

MORHAN

The Movement for the Reintegration of
People Affected by Hansen's Disease

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1 Hansen's disease, Listen to know

Methods:

- Google Form: Rapid situational diagnosis of problems related to access to rights by people affected by Hansen's disease, members of the Morhan Organization, a sample of the voices of people affected by disease in Brazil.
- Qualified Listening: In person with the participation of affected people from the cities of Teresina and Paranaíba in Piauí and Timon in the state of Maranhão. It deals with collaboration for the situational diagnosis and the proposal of new strategies to guarantee the rights of people affected by Hansen's disease.



Reach Summary:

Total reached: 179 people

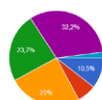
Women: 123 / Men: 54

Participants aged between 20 and 80 years old

2 Right to Health

Com que frequência você tem ou teve dificuldades para agendar consultas médicas relacionadas ao acompanhamento da hanseníase?

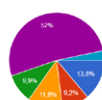
152 respostas



32% of respondents reported that they NEVER had difficulty scheduling medical appointments, 25% SOMETIMES, 23.7% RARELY and 10.5% reported ALWAYS having had difficulty accessing them.

Com que frequência você recebeu algum tipo de suporte para saúde mental durante ou após o tratamento para hanseníase?

152 respostas

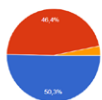


52% of respondents NEVER had access to mental health support, 13.8% ALWAYS, 11.8% SOMETIMES, 9.9% RARELY and 9.2% reported having had access FREQUENTLY.

3 Right to non-discrimination

Você sofreu discriminação e/ou violência por ter Hanseníase?

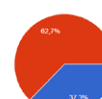
153 respostas



50.3% of respondents reported having suffered some type of discrimination and/or violence for having Hansen's disease, 46.4% reported NEVER and 3.3% PREFER NOT TO RESPOND

Você conhece serviços ou canais de atendimento para denúncia e apoio em casos de discriminação por ser pessoa afetada pela hanseníase?

153 respostas



62.7% of those interviewed say NO, they are aware of services or channels for reporting and providing support in cases of discrimination for being a person affected by Hansen's disease, 37.3% report YES

4 Possible Solutions

Right to non-discrimination

Implementing a social support community to discern knowledge of the stigmas imposed by the disease, training health and social assistance professionals on the social rights of people affected by Hansen's disease, in partnership with governments, discussion groups and other educational actions, disseminating information, sharing reports from people affected, partnerships with other organizations that deal with neglected diseases, with the aim of strengthening claims for rights with the Public Prosecutor's Office and other institutions that guarantee rights.



Right to Health:

Identify affected people with a leadership profile and availability, to carry out social mobilization to create conversation circles for people affected by Hansen's disease with lived reports, exchange of experiences, establish partnerships with psychology and law professionals for training and participation in the organizations' activities, promoting continuous support.

5 Organization Process

The methodology used was the qualified listening process, through a Google form, workshops with affected people, home visits, virtual conversations. A special thanks to all the people affected by Hansen's disease involved in this process, those who are part of our organization and those who are not, but who contributed to these activities.



Author of the proposal: Faustino Pinto

Intellectual Collaborators: Paula Brandão e Vanessa Raquel

Supporters: Francilene Mesquita, Clodis Tavares, Edmilson Picanço, João Vitor

6 Needs Assessment

We work in the workshop on thematic axes, discussing our strengths and difficulties, with the aim of filling gaps and visualizing opportunities and strategic areas for the best development of our organization.



AXIS 1: ORGANIZATIONAL

Objective: Improve institutional relations with volunteers and partners

AXIS 2: MENTAL HEALTH OF PATIENTS AND FAMILIES

Objective: Strengthen the role of the social movement in providing support and psychosocial care to people affected by Hansen's disease and their families

AXIS 3: NATIONAL OBSERVATORY OF MEDICATION SHORTAGES

Objective: Strengthen the role of the social movement in monitoring, reporting and addressing the discontinuation of medications.

AXIS 4: GUIDANCE AND GUARANTEE OF RIGHTS

Objective: Enhance the role of the social movement in defending and promoting the rights of people affected by Hansen's disease.

7 Recommendations

- Training of the organization's members, offering training courses aimed at affected people on topics relevant to their daily experience with the disease.
- Legal support in preparing records and participating in public notices, in addition to support for coordination with government and non-government partners, and the legalization of the centers.
- Health education through social media, with the active participation of affected people, sharing information, guidance and experiences.
- Promotion of discussion groups with affected people, aiming to listen to their demands and forward them to the appropriate agencies, strengthening social participation and conflict resolution.
- Holding itinerant meetings in various spaces in the community, expanding the scope of awareness and mobilizing a greater number of people for active participation.
- National virtual meeting on the accountability of projects, events and expenses incurred, with the dissemination and provision of financial spreadsheets on a semi-annual basis.

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What we wish!



Dona Elmira
Person affected by
Hansen's disease,
79 years old

- May Hansen's disease be eliminated, but may we not forget the people affected...
- Prevention, physical rehabilitation and surgeries.
- More health education for the entire population so that they know how to recognize the disease.
- More investment in the people affected and not just in killing the bacillus.
- More combat against violence and institutional stigma.
- Guaranteed access to more medicines and other clinical specialties.
- Protection and guarantee of human rights, for us and our family members.