

STIGMA AND DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY IN ANGOLA

Submitted for the consideration of the 13th Pre-Session of the CRPD Committee

Submitted by:

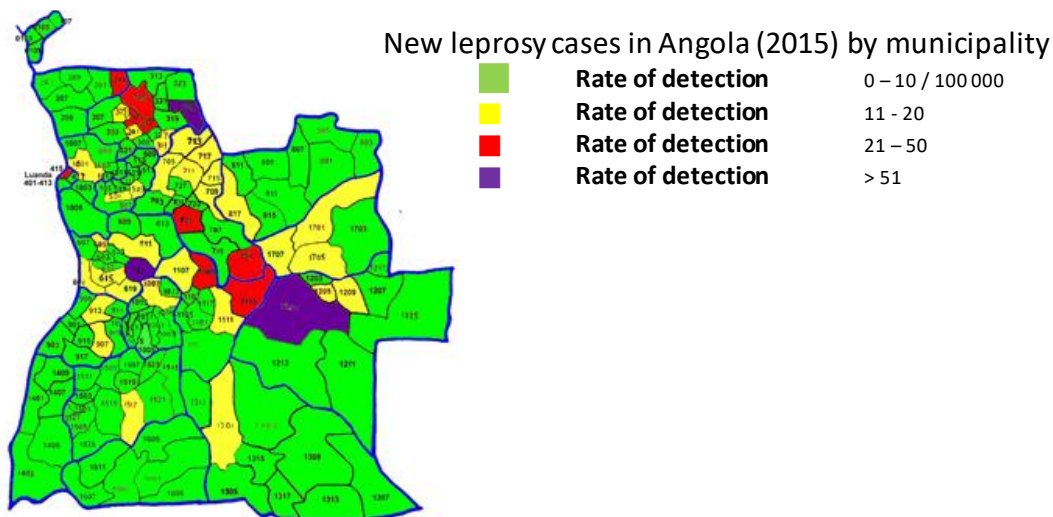
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(The submission may be posted on the OHCHR website)

This submission is written by ARPAL, an association of persons affected by leprosy,¹ and SOLE Angola, which works in health and social services in leprosy. The two organisations collaborate closely with the result that persons affected by leprosy have played the leading role in this submission. ILEP, a federation of anti-leprosy agencies based in Geneva, has supported the process. Website: www.ilepfederation.org. Email officer@ilepfederation.org. Phone +41 22 940 3412

1. Leprosy in Angola: disease status

Data on leprosy in Angola has been sourced from the Ministry of Health. In 2018 in Angola there were 847 new cases of leprosy, and 1,070 patients were undergoing treatment. Of the new cases, 6% were children, 37% were female, and 17% had visible impairments at the time of diagnosis. Because of the disabling effects of leprosy, this latter percentage increases during treatment and during the lifespan after treatment. As the map shows, the number of new cases, and accordingly also the number of people with personal experience of leprosy, varies across the country. The number of new cases has remained stable for the past ten years, demonstrating that disease transmission is still happening.



¹ Persons with personal experience of leprosy prefer this descriptive term. The alternative term 'persons with leprosy' is rejected as being more descriptive of persons currently suffering from the disease, rather than its consequential effects in terms of disability, stigma and discrimination.

2. Inclusion, participation and stigmatization of persons affected by leprosy

In 2017, a survey was carried out in 2 provinces of Luanda and Benguela among 40 people, which represented 14% of patients being treated. The people covered a range of ages. Half of them had visible deformity of the face, hands or feet, evidence of late diagnosis. The survey investigated the experience of stigma and discrimination.

Table 1: Elements of denial of rights due to leprosy discrimination

	Male	Female	Total	%
No right to housing	1	3	4	10%
No equal right to health	3		3	7.5%
No right to stay in the family	8	2	10	25%
No right to marry	4	3	7	17.5%
No right to participate in social life		2	2	5%
No legal right to education		2	2	5%
No rights related to burial		2	2	5%

Table 2: Experience of insults or discriminatory attitudes and behaviour related to leprosy

	Male	Female	Total	%
Was insulted or discriminated against	7	1	8	20%
Can't say	1	0	1	2.5%

Table 3: Location of personal discrimination

	Male	Female	Total	%
In the village or community	5	2	7	17.5%
In the family	1	0	1	2.5%
At work	1	0	1	2.5%
At school/hospital	2	2	4	10%
Self-discrimination	4	3	7	17.5%

In the family and in the community, people felt *words* of contempt or exclusion. At school and in health centres, there were also *attitudes* of contempt or exclusion. Visible impairments were often the cause of discrimination, but even among those with no visible impairments there was fear of being revealed as a leprosy sufferer.

One of the most significant findings was to do with poverty, vulnerability and precarious life situation. 60% of those surveyed were subsistence farmers or in low-paid work or retired, without financial support from social assistance. These people were living with very few resources.

