

Morhan

MOVEMENT FOR THE REINTEGRATION OF PEOPLE AFFLICTED BY HANSEN'S DISEASE

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Public Utility Law 3619 dated 01/03/91

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TELEHANSEN® TECHNICAL REPORT 2008

Sponsored by the Nippon Foundation

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PRESENTATION

Driven by the social struggles of the Brazilian people that occurred in the 1980s, the Movement for the Reintegration of People Afflicted by Hansen's Disease – Persons Affected was created on June 6th, 1981. Founded by Francisco Augusto Vieira Nunes - the Bacurau¹, Antônio Borges Junior² and another four ex-Hansen's disease colony hospital interns, the Movement is a private non-profit association that seeks to promote educational measures for the prevention, early diagnosis, treatment, rehabilitation, information, participation and awareness of people affected by the disease and the whole of society.

The work that Persons Affected develops is executed by dozens of volunteers spread throughout its various nuclei in Brazil. In general, they are people who have or have not had experience with the disease, or that are simply moved by the desire to fight for the cause. The activities developed by Persons Affected are directed at the whole of Brazilian society, conveying information by means of the main means of communication. The institution also promotes meetings in health centers, lectures, theater or puppet shows in schools, associations, labor unions, community centers, social movements and churches in various states throughout the country.

Currently, the National headquarters of the movement is located in the Praça da Bandeira neighborhood in Rio de Janeiro, RJ and its nuclei are represented in 22 states of Brazil. However a large part of these states have more than one Persons Affected nucleus. Additionally, there are other institutions that are considered affiliates that, although not having physically constituted a nucleus, develop and implement the movement's work and use Persons Affected's power and social pressure to fight for the guarantee of their users' rights.

Hansen's disease is the object of Persons Affected's investigation and social intervention efforts. However, it is not only for the disease or through it that the exercise and political project of the movement is promoted, but rather by always seeking results

¹ See: Bacurau memorial room at www.casadebacurau.com.br.

² To learn more about life in the old colony hospitals before the construction of Persons Affected, see: BORGES JÚNIOR, Antonio de Oliveira. *Fragmentos da Vida*. 2nd ed. Salvador: Helvécia, 2000.

capable of contemplating the complexity of the entire dynamics of the social being. As said by the Persons Affected National Coordinator:

*“Hansen’s disease is just an excuse that we found to continue fighting”*³. While there are people suffering from the sequels of the disease, at the same time, millions and millions of people all over the world suffer from hunger, droughts, lack of decent living conditions and all kinds of inequalities caused by the current world economic policies.

Persons Affected presents itself as a privileged space for the further study of these factors. For more than two decades, the movement has been engaged in important struggles and has inserted itself in various fields of articulation, allowing for greater visibility of the peculiarities of Hansen’s disease and of the people afflicted by it. Within these spaces, Persons Affected is represented in the National Health Council (CNS - Conselho Nacional de Saúde), the Municipal Council for Social Assistance (CMAS - Conselho Municipal de Assistência Social), Municipal and State Health Councils, National Handicapped Persons Council (CONADE - Conselho Nacional da Pessoa com Deficiência), State and Municipal Councils for Handicapped People, National Forum of Pathology and Physical Handicap Entities and other state and municipal councils and forums for the defense of rights.

One of Persons Affected’s major concerns is to always think and act in unison, with and for the collective interests of the people afflicted by Hansen’s disease, in a manner that allows them to actively participate in the processes of fighting for and defending their rights. In order to act on this proposal, the implementation of the finalities of the social movement’s statutes is fundamental. The latest update of the Persons Affected Statutes was approved during the 12th Extraordinary General Meeting held on July 31st, 2005. These statutes provide, amongst others, for the following basic objectives:

- Develop works and educational materials seeking to defend, clarify and disclose the rights and duties of the sick person, by informing him/her, the family, community and health professionals, through the means of communication.

³ Artur Custódio Moreira de Sousa in an interview held on 14/10/2008 for the production of: SILVA, Lilian D. A. from the Social and Citizenship Movements: One for all or all for them? A study conducted based on the Movement for the Reintegration of People Afflicted by Hansen’s Disease – Persons Affected. Final paper for the Graduate Course in Social Services. PUC-RIO, November 2008.

- Integrate the movement to other local, regional, national and international movements, in favor of the people with handicaps and other pathologies.
- Encourage the participation of volunteers, who may be people afflicted by Hansen's disease – in treatment or post-treatment – or even people from the community, to contact non-informed Hansen's disease patients, promoting them both personally and socially and stimulating them to participate in the defense of their rights.
- Implement measures, with the competent organs, against any kind of behavior that impairs the human rights of a person afflicted by Hansen's disease.
- Provide, in conjunction with the governmental organs, for the creation of laws that help Hansen's disease patients, offering them social and economic well being.

National Statutes – 12th Extraordinary General Meeting held 07/31/2005

The largest challenges for Persons Affected are: demand the implementation of the rights inserted in the Brazilian Constitution, ensure alternatives for people who are not able to access them and encourage the occupation of the population affected by Hansen's disease in public and political spaces. Persons Affected and its militants, ever since their entrance into Brazilian society, have strived to overcome these challenges. The strategies adopted are based on the strengthening of the social group organized to stimulate mobilization and pressure on the government and society itself, for the emergence of more dignified conditions of life for people affected by Hansen's disease.

If it were not for the voluntary workers' dedication, or for the institutions that act as networks and offer directives for Persons Affected demands or for the financial sponsorship from the entities that invest in the movement's work, the projects and actions performed by Persons Affected throughout these long years would only be dreams. In the same manner it is worth highlighting that the volunteer efforts of the social actors committed to the fight against Hansen's disease, like artists, representatives of national and international organs, both public and private, amongst others, represent a strong apparatus for popular mobilization through the media and society.

In this sense, the Hansen's disease information center – Telehansen® – constitutes an important instrument in the constant battle against disinformation. Through the toll-free number 0800 26 2001, Persons Affected volunteers answer calls from all over Brazil to clarify doubts, give advice on the disease, forward the callers to Hansen's disease treatment

reference centers, receive denouncements on the lack of medication, prejudice, lack of quality in attendance by the health units, etc.

People from the entire country, from all social economic levels and qualifications, make contact to obtain information, receive support, indications and/or request informative material on Hansen's disease. The main demands of the social movement come through this channel. For this reason, Telehansen® is considered Persons Affected's "front door", and qualifies and increases the representation of the movement's actions. In the majority of cases, it is also through Telehansen® that requests are answered, in addition to the use of the internet and mail.

It is with the strengthening of their networks that Persons Affected volunteers have managed to obtain results for this work. They need to constantly seek alternatives and mediations by means of the contacts they already have with the social network and try to increase these contacts even more. In general, the measures adopted arise from the contacts made with municipal and state Health Departments and Coordinations, partnerships with professional Councils, institutional visits, sending of denouncement reports, campaigns, etc. This service is challenging work that requires constant professional qualification.

