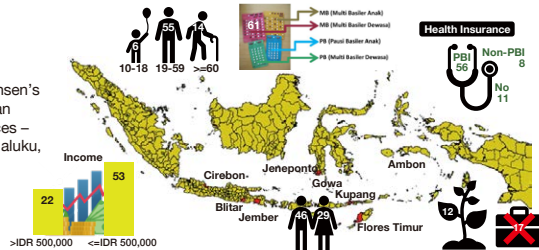
**Method 2 – In-depth Interview:** conducted with respondent from survey. The tools used question structured.

**Online Focus Group Discussion:** four online FGDs conducted at province and one online FGDs at district level, organized by area, gender, and age.

### Reach Summary:

#### Total respondent:

75 persons affected by Hansen's disease from rural and urban communities in five provinces – Jawa Barat, Jawa Timur, Maluku, Nusa Tenggara Timur and Sulawesi Selatan



## 2 Result – Physical and Mental Health Rights Findings)

### Health Care Access: Still Out of Reach for Many Persons Affected

- 8% had stigma and discrimination from health worker
- 93.3% didn't receive timely intensive medical attention treatment when reaction
- 9.3% reaction mortality, according FDG total of mortality 17 persons (the highest numbers in Sulawesi Selatan)
- Some peoples un-reaction because they have strategies:
  - Mitigation of reaction trigger (example avoid of stress, anxiety and depression)
  - Keep health lifestyle
  - Using vitamin boosters
  - Regularly checking to health care
- 67% needs intensive care for reaction cases

### Barriers Remind High

81.3% face obstacles in accessing essential medicines like MDT due chain management system failure, due to cost



Collecting Data – Awareness Raising – Peer Counselling by PerMaTa Members

### Mental Health

- 98.7% had mental health disorder
- 54.1% reported anxiety because isolated, stigma and discrimination from health worker and their community
- 55% time of mental health disorder happened in early treatment (1 – 6 months MDT treatment)
- 27% received counselling or mental health support, both PHC and or peer counselling (PerMaTa)
- Result reported that peer counselling more trusted than other counselling (according FGD)

Type of Mental Health Disorder – Time Happen – Counselling Services						
Counselling		Mental Health Disorder				Total
		Stress	Anxiety	Depression		
Yes	Time	1-6months MDT treatment	7	21	1	29
	Total	7-12months MDT treatment	4	4	0	8
		When leprosy reaction	9	7	2	18
No	Time	1-6months MDT treatment	2	7	2	11
	Total	7-12months MDT treatment	2	0	0	2
		When leprosy reaction	5	1	0	6
Total	Time	1-6months MDT treatment	9	29	3	41
	Total	7-12months MDT treatment	6	4	0	10
		When leprosy reaction	14	8	2	24
		Total	29	40	5	74

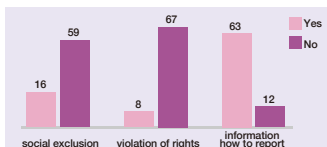
## 3 Violations of Rights – Key Findings on Human Rights & Discrimination

### Lack of Educational and Skills

- 8% student had Hansen's disease got stigma and discrimination on educational institution from their friend "My friend always made distance with me, sometimes I never haven't been invited to playing together, I never haven't been invited to group study", (F, 2025)
- They haven't assistance when they had stigma and discrimination

### Challenged on Stigma Remains

- 21.3% had social exclusion
- 10.7% faced stigma in community, institutions (government and other), and environment
- 84% respondents know how to report a violations
- Almost 100% make a report to health worker



### Neglected The Livelihood & Empowerment

- Nearly quarter (27.5%) respondent un-employment
- 30.4% loss the jobs, due medicine treatment, long treatment
- 61.3% reported un-received social assistance from government
- 58.7% reported un-received social assistance from organization
- 84% had no access to training skill, both from government and or organization

### The Residence & Environment and Family-Social-Election Participation Inclusion

- 88% just normal life (no felt must moving from home because leprosy)
- 78.7% had habitable of residence
- 93.3% reported no access to participation in the community
- 72% respondents didn't involve to decision making in the community
- No difficult to access of election participation
- Majority the family and leprosy organization given support, like spirit, money, attention, motivation and other "My family have been supporting motivation, and assisting to remind me take a medicine", (ASH)
- "Just spirit support, other support is meal from PerMaTa", (AA)
- "Field visited, given motivation, and therapy to prevention of permanent disability", (ASH)