3. CRPD Article 4: General obligations

WHO considers that 15% of the population suffers from a disability. According to the Government of Angola's report to the CRPD Committee in 2016, only 2.5% of the population were persons with disabilities (2014 census). The Government's definition of disability does not consider people with leprosy: it is limited to people where the degree of disability is 60% or more, or people who have lost

more than 95% of their visual acuity. This definition is very restrictive and does not include people with motor sensory disabilities or people disabled by stigma and discrimination.

Recommendation

- We ask that the Government's definition of disability be broadened and incorporate persons affected by leprosy where there is disability caused by stigma and social discrimination.

4. CRPD Articles 13 and 18: Access to Justice and Liberty of Movement

It is the citizen's right to have personal identification documents: birth certificate (Cédula), license (Assento) and ID card. Many leprosy patients do not have a civil registration document. In some cases this is due to deformity of the hand (no fingerprint). In other cases it is due to fear of contempt, or that the person does not consider himself or herself worthy of being a citizen. People affected by leprosy have the experience of not being attended, nor their children, when they go to the Civil Registry. As a result, the person disabled by leprosy has no identity! Without this civil registration, persons affected by leprosy cannot go to school, or enter employment, or own a home.

Recommendation

- We ask that the Government and Ministry of Justice facilitate access to the Civil Registry by persons who are incapacitated with visible deformity due to the consequences of leprosy, and guarantee exemption from payment to those who hold leprosy identification and treatment cards
- We ask that a subsidy, food allowance or minimum salary be granted as social protection to people affected by leprosy who are living in poverty

5. CRPD Article 23: Respect for family and home

Although there is no law permitting divorce due to physical impairment, the fact is that 30% or more of people with personal experience of leprosy (former patients) are abandoned due to having had leprosy. Husbands are abandoned by wives and children, and wives are abandoned by husbands and family. More women seem to suffer this social exclusion. We are aware of these cases all over Angola, but this situation predominates in the north and east of the country. We have evidence of children on the street begging as a result of being excluded from the family, who are picked up by a priest or a pastor, and of women being excluded from the village for having leprosy in Cabinda, Bié, Huila and Luanda.

Recommendation

- We ask for support from the Ministry of Family and Protection of Women to assist these cases of abandonment and great precariousness
- We ask that a subsidy, food allowance or minimum salary be granted as social protection to people affected by leprosy who are living in poverty

6. CRPD Article 24: Education

Children can be cruel and discriminate against or insult a child with disabilities or skin blemishes. There are several cases of children stopping going to school because of discrimination by teachers or students, and of young people stopped their studies because of leprosy complications. These children and young people are not 60% incapacitated, according to the Government definition, but they have been discriminated against unfairly. Examples we have encountered include a child who could not write because of deformity of the right hand and was excluded from school, and a child who cannot go to school because of weakness and deformity of the feet.

Recommendation

- We ask the Ministry of Education to sensitise teachers not to exclude a student because he or she is being treated for leprosy or has physical impairments linked to leprosy
- We ask that a subsidy, food allowance or minimum salary be granted as social protection to people affected by leprosy who are living in poverty

7. CRPD Article 25: Health

Patients are denied treatment or admission to a hospital for having leprosy. Sometimes they arrive early but are attended only at the end of work or told to return the next day for having leprosy. Health technicians refuse to treat someone with leprosy or even refuse to admit him or her to the operating room to have an amputation indicated by a doctor. Access to health care is not the same when someone has disability or leprosy.

Recommendation

- We ask that people with leprosy, leprosy-related impairments or other physical consequences of the disease (such as ulcers) be treated with respect, dignity and be exempted from paying for health services
- We ask that a subsidy, food allowance or minimum salary be granted as social protection to people affected by leprosy who are living in poverty

8. CRPD Article 27: Employment and Work

People with leprosy lose or are denied jobs in the police, in the army, in education, in private businesses or in public services because they have leprosy or visible impairments. We have accounts of dismissal or denial of work opportunities affecting a driver in Lunda Norte, a young man in the security service, a teacher in a private school who was dismissed on the demand of parents of the other students, police in Cunene, a young man in the restaurant business, a bricklayer, a coastal fisherman, and a member of the Armed Forces who was demobilized on account of having leprosy, without access to veteran's subsidy etc.

Recommendation

- We ask that it be prohibited to expel someone from employment, or to refuse to employ someone, on the basis that he or she is being treated for leprosy or has had leprosy in the past. Persons with impairments or disability should be assessed by qualified occupational specialists in relation to their disability and work
- We ask that a subsidy, food allowance or minimum salary be granted as social protection to people affected by leprosy who are living in poverty

9. CRPD Article 28: Social protection and adequate livelihoods.

People with leprosy are often in extreme poverty, without income and depending on help from neighbours or grandparents. Sometimes they cannot even afford to travel to treatment. Some lack the means to cook or even to wash themselves because of physical deformity. Some are even sent to look for food in the trash.

Persons affected by leprosy experience prejudice as vulnerable persons, but do not receive social protection, nor are they covered by social insurance, and sometimes they lack individual documentation.

Recommendation

- We ask that persons affected by leprosy be recognized as people disabled by deformity and social stigma and are able to access and benefit from social security.

- We ask that a subsidy, food allowance or minimum salary be granted as social protection to people affected by leprosy who are living in poverty