Being the only entity in Brazil dedicated to the supply of this type of guidance, Telehansen® receives approximately 60 calls per day and operates from Monday through Friday from 8:30 to 17:00. This information service is the principal object of analysis in this Report, which has the purpose of showing the data collected by the Persons Affected volunteers in the year of 2008.

DEVELOPMENT

During the period that covers the months from April to December 2008, **4342** (four thousand three hundred and forty two) calls were recorded, corresponding to an average of 482 (four hundred and eighty two) calls per month. It should be considered that these call records correspond to attendances performed during 9 of the 12 months in the year. Because of a lack of financial resources, during the first quarter of 2008, the Hansen's disease information service – Telehansen® - did not operate. Without doubt, this

interruption had an impact on the final result and on the analysis of the data surveyed in this report.

If we consider that the functioning of Telehansen® occurred from April 1st to December 18th, and that the year 2008 had 184 (one hundred and eighty four) working days during this period, we can identify a gap of 62 (sixty two) working days without Telehansen® attendance. Taking into account the same monthly average found above, this means a loss of approximately 1447 (one thousand four hundred and forty seven) calls that were not received.

In the same manner, considering the campaigns that were launched at the end of January and the start of February, this number may have been even greater. Also, the discontinuity of the service may have had an impact on the following months, reducing the monthly call average. The table below shows the number of calls answered in each month.

TABLE 1 – TELEHANSEN® Attendance in 2008 Broken Down by Month

MONTH	NUMBER OF CALLS
JANUARY	0
FEBRUARY	0
MARCH	0
APRIL	249
MAY	274
JUNE	342
JULY	945
AUGUST	567
SEPTEMBER	681
OCTOBER	479
NOVEMBER	493
DECEMBER	312
TOTAL=	4342

Source: Own preparation

This monthly survey indicates a balanced volume of calls during the first three months of attendance, with a significant increase in the number of contacts as from July. Such an increase can be justified by the informative campaign on Hansen's disease held by the Ministry of Health in partnership with Persons Affected. This campaign started in July and was published in the main means of communication, including also pamphleting efforts and the distribution in different places of posters and booklets advising on the disease.

The routine activities performed by Persons Affected, such as presentations by the theater group in various parts of Brazil, in partnership with the Ministry of Health – MS, SEGEP and the Secretary of the Sanitary Vigilance – SVS, talks given in partnership with the Active and Inactive Public Teachers Beneficent Association of the state of Rio de Janeiro - APPAI, the Health Truck campaign in partnership with FEBRAFARMA, the implementation of the GAPH – Support Group for People with Hansen’s Disease, offered by the Social Service team of the National Persons Affected group, amongst others, have stimulated and encouraged the use of Telehansen® as a tool for social emancipation.

In fact, located throughout all regions of Brazil, Persons Affected has managed, through each one of its nuclei, to promote the multiplication of indispensable information on Hansen’s disease, in a manner that Telehansen® functions as a vehicle that further strengthens this proposal. The objective is to extend this work even further. This because, wherever Persons Affected is present, also present is the emergence of social intervention and articulation in order to act in the defense of the Human Rights of those persons afflicted by Hansen’s disease.

As we know, Brazil has the second largest number of cases of Hansen’s disease in the world and the greatest prevalence of the disease is in the Northern regions, the largest incidence of cases in the country. Brazil made the commitment to reduce the incidence of the disease to at least 1 (one) case for every 10 (ten) thousand inhabitants by 2005. The same commitment was signed in 1991 with a goal for 2000, which also did not occur. (OPAS, 2005)

If we compare the data shown in the tables below, we will have information to identify the true relevance of the expansion of information on Hansen’s disease in Brazil. Although Persons Affected is present today in a large number of Brazilian states, there is still a lot of work to be done. Even though the size and/or number of inhabitants of each State or municipality is not stated in the tables, allowing for the investigation of the proportion of the population affected, it appears obvious that Hansen’s disease should be taken ever more seriously by the federal government and the civil society organizations in Brazil.

The magazine ‘RADIS⁴-Communication in Health from ENSP - National Public Health School from FIOCRUZ –Oswaldo Cruz Foundation in its edition no. 68 April 2008, warns of a growth in the diagnosis of the disease in children and adolescents of up to 15 years of age in the North and Central-West regions of the country. Thus, the earlier the dissemination of information on the disease occurs, the less will be the negative results.

Table 2 presents the latest index registered by the SUS – DATASUS, an Executive Secretariat of the Health Ministry, together with the Information System for Notification of Illnesses - SINAM and the National Program for Elimination of Hansen’s disease - PNEH by the Department of Health Vigilance - SVS from the Health Ministry. There were 111,875 patients attended in Brazilian capitals in 2006, which reveals the need for giving priority to Hansen’s disease as a public health problem.

TABLE 2 – Monitoring of Hansen’s disease in Brazilian capitals in 2006

HANSEN’S DISEASE IN BRAZIL CAPITALS IN 2006		
Ranking and Capital	Brazilian regions	Number of Patients Attended
1° Goiânia	Center-West	13412
2° Recife	Northeast	12134
3° Rio de Janeiro	Southeast	10218
4° Teresina	Northeast	8902
5° Fortaleza	Northeast	8692
6° São Luís	Northeast	6882
7° Manaus	North	5807
8° Cuiabá	Center-West	5746
9° Belém	North	4694
10° São Paulo	Southeast	4052
11° Brasília	Center-West	3912
12° Boa Vista	North	3674
13° Salvador	Northeast	3318
14° Aracaju	Northeast	2209
15° Palmas	North	2166
16° João Pessoa	Northeast	1950
17° Belo Horizonte	Southeast	1856
18° Rio Branco	North	1766
19° Maceió	Northeast	1745
20° Vitória	Southeast	1722
21° Porto Velho	North	1654

⁴ Ver: www.ensp.fiocruz.br/radis

22° Curitiba	South	1428
23° Campo Grande	Center-West	1343
24° Macapá	North	1226
25° Natal	Northeast	825

Source: Adaptation of data from Health Information in www.datasus.gov.br

Certainly, in order to understand these numbers better, it is necessary to consider the socio-economic factors of the regions that stand out with high indexes of the disease. Brazil is one of the rich countries that presents itself as a champion in the poor distribution of its income. The Northeast region is where we find the greatest social inequality in the country, which favors the elevated rate of the incidence of Hansen's disease in the region, since the poor living conditions may cause low immunological resistance in the local population. It is within this scenario that Persons Affected presents itself and constitutes its nuclei:

TABLE 3 – Distribution by State of the Persons Affected Nuclei in Brazil in 2008

STATES	MUNICIPALITIES IN BRAZIL WHERE THERE ARE PERSONS AFFECTED NUCLEI					TOTAL
AC	Rio Branco		Cruzeiro do Sul			2
AM	Manaus	Labrea		Alto do Juruá		3
BA	Salvador					1
CE	Redenção	Maracanaú	Juazeiro do North	Fortaleza	Sobral	5
ES	Cariacica					1
MA	São Luis (pre-nucleus)		Timon			2
MG	Belo Horizonte	Ubá	Betim	Itajubá	BambuÍ	5
MS	Campo Grande		Corumbá			2
MT	Juina					1
PA	Belém	Paragominas	Marituba	Parauapebas		4
PB	João Pessoa					1
PE	Paulista		Recife			2

