



**PERMANENT MISSION OF BRAZIL TO THE UNITED NATIONS OFFICE
AND OTHER INTERNATIONAL ORGANIZATIONS IN GENEVA**
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The Permanent Mission of Brazil to the United Nations Office and other International Organizations in Geneva presents its compliments to the Office of the United Nations High Commissioner for Human Rights – Special Procedures Branch – and, with reference to the note verbale AL BRA 9/2021, dated 7 October 2021, has the honor to transmit herewith the submission of the Brazilian Government.

The Permanent Mission of Brazil in Geneva avails itself of this opportunity to renew to the Office of the United Nations High Commissioner for Human Rights the assurances of its highest consideration.

Geneva, 08 December 2021



To: Office of the UN High Commissioner for Human Rights (OHCHR) -
Special Procedures Branch
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SUBMISSION OF THE GOVERNMENT OF BRAZIL

The Brazilian government, through the General Coordination for the Elimination of Diseases of the Department of Chronic Diseases and Sexually Infections, of the Health Surveillance Secretariat of the Ministry of Health (CGDE/DCCI/SVS/MS), has been proposing, throughout the years, the elaboration and implementation of policies, guidelines and strategic projects regarding the promotion of surveillance actions and of prevention and control of leprosy, aimed at early diagnosis, timely treatment, prevention of physical disabilities and coping with stigma and discrimination, always based on human rights and on the principles and guidelines of the Unified System of Health (SUS).

Concerning Brazilian laws aimed at people affected by leprosy, the Decree 16.300/1923, in its articles 148 and 161 transcribed below, states that:

Art. 148. "In the facilities of lepers, in addition to provisions already determined and the main ones prescribed in its bylaws, the following is to be observed: f). The children of lepers, although one of the parents is sick, shall be maintained in special sections, attached to the healthy people areas of the establishment, where they will be transported soon after being born. g) These same children shall not be nurtured by nurses and will not be breastfed by the mother if she has leprosy".

Art. 161. "The isolated patient at home, in addition to recommendations that in each case will be made by the health authority, must comply with the following determinations: h) Always stay away from children who reside or remain in the household".

In 1949, Law No. 610 made reference to the prophylaxis of "Leprosy" and also regulates the removal of children from people affected by leprosy in the following articles:

Art. 15. "Everyone newborn, child of a sick leprosy carrier, will be compulsory and immediately removed from the coexistence of parents".

Art. 16. "The children of leper parents and all minors living with lepers will be assisted in a suitable family environment or in special preventive institutions. (Law No. 610, 13 January, 1949) ".

In the first decades of the 20th century, the first institutions called "educandários" or "preventórios", intended for care and hospitalization aimed at children from families affected by leprosy, which were built

through the public-private partnerships and having their own Bylaws. According to reports of children of people affected by leprosy, the permanence in these institutions was allowed until up to 16 or 18 years of age depending on norms of each school.

With the advancement of scientific knowledge regarding the disease and the introduction of multidrug therapy recommended by the World Health Organization (WHO), in the 1980s, the scenario and approach to leprosy have both suffered important changes, which culminated in the extinction of the compulsory isolation model, due to the Decree of Law No. 968, of May 7, 1962.

Subsequently, Law No. 11,520, was enacted in September 18th, 2007, which provided for the granting of special pensions to people affected by leprosy who were subjected to compulsory isolation and hospitalization in colony hospitals. According to the contents of Paragraph 1 of Article 1 of the Law in question, the pension is strictly personal, not transferable to dependents and heirs.

Based on Decree No. 6.168, of July 24, 2007, the assessment of special pension applications is analysed by the Interministerial Evaluation Commission (CIA) of the National Secretariat for the Rights of the Person with Disabilities (SNDPD), inserted in the Ministry of Women, Family and Human Rights (MMFDH). After the granting of the indemnity by SNDPD, the administrative procedure is sent to the National Institute for Social Security (INSS) so as to start the payment of the pension, directly to the beneficiary, except in justified cases, when an attorney may be appointed especially for this purpose.

Within the scope of the federal public administration, the Ministry of Women, Family and Rights Humans has as one of its attributions the coordination of the Interministerial Evaluation Commission (CIA), created by Decree No. 6.168, in July 24, 2007.

