

## Problems of access to health services for people affected by leprosy in Indonesia

### Context to the study

We meet more and more persons affected by leprosy in Indonesia who do not have adequate medical and rehabilitative care. This worrying development needs attention and concrete action. This policy brief is intended to provide an overview of the problem.

### Summary of findings

Our investigations show that 'special' care for people affected by leprosy has been stopped in recent years, but has not been replaced by adequate inclusive services. In order to ensure access to medical care and rehabilitation for people affected by leprosy, reasonable accommodation must be enacted according to Law No. 8 / 2016. This will help end the stigma and thereby achieve the successful elimination of leprosy in Indonesia.

### Preface

Even after treatment of leprosy, people affected by leprosy often require years of wound care, medical rehabilitation and treatment of reactions. The right to health encompasses the elements of availability, accessibility, acceptability (including dignified treatment) and adequacy (or quality). People affected by leprosy in Indonesia experience barriers in each of these elements and therefore do not have adequate access to health services according to their medical needs, both in terms of leprosy and other health issues. This situation has worsened in recent years. Three developments are responsible for this, as will be detailed in our findings:

1. The transformation of the three former referral hospital for leprosy (Tadjuddin Chalid Special Hospital/ former Daya Hospital in Makassar, Sitanala Hospital in Tangerang and Rivai Abdullah Hospital in Palembang into general hospitals.
2. The regulations of the UHC system in Indonesia, called BPJS
3. The purpose of the Indonesian government to declare leprosy as eliminated as far as possible, resulting in a lack of funds and capacities.

If these barriers to medical care and rehabilitation are not taken seriously and removed, the number of persons disabilities due to leprosy will increase. This in turn will lead to increased poverty and increasing stigma in the population. More infections with leprosy will be the result.

### Method

Desk Review; Discussions and hearings with Tadjuddin Chalid Hospital Makassar, BPJS (Makassar Province and City), leprosy

control programs of high endemic districts in South Sulawesi, the provincial leprosy control program, the Jeneponto District Hospital. Conducted by PerMaTa South Sulawesi and YDTI, with active participation of members of PerMaTa district branches and KPSS, a local organisation of persons affected by leprosy.

### Findings

- Although RI Health Secretary Ordinance No. 76/2016 continues to provide for special leprosy hospitals and special treatments for persons affected by leprosy, this has not actually been implemented. There is no longer any special treatment for people affected by leprosy in the regulations of the BPJS.
- Even if we welcome and support every development towards equality and inclusion, this lack of special treatment has little to do with the wish to achieve equality, since, for example, people affected by leprosy in the former leprosy hospitals are still separated in their own "leprosy" wards.
- More importantly, the BPJS regulations do not recognize the need of persons affected by leprosy for reasonable accommodation as required by Disability Act 8/2016. Reasonable accommodation for people affected by leprosy is required because stigma, discrimination and self-stigma are still a major part in the lives of persons affected by leprosy, complicating access to public health services to an extent that their needs are often very different from that of other people.
- As a consequence, the BPJS tiered referral system is a major barrier for persons affected by leprosy to access health care: it requires them to report to the primary

healthcare facility first, usually the health centre. From there they can be referred to the district hospital and, if necessary, to another facility at the province level. This does not necessarily include the (former) leprosy hospital, since this specialization no longer exists. Persons affected by leprosy who report directly to the former leprosy hospital and hope for the care they used to have there will not be admitted unless their life is threatened.

- It needs to be understood that people affected by leprosy often refuse to be treated in district hospitals because they have experienced discriminatory treatment and expect nothing more than that, often rightly so. As a result, when they cannot get help in the (former) leprosy hospital, they typically do not seek treatment at all for their wounds or reaction but surrender to their fate.
- For certain services that are still only available in the (former) leprosy hospital, for example operations and prostheses, people are treated on an outpatient basis, which means that they have to pay for room and board in the provincial capital, or they are only admitted for a minimum period (normally 3 days) and then sent back to

the district level for follow-up.

- Capacity to treat complicated wounds, severe reactions, conduct reconstructive surgery etc. is rarely available at the district level.
- Home care (self-care), which is an important part of chronic care and the referral system, poses a high risk of deterioration in persons affected by leprosy with post-op wounds, on the one hand due to the loss of sensitivity in limbs, and on the other hand due to frequent poverty, which means that people have to return to work immediately.
- In addition to the above, with the general loss of leprosy knowledge, rehabilitation capacities such as reconstructive surgery and the manufacture of protective and orthotic shoes are almost unavailable in Indonesia, even on province or national level. With the withdrawal of funding from INGOs and the lack of government takeover, services such as prostheses have to be paid for by patients themselves as BPJS only covers a small part and hospitals are limited in their financial capacity to help.

## Recommendations

1. BPJS must have regulations on reasonable accommodations for persons affected by leprosy that apply to general hospitals on all levels. These regulations should be drafted in the form of Presidential and/or Ministerial Regulation. They should entail, amongst others:
  - Direct referral from health centre to hospitals that are acceptable for persons affected by leprosy and capable of handling their medical and rehabilitation needs.
  - Ensuring adequate length of stay
  - Ensuring home support after being released from hospital (e.g., home-based wound care by health centre staff)
2. Capacity building of medical and rehabilitation personnel on primary, district and province level is urgently required.
3. Ensuring availability of advanced services on provincial level (reconstructive surgery, Prosthetics & Orthotics)
4. Intensive efforts to reduce stigma and discrimination in health facilities

## Legal Basis

1. The 1945 Constitution of the Republic of Indonesia, Article 28H concerning the Right to Health Services, Article 34 paragraph (3) reads "The State is responsible for the provision of proper health care facilities and public services".
2. Law No. 40/2004 on Social Security
3. Law No. 36/2009 on Health. Articles 4 and 5 concerning the right to health and health services. Article 15 reads "The government is responsible to provide the environment, arrangements, health facilities, both physically and socially for the community to achieve the highest degree of health".
4. Ratification of the Convention on the Right of Disabilities in 2011
5. Law No. 08 of 2016 on Disability
6. Minister of Health Regulation No 11/2019 on Leprosy Control
7. Decree of the Minister of Health No 308/2019 on Leprosy Control
8. RI Health Secretary Ordinance No. 76/2016

**PerMaTa South Sulawesi** is an organisation by and for persons affected by leprosy in South Sulawesi, Indonesia  
**Dare This Indonesia (YDTI)** is a non-profit organisation in South Sulawesi supporting persons affected by leprosy.