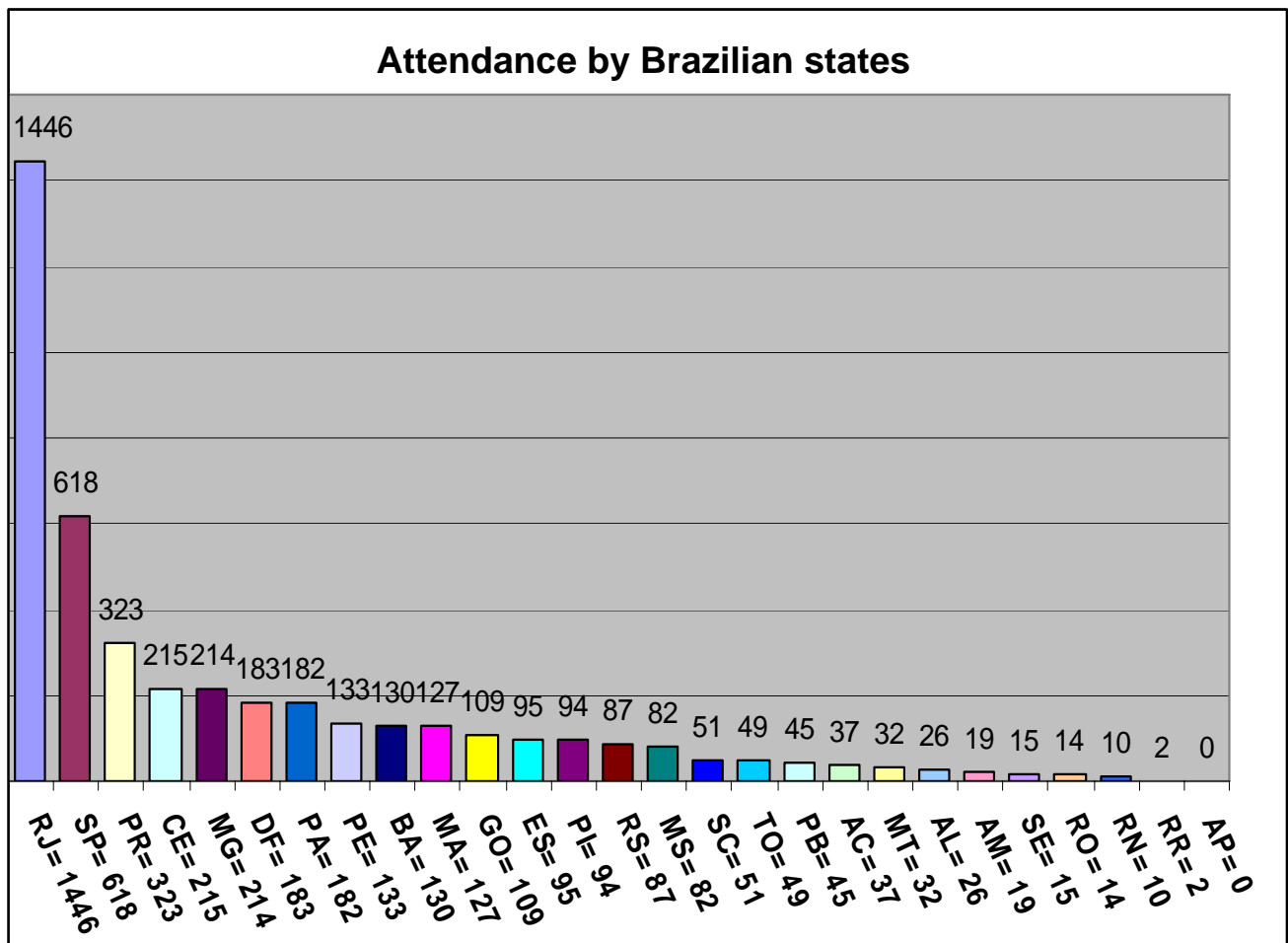
PI	Teresina								1
PR	Piraquara								1
RJ	Italva	Rio de Janeiro	São Gonçalo	Baixada Fluminense ⁵		Niterói			5
RO	Porto Velho								1
RR	Boa Vista								1
SP	Jabaquara	São Bernardo do Campo	Ribeirão Preto	Mogi das Cruzes	Sorocaba	Jundiaí	São Vicente	São José do Rio Preto	8
Note: Affiliated institutions are: MG /Teófilo Otoni - AMAS Associação dos Amigos Aliados pela Saúde, GO /Goiânia – Associação dos Moradores da Colônia and SC /Campinas - São José.									3
GRAND TOTAL: *Considering the 4 municipalities represented by the unified nucleus of the Baixada Fluminense, the total becomes 52 Persons Affected nuclei spread throughout Brazil.									49*

Source: Own preparation.

Thus, the National Persons Affected located in Rio de Janeiro, where the 0800 26 2001 call center is based, receives and also attends requests coming from all states in Brazil. In the 2008 year, it was registered that 26 of the 27 Brazilian states received guidance provided by Telehansen®. Amapá was the only state that did not use the Hansen's disease information service. Within these contacts, 3 people did not state the origin of the call and 1 person made contact from a city located in France.

GRAPH 1 –Telehansen® Attendance supplied to each State in Brazil – 2008

⁵ The Baixada Fluminense is a unified Nucleus that represents São João de Meriti, Nova Iguaçu, Duque de Caxias and Queimados.



Source: Telehansen@ database.

It is relevant to note that, although in the ranking of the States with the largest number of 0800 26 2001 calls, there appear respectively RJ, SP, PR and CE, upon considering the estimated population of each Brazilian State in 2007, according to the Brazilian Institute for Geography and Statistics – IBGE, this picture changes position. For a more appropriate analysis of the reach of Telehansen in each part of Brazil, it becomes important to take into account the average number of inhabitants of each State, as well as the presence of Persons Affected in each location. Thus, the comparison between the data summarized in the table below leads us to the conclusion in graph 2 that shows the representation of the contacts made by each State with Telehansen in another manner.

TABLE 4 –Comparative table between total calls - 2008, population of each Brazilian State – 2007 and Persons Affected nuclei– 2008.