The CIA aims to analyze the special pension requirements by people affected by leprosy who were hospitalized and compulsorily isolated until December 31, 1986. The regulation regarding the concession of special pensions is provided for in Law No. 11.520, of September 18, 2007, which authorized the Executive Power to grant special, monthly, non transferable, lifelong pensions, to those affected by leprosy and who were subjected to isolation and compulsory admissions to colony hospitals, up to 31 of December 1986, who request it, as a special indemnity, and the pension corresponds to R\$ 750.00. The value of the special pension is adjusted annually, according to

the rates governing the value of benefits that surpass the minimum of the General Regime of the Social Security.

Thus, the Interministerial Evaluation Commission came to be with the attribution of issuing a prior opinion on the requirements formulated in this regard. The granting of pensions occurs through an act of the State Minister for Women, Family and Human Rights, following the opinion of the Interministerial Commission for Evaluation. It is up to the National Institute of Social Security (INSS) to do the processing, maintenance and payment of the pension.

To prove the applicant's status, it is allowed an extensive production of documentary and testimonial evidence and, if necessary, the introduction of expert evidence. During the carrying out of its activities, the Commission follow the steps it deems appropriate, including requesting technical support, documents, opinions and information from public management bodies, as well as taking testimonies from third parties.

There are negotiations within the scope of the Legislative Power, with the purpose of obtaining the concession of economic reparations, as means of indemnity. Nonetheless, due to the absence of legislation in force regarding this contribution, such processes are dismissed at the federal level.

Currently, at the National Parliament, Bills of Law are being discussed, which aim to the children of affected people the payment of pain and suffering compensation, considering the possibility of analog application or expansion of Law No. 11.520/2007 - by way of example there is the Bill (PL) No. 2104/2011, which amends § 1 of the art. 1 of Law No. 11.520, of September 18, 2007, which provides for the granting of a special pension to people affected by leprosy who were subjected to compulsory isolation and hospitalization, so as to allow the transfer of the benefit to dependents who meet the monetary insufficiency threshold. The aforementioned PL is being discussed by the Finance and Taxation Commission (CFT) since 12/09/2015; and, to it, the following PLs are connected: 2962/2011; 3303/2012; 4907/2012; 1929/2015 and 2330/2015.

Actions that have been developed for the comprehensive care of the leprosy affected people: leprosy is a chronic, infectious disease, whose etiological agent is the bacillus *Mycobacterium leprae*, which affects the skin and peripheral nerves. There are case records in all of Brazil's states, with some areas being hyperendemic. When not diagnosed and treated in a timely manner, leprosy can cause serious physical disabilities, that contribute to the maintenance of stigma and discrimination against affected people, in addition to economic and social to affected families.

The distribution of cases in the country is heterogeneous, with cases in all federative units, with greater concentration in the north, northeast and midwest regions. The diagnosis of the disease is still performed only by identifying signs and clinical symptoms by an experienced practitioner. Thus, it is prone to errors, since leprosy may have signs and symptoms very similar to other dermatoses.

To achieve the global and national goal of reducing the burden of this disease, it is essential to promote early diagnosis, timely treatment, the prevention of physical disabilities and surveillance of close contacts of the affected. Brazil has developed several actions in this regard, integrating patient care in the set of healthcare actions. However, further articulated efforts are needed to expand the effectiveness of these actions, in order to change the status quo of the disease in the country.

The Brazilian government has developed and strengthened various actions aimed at diagnosis, prevention and comprehensive care for leprosy, with an emphasis on:

- i) A Technical Cooperation Agreement was signed with the National Secretariat of Social Assistance (SNAS), a part of the Citizenship Ministry, which aims to establish mutual technical cooperation aimed at the planning, monitoring, execution and evaluation of actions aiming to improve the articulation between the Unified Health System (SUS) and Unified Social Assistance System (SUAS), especially related to the social inclusion of people in a situation of social vulnerability, among them the people affected by leprosy;
- ii) Updates to the guidelines for experts physicians have been made;
- iii) Webinars (online seminars) on different topics related to leprosy have been held;
- iv) There have been publications related to the confrontation of the stigma and the discrimination, and to the rights of people affected by leprosy; and
- v) Technical support for the establishment of a parliamentary union dedicated to the theme of leprosy.