## 4 Lessons and Problem Solving

### Lessons for Stakeholder in All The World – Persistent Gaps

- No integrated on leprosy services with other services and over-reliance on NGOs
- Misdiagnosis and poor caring continue due to lack of trained and skilled health worker
- Limitation of meaningful participation of persons affected by Hansen's disease (partial participation)
- Stigma and discrimination persist in the community, health facilities, and schools
- Legal protections implementation just symbolic and in-effective
- Less mental health care and the capacity of persons affected by Hansen's disease to give counselling, where peer counselling more trusted
- Poor awareness among affected individuals on the rights, leprosy and the importance of participation
- Increasing of education, skills, empowerment, and livelihood unevenly

### Priorities Action

**Fully integrated leprosy services into public services at all level:** reliable essential medicine and MDT supply, ulcer and reaction intensive care, social assistance, accessibility

**Empower Health Workforce:** early detection and diagnose ability, care (MDT and reaction treatment), referral, ability to partnership with persons affected

**Free Stigma – Mental Health Response:** developing professional peer counselling team, awareness raising in the village level, open dialogue to develop inclusive society

**Participatory and Rights-Base Approach:** ensure meaningful participation at all level, call center for violations, train officials in the rights laws

**Inclusive Social – Economic Rehabilitation:** business loan, additional of vocational training, inclusive and equal job access especially for youth and women

**Empower Leadership Among Persons Affected by Hansen's Disease:** develop self-organization, abilities to mobilize of community, peer advocacy

## 5 Organization Needs Assessment

### Methods

SWOT analysis approach and online FGD with management of PerMaTa from 5 provinces to collecting data

### Participant: 14 persons

- 1 trustee of PerMaTa Indonesia
- 1 persons PerMaTa of Jawa Barat
- 2 persons PerMaTa of Jawa Timur
- 2 persons PerMaTa of Maluku
- 4 peoples PerMaTa of NTT
- 3 peoples PerMaTa of Sulawesi Selatan
- 1 person of facilitator



## 6 Gaps & Opportunities for Development and Sustainable Growth

### Key Gaps

**Policy Changes:** budget efficiency and elimination process effected leprosy program in the future

**Human Resources:** lack of professional human resources to develop of organization.

**Lack of Key Management:** in planning, implementing, reporting, evaluating digital tools (Information Technology) and financial skills.

**Educational Gaps:** limit members technical capacity

**Un-Sustainable Financial Support:** project base, limited of donor

**Minimum on Partnership,** for collaboration or and to build networks

**No Full-Time Staff,** to management support

**Poor Visibility,** due no periodically coordination

**No Independent Office,** base on donor support

**No MEAL System,** un-know long-term outcome so difficult to ensure exactly strategic

### Strategic Opportunities

**Strong ownership members base:** over 750 members, potential to build local management and leadership, potential to mobilize peer advocacy

**Trusted donor and partner:** strong base to grow up

**Organization involved on many issues:** opportunity to get lesson learnt

**National and Global Policy:** inclusive program, grassroots credibility to contribute in national and global efforts for achieve zero leprosy, SDGs

**Global Stage:** opportunity to share lessons, build partnership, awareness raising in the global level, meaningful participation

**Community Development Role:** can grow role model in the community to development leader

**Organization Legality:** increasing trusted

## 7 Capacity Building Programs Recommendation

### PerMata Capacity Building Priorities

**1.Build Human Resources:** develop a full-time professional team with defined roles, enable peer learning, activate membership through structured outreach, open new branch to reach added human resources with good capacity.

**2.Strengthen Leadership and Governance;** train members in PerMaTa management on Project Cycle Management (PCM), train in digital skills, effective communication, train members in community mobilize, organization strategic policy

**3.To Enhance Financial Management;** create fund-raising team and sustainability fund planning, increasing donor partnerships, financial incentive for PerMaTa management, financial support for legality of PerMaTa

**4.Foster External Linkages;** build inter-organizational collaboration, study banding, inter-organization gathering

**5.MEAL System;** develop MEAL team, capacity building to learn MEAL system so impact and outcome measurable where a long-term base

**6.Promote Formal Education;** support formal educational scholarship MEAL system so impact and outcome measurable where a long-term(both national and international scholarship) and vocational training especially for organizational technically base

**7.Improve Capacity and Visibility;** to enhance skills social media communication, journalistic skill, video documentation skills, content and book writer training, story telling



## 8 Wishlist Before Next ILC

- Remembering about to fulfil a recommendation of GF 1 and GF 2
- Theme next ILC and GF:

"Women and Child Affected by Hansen's Disease Friendly Health Services based on GEDSI (Gender, Equality, Disability and Social Inclusion)"

"Persons Affected by Hansen's Disease Involved on Climate Changes and Food Security World Program"

"Leprosy Organizations become grant-ready and financially sustainable"

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