STATES	No OF CALLS	POPULATION	PERSONS AFFECTED NUCLEI
RJ	1446	15,420,375	8 (4+4 Baixada)
SP	618	39,827,570	8
PR	323	10,284,503	1
CE	215	8,185,286	5
MG	214	19,273,506	6 (5+1 affiliate)
DF	183	2,455,903	0
PA	182	7,065,573	4
PE	133	8,485,386	2
BA	130	14,080,654	1
MA	127	6,118,995	2
GO	109	5,647,035	1 (affiliate)
ES	95	3,351,669	1
PI	94	3,032,421	1
RS	87	10,582,840	0
MS	82	2,265,274	2
SC	51	5,866,252	1 (affiliate)
TO	49	1,243,627	0
PB	45	3,641,395	1
AC	37	655,385	2
MT	32	2,854,642	1
AL	26	3,037,103	0
AM	19	3,221,939	3
SE	15	1,939,426	0
RO	14	1,453,756	1

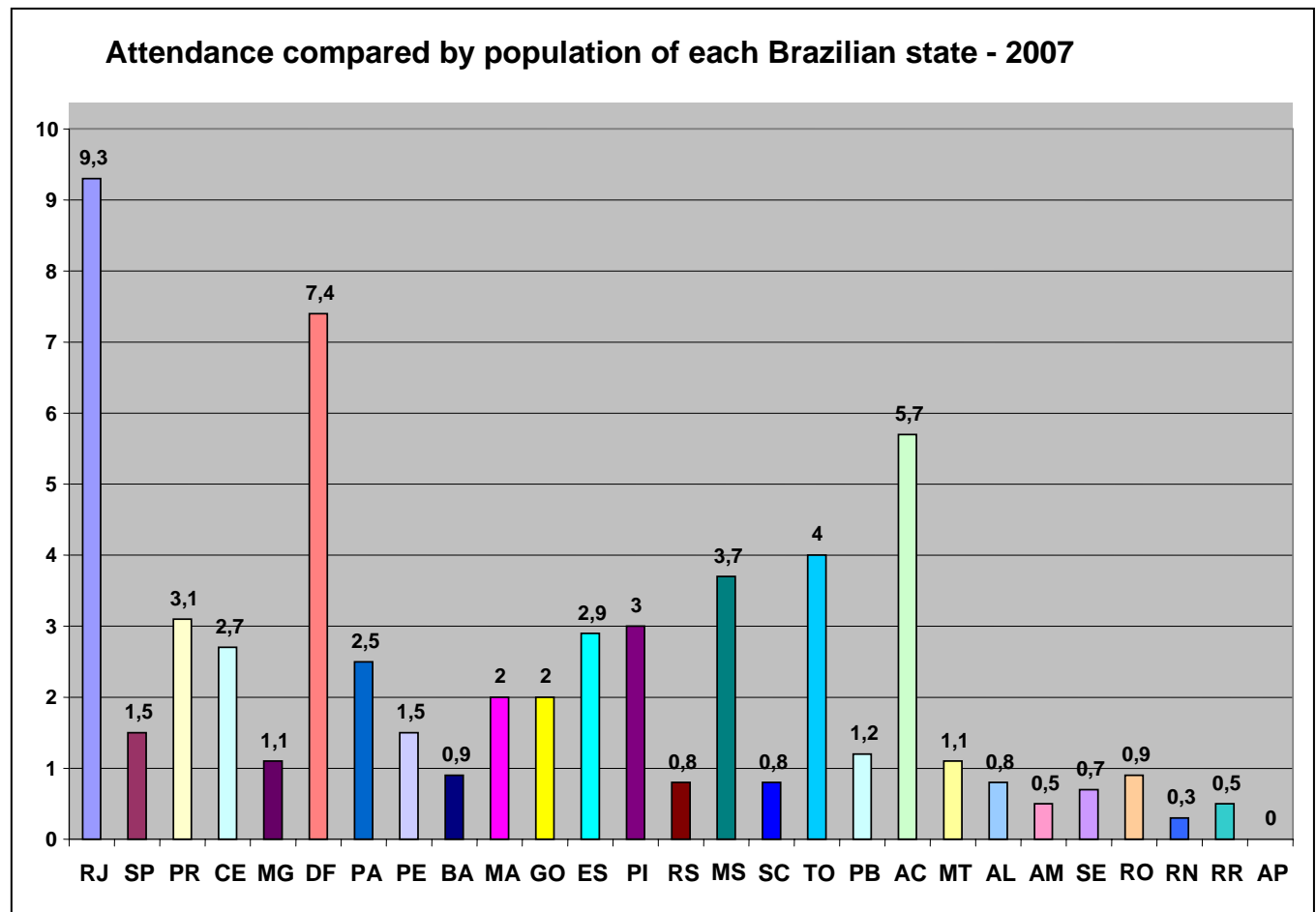
RN	10	3,013,740	0
RR	2	395,725	1
AP	0	587,311	0
TOTAL:	4338	183,987,291	52

Source: Own preparation.

Based on this data, we can construct a new scenario that will consider the estimated population in each Brazilian State in 2007 in order to understand the proportion of calls made from each region to Telehansen in 2008. To attain the result set out in the graph below, we used the following formula: number of calls multiplied by 100,000 (one hundred thousand) and divided by the estimated population of each State, will be equal to the average calls handled by each Brazilian State. It is worth noting that the value 100,000 was taken as a base for performing this calculation, it would also be possible to do it using another reference value.

Comparing the results found in Telehansen attendance with the average population of each State, we can see in the graph below that the sequence of ‘champions’ in total calls, now starts with RJ, DF, AC and TO. In this manner, we can identify the role of the public utility adopted by Telehansen, which is capable of reaching in a proportional manner, different regions of Brazil. Regarding Persons Affected, it is relevant to state that although there is a large Persons Affected presence in RJ and this state remains in first place, on the contrary, in the DF and TO there are no Persons Affected nuclei and only 2 Persons Affected nuclei in AC. Let us see:

GRAPH 2 – Attendance compared with estimated population by State - 2007



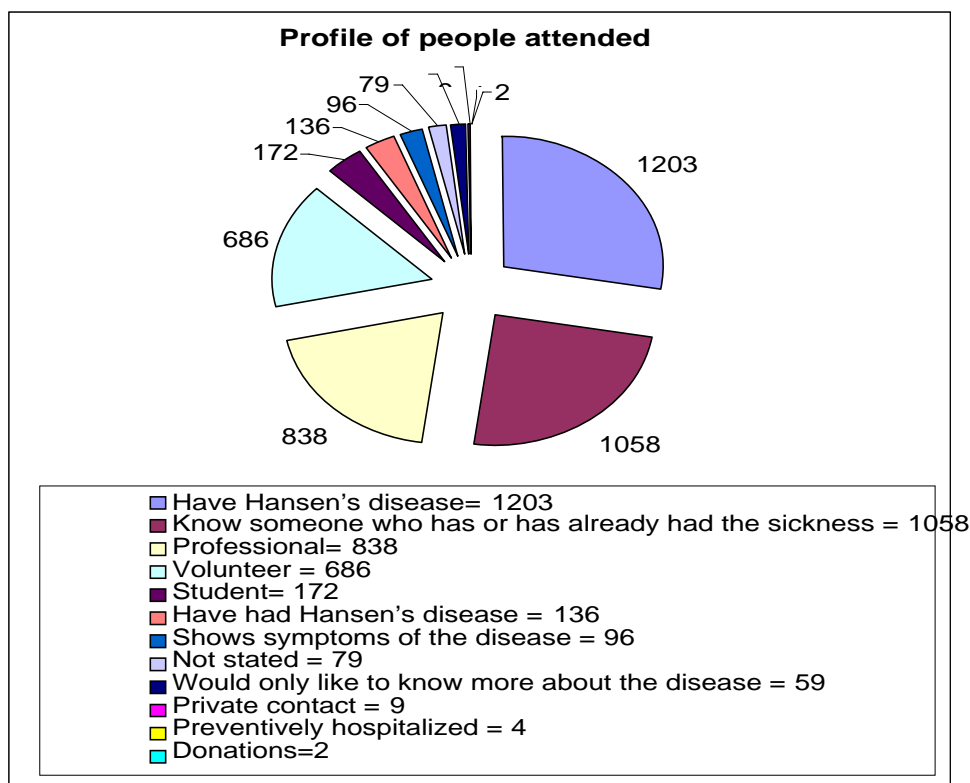
Source: Own preparation as from data from: www.ibge.gov.br.

We can now see the difference of the data in this graph if compared to graph 1. This distinction becomes even clearer when we see that the same data layout was kept in both graphs.

In the same way, it becomes important to investigate the profile of the population that use Telehansen®. In this area, it was interesting to observe that the greater part of those who made contact have Hansen's disease. However, not far behind were those who only know someone who has the disease or who have already had the disease. Here, once again, the relevance of the service in providing guidance to society and demystifying biases and prejudices against Hansen's disease is obvious.

GRAPH 3 – Profile of the population attended by Telehansen® - 2008

Profile of people attended



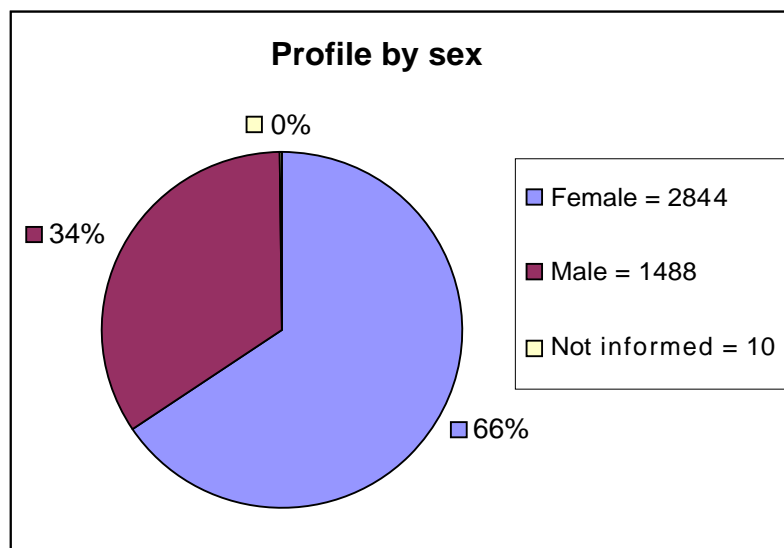
Source: Own preparation.

Also, in analyzing Graph 2, we can identify the preventive nature that the work developed through Telehansen® has. It is possible to conclude that we have a significant number of students, people who show the initial symptoms of the disease and others who enter into contact just to know more about the pathology, thus we have a service capable of offering the individuals the early knowledge essential to avoid contagion of the disease or worsening of it when they already have it. Another point that deserves special note is the strong presence of professionals from various areas using the channel to obtain clarification regarding Hansen's disease or make complaints in this respect.

Within these people who make use of Telehansen®, it is traditional to always record a higher incidence of the feminine population. We know that culturally the woman performs the role of family *caretaker*, offering the protection necessary to protect her family for the threats of life and society. For many years, this was the main attribution of

the feminine figure. However, the family has changed and gained new arrangements. Women have conquered new spaces. Today, we have homes headed by women or lead by other family members who are not men and, although the inequalities of sex are still striking, in particular, the financial aspect, research already shows that women have exceeded the male levels of education. They inform themselves more and seek more knowledge concerning what interests them. Maybe for this reason, women remain at the top of the Telehansen® callers.

GRAPH 4 – Profile by sex of people who made contact with Telehansen® - 2008

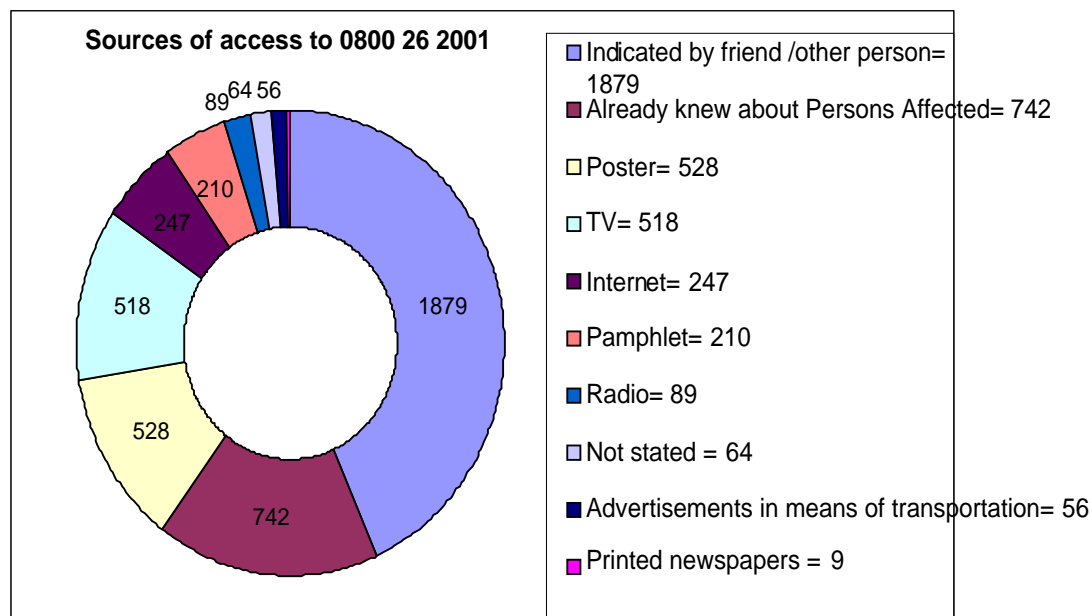


Source: Own preparation.

For a better interpretation of the dimension of the work performed by Telehansen® attendance and an understanding of the reach of this activity, it becomes equally necessary for us to identify the sources of the contacts received. The graph below shows us that almost 50% of population who called Telehansen® during this period, received the telephone number from a friend or other known person. We also see that a large part of the people already knew about Persons Affected, whether through the social

movement nuclei spread out throughout the country, or whether by means of the campaigns carried out in various areas.

GRAPH 5 – Sources of access to Telehansen® - 2008



Source: Own preparation.

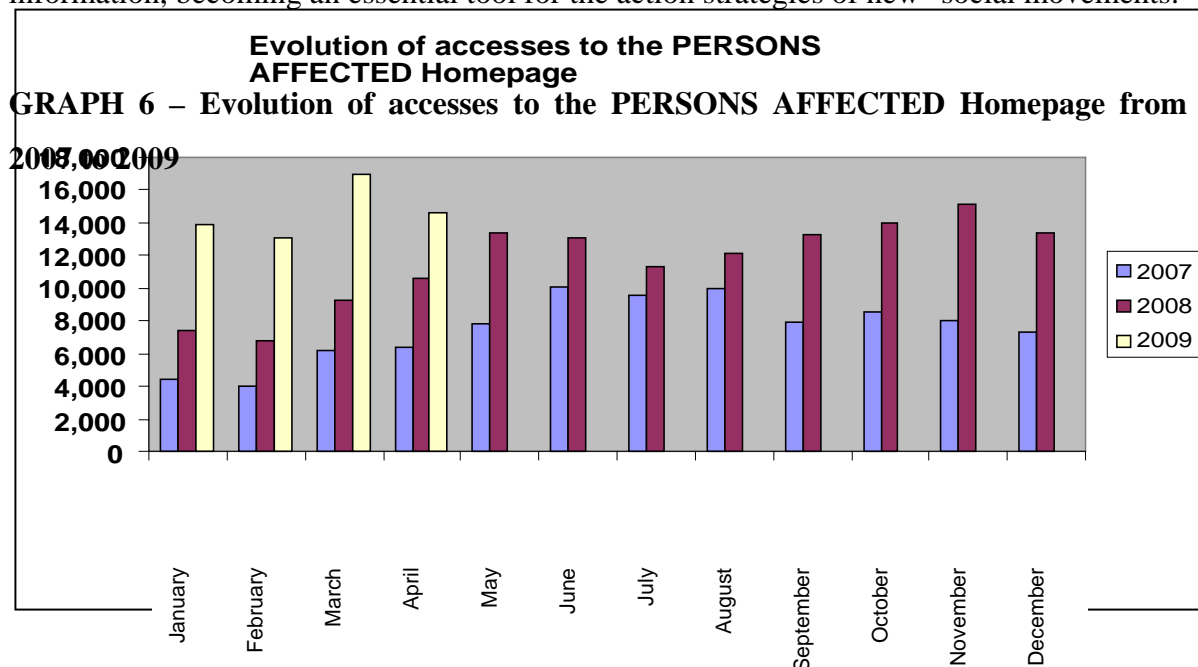
Under this aspect, what has drawn our attention and effort is in respect to the increase in the propagation and distribution of advertisements via communication channels or print material, seeking to reach other sectors of society. The informative campaigns on Hansen's disease carried in the media, generally, have a greater repercussion on Telehansen®, since the 0800 (toll-free) number is shown or spoken by the advertiser. In 2008, we registered calls receiving having as a source of access the large television networks, like REDE GLOBO – 292 calls, SBT – 79, TVE – 55, SEM CENSURA – 25, TV SENADO – 24, REDE RECORD – 24, local channels – 10, TV BRAZIL – 5 and BAND – 4.

Not less important, the effort of the Persons Affected volunteers in promoting actions so as to increasingly multiply the information on Hansen's disease in various spaces, also results in returning to Telehansen® some of the main doubts of the target public. Pamphleting activities, recreational presentations, placement of posters in means of transportation, such as subways, trains, boats, buses and other areas with a large circulation

of people, result in the 0800 number being more disclosed and used as a communications vehicle.

Furthermore, actions are conducted on commemorative dates or at public manifestations, like the World Day for Combat against Hansen's Disease, celebrated in various places on January 25th; a public act denominated: 'Get up and do your part', that reunites social movements from all corners of the world; manifestations such as the 'Day for Making a Difference', where the National Persons Affected volunteers supply information on Hansen's disease in a Rio metro station; amongst other mobilizations that Persons Affected promotes or is invited to participate in. These actions also include the Regional and National Persons Affected meetings.

Another topic that also deserves highlight in the graph above refers to the increase in the search of information on the Persons Affected site – www.Persons Affected.org.br. Every day, more internet users have demanded the constant updating of this site so as to access data relating to Hansen's disease. Persons Affected has worked to improve this service. Internet has come to represent an important role in the dissemination of information, becoming an essential tool for the action strategies of new⁶ social movements.

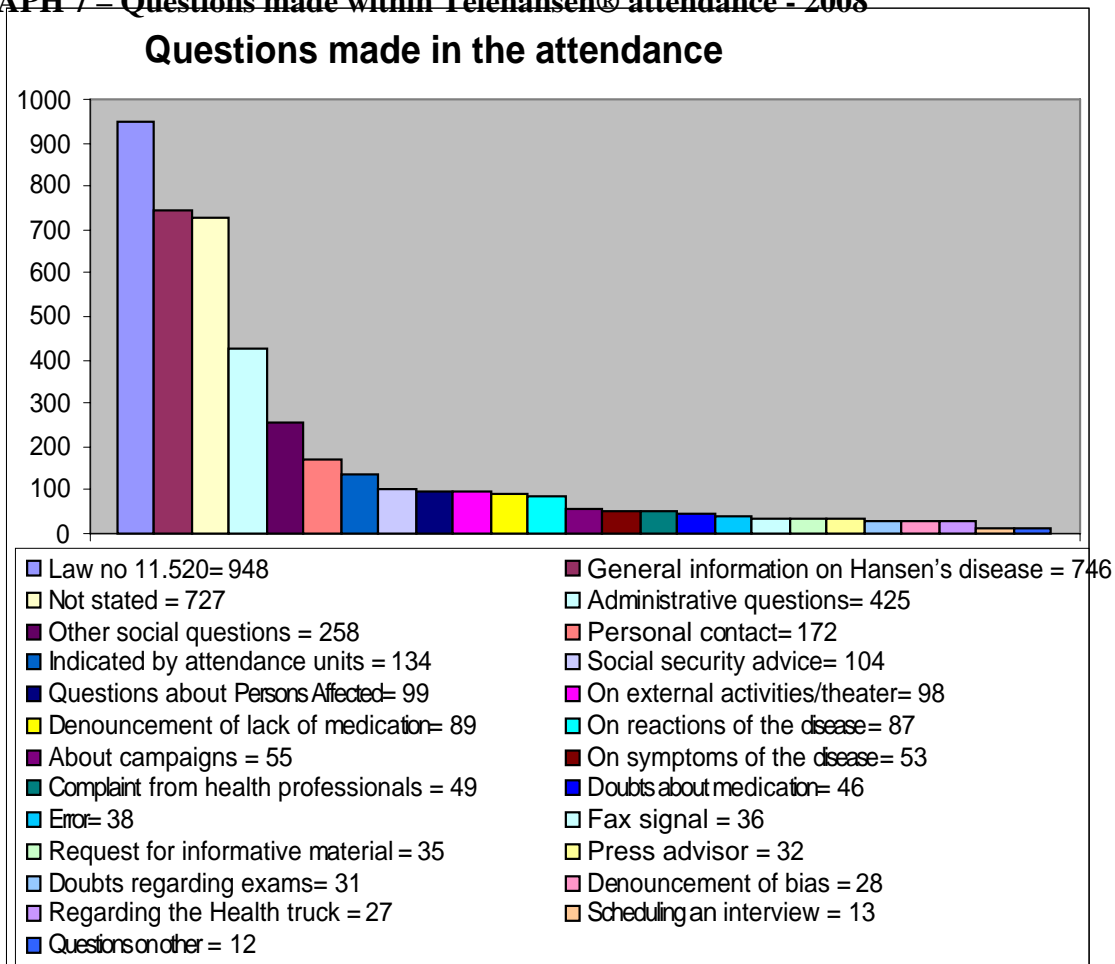


⁶ GOHN, Maria da G. The protagonism of civil society. Social movements, ONG's and mutual help networks. Cortez, 2005.

Source: Database on the PERSONS AFFECTED site.

After all of what was shown above, it remains for us to survey and analyze which were the types of questionings made by individuals in the Telehansen® attendance. This, however, constitutes the item that most interests us for further analysis, bearing in mind that in it reside the main reasons for existence and the maintenance of this service, and as already mentioned, Telehansen® represents the Persons Affected “gateway”. All the volunteers are invited to answer calls because they have the same commitment to keep the attendance center in full functioning and because of the learning that it provides. See the data collected by them:

GRAPH 7 – Questions made within Telehansen® attendance - 2008



Source: Own preparation.

As can be seen, one of the most frequent questions by users refers to Law no 11.520, that, since 2007, occupies position no 1 in this ranking. This law is related to an issue that Persons Affected has been fighting for for years, regarding the possibility of a compensatory measure by the government, a way of compensating people for the social life time robbed from them by being obliged to live in the old “leper colonies”. Ever since the initial struggles of Bacurau⁷, a manner has been discussed to compensate (if this is at all possible) all the suffering people were submitted to by being in total exile within their own nation. There were many manifestations and much pressure exerted by the social movement along with the people afflicted by Hansen’s disease to demand from governmental agencies the legitimation of a special pension for this population.

Only at the end of 2007 and, with the strong presence of Persons Affected, was Law No 11.520 (dated 18 September) passed, guaranteeing an indemnification of R\$ 750.00 (seven hundred and fifty Reals) per month, for life and non-transferable, for the social life taken from people submitted to compulsory isolation in hospital-colonies up until 31 December 1986. The indemnification is retroactive as from the date of signature of the Provisional Measure 373 dated May 2007, and cumulative to social security benefits. To conquer this result, the Persons Affected militants occupied, more than once, the premises of the Planalto Palace in Brasília - DF. The President of the Republic even received Persons Affected members in the Presidential cabinet. Recent images of protests in Brasília are to be found on the site of the institution: www.Persons Affected.org.br.

Persons Affected participated in the entire process of the implementation of the Law, since its beginning. Currently, it accompanies the analysis and concession of the pensions, where sometimes it is faced with localized problems. In order to solve them, the movement uses its link with the Presidency’s Special Secretariat for Human Rights– SEDH, the National Social Security Institute – INSS and people with influence in the political-administrative area.

Also, the weekly list supplied by the SEDH with the name of people that had their indemnification granted is made available on the Persons Affected site and through the 0800 26 2001 - Telehansen® toll-free number. Today, without any doubt, this payment

⁷ See Bacurau Memorial room at: www.casadebacurau.com.br.

represents one of the greatest victories for those who were segregated in the old leper colonies. And, as the number of processes to be analyzed by SEDH is large, we know that Telehansen® will continue to receive calls, requests, complaints and suggestions for a long time from people concerning this law and will continue to be a means of reply for the main demands of users.

The second place in the ranking of questions made to Telehansen®, is related to general information on Hansen's disease. In addition to the constant doubts by users in relation to the symptoms of the disease, possible sequels, reactions, treatment and the use of medicines, questions concerning the contagiousness of Hansen's disease are also made; if there is still the need for compulsory isolation of the patient; if the pathology is sexually transmissible or what are the ways to prevent the disease, amongst others. This category of more general doubts on Hansen's disease is due to certain factors, amongst which we point out: the lack of due information on the disease, which ends up creating new myths, and the increase in discrimination of the people afflicted by Hansen's disease.

For these and other reasons, motivated by the many situations of exclusion and prejudice committed by society against people afflicted by Hansen's disease, Persons Affected was forced to pressure the governmental authorities for the creation of a law that stimulates changes in this scenario. In 1995, with the decisive participation of Persons Affected, Law no. 9.010 dated 29 March, 1995, was sanctioned, replacing the term Leprosy by Hansen's disease in Brazil. This change started several years before, helping to end the stigma of a person with the disease being called a "leper" in society, which still continues until today. However, as the English writer Graham Greene said: *"Leprosy is a word, it is not a disease. People will never believe that leprosy will be cured – Words cannot be cured"*.

Many people see Leprosy and Hansen's disease as the same thing and, for this reason, do not think it necessary to differentiate the term. Part of this argument resides in the fact that certain countries still denominate the disease as *Leprosy*⁸. Furthermore, Leprosy is translated in the Bible as ""The priest shall look at the mark on the skin of the

⁸ International Classification of Diseases.

body, and if the hair in the infection has turned white and the infection appears to be deeper than the skin of his body, it is an infection of leprosy; when the priest has looked at him, he shall pronounce him unclean” (Leviticus, 13:3). This biblical consideration should be analyzed by its historical nature and not by its religious nature, thus avoiding the propagation of even more prejudice.

Discrimination results from an action or omission that violates the rights of man. The myths that still exist in society regarding Hansen’s disease are due to factors like: disinformation on the nature of the disease, its transmission, the forms of treatment; not knowing that the pathology has a cure; imagining that the disease is transmitted by touching, etc. Discriminatory attitudes inhibit people with Hansen’s disease who start to avoid public areas with fear of being rejected. All and any form of prejudice should be denounced!

It is in this sense that the role of the Persons Affected Social Service in attending to the main demands of the social movement becomes relevant. This team is responsible for the work of advising, forwarding, intermediating relationships and intervening by means of actions that are necessary for the intransigent defense of Human Rights of people who are afflicted by Hansen’s disease. The Persons Affected Social Service was created in 2003. The need for this technical team in the institution results from the need to conduct *self help groups* with people who have Hansen’s disease, health professionals and volunteers, to debate the various phases of the disease.

With the passing of time, it was seen that it would be necessary to divide the space and extend the strategies of professional intervention, since it was shown that it was necessary to contribute to the facing of the adversities presented by the disease in all aspects of the user’s life. For such, it was necessary to understand which were the greatest difficulties encountered by this population in its relationship with Hansen’s disease. Amongst which we identified: The reaction period of the disease, sequels that cause body changes and physical limitations, the threat to daily life and the intra and extra-family discrimination.

Today, as we can see in graph 5, there are various demands of a social nature received by Telehansen® that require more direct action by a professional from the Social

Service. Amongst them, we highlight the following guidelines supplied by the team: Other social questions= 258 attendances, Indication of reference centers that offer treatment of Hansen's disease= 134 calls, Social Security advice = 104, Denouncement of lack of medication at health units= 89, Complaint of the attendance by the health professionals = 49 and Denouncement of prejudice = 28. This data totals the 662 attendance supplied by the Telehansen® Social Service during the period.

It is relevant to explain that the item 'other social questions' received this classification to summarize a greater range of questions directed to the Social Service. In this category are included, for example, doubts on: concession of free transportation passes, exemption from income tax and indications of job vacancies for handicapped people, directions regarding the Thalidomide syndrome, providences regarding TFD – 'Away from Home Treatment' and scheduling of medical consultations.

In the majority of these cases, Social Accompaniment is performed during all stages of attendance, until the user achieves the guarantee of his/her rights. In other cases, the preparation of a Social Report, the sending of official notifications and denouncements and/or an institutional visit are required. Whenever necessary, a more detailed investigation on the social conditions in which the subject lives is made, a home visit is also conducted, an action understood as educational and assistential attendance that seeks to support the intervention in the health-disease process of the individuals. Additionally, the Support Group for People with Hansen's Disease (GAPH - Grupo de Apoio à Pessoa com Hanseníase), which includes sick people, family, ex-patients, volunteers and guests, allows for a dialog between people regarding all these factors.

Still within the social aspect, the problems/questions found by users in relation to Social Security Institute should also be pointed out. Hansen's disease is classified as a disease, like others, that does not have a minimum contribution period for a user to have access to social security help. A person afflicted by the disease is not required to have 12 (twelve) monthly contributions, but must have the quality of an insured individual, which means he/she needs to have made his/her last contribution within a maximum period of up to 12 (twelve) months. Even when within the above profile, there are innumerable cases of attendance in which we identified difficulties by the user in this process. The request for

social security benefit is frequently denied under the allegation that the contribution only began after acquiring the disease or by the “devaluation” on the part of specialist doctors of the physical and psychological consequences that Hansen’s disease may cause.

Certainly, the sequels caused by Hansen’s disease may make it impossible for a person to have the full capacity for work and, for this reason, require the guarantee of social assistance. In a country which has shown to be a champion in social and economic inequality, people who need the assistance of a social welfare state suffer with the deficiency and impotence of this system. In these cases, the National Social Security Institute – INSS, in addition to making it difficult for the user to gain access to the help/benefit he/she requests, whether because it is unaware of or ignores the particularities of certain diseases, denies a basic right guaranteed to all people in article XXV of the Universal Declaration of Human Rights:

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, disease, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

It is at this time that we tend to identify the increasing importance of the Social Service to be inserted and perform its professional action *in loco*. As states Yazbek (2008), it becomes essential for a social assistant to extrapolate the limits of his/her actuation to act in ensuring the rights of the users, in a field as contradictory as Social Security. As the author states:

It is within this perspective that should be placed the emergence, in the area of Social Security, of a new way professional manner of thinking and acting, (...) directed to the interests of the users of this public policy, in the search for guaranteeing for them a new statute of citizenship and concretization of rights. This new thinking by the social assistants(...). The new plan, based on the knowledge of reality in its multiple determinations” (Brazil, 1994:8) seeks to construct a theoretical methodological model of professional exercise that really contributes to the effectiveness of social rights for the population that uses this social policy. (YAZBEK and BRAGA and CABRAL (orgs.), 2008 p. 119).

Thus, we can analyze how access to Citizenship by different social subjects, passes through the enlightenment of society in relation to the equal and inalienable rights of the human being and what he/she should do to access his/her rights. One of the greatest challenges of the Persons Affected Social Service for the guarantee the Human Rights of a person afflicted by Hansen's disease, is to allow the deep development of the user in his/her process of social formation, in the construction of public policies for Hansen's disease and in the participation in combating the disease, in a more enlightened, more tolerant and less discriminatory society.

In addition to all the social factors listed above, Telehansen® also receives a large number of calls referring to questions that relate to the functioning of the social movement. We therefore have, in graph 5, the item classified as 'administrative questions' that appears with 425 calls answered; the topic 'questions about Persons Affected' with 99 contacts; on external/theater activities - 98; subjects concerning campaigns- 55; press advisor - 32 and scheduling interviews with Persons Affected representatives- 13.

This set of points more directly related to Persons Affected refers to all that that involves the Statutes of the movement, the maintenance of spaces where its nuclei are located, the formation of partnerships, the input and output of projects in the institution, the organization of the work and reception of new volunteers, the presence of Persons Affected at places where it is requested, the production of articles, publications, materials and everything else connected to the development of the social movement's actions.

Of the points observed in this report, possibly considered unproductive in terms of advice about Hansen's disease, are to be noted the calls without a record of the reason for the contact, personal calls for Persons Affected volunteers, wrong numbers, calls with a fax signal, doubts regarding other diseases and practical jokes, which occur often in 0800 services.

A piece of data considered insufficient, bearing in mind the 4342 calls answered by Telehansen® during the 9 month period, was the number of requests for informative material, which had a number of only 35 requests. This element may be relevant only to show the need for an increased effort by the attendants of Telehansen® in informing about the possibility of distribution of informative material on Hansen's disease, via Persons

Affected. The 'Health Truck' subject also showed little visibility in Telehansen®, if we take into account the socio-educative role that this project has.

We may identify the work of the 'health Truck' as one of the more recent gains in terms of detection of Hansen's disease in Brazil that will contribute to the proposed elimination of the disease up to 2010. Through the social responsibility program of a private company, in partnership with Persons Affected and with the National Council of Municipal Health Secretaries - CONASEMS, a mobile unit that travels around the country making early exams for Hansen's disease was constructed. This is an innovative undertaking, which is quite efficient in clarifying the panorama of the disease in Brazil, and also involves various professionals.

The Health Truck, as it is known, was launched in the first half of 2008. Equipped with 5 (five) consulting rooms and 1 (one) laboratory for performing bacilloscopic exams, the air conditioned interior has a rest room and hydraulic elevator for access by wheel chair users and elderly persons and more: the truck is equipped with a stage and sound system for artistic presentations and a multimedia projector with a large screen for showing films. The vehicle also has its own power generator and a capacity to attend approximately 15,000 people/year.

The first activities of the Health Truck, which occurred in Brazilian municipalities characterized by the high rate of detection of Hansen's disease, like São Luiz MA, for example, 902 consultations were performed and 50 new cases of Hansen's disease were detected. Today the Health Truck also travels to areas that request its visit, attending the population in consultations and starting treatment in positive cases, in addition to the offering of educational programs. This project also involves Community Health agents, to increase the awareness of communities as to the particularities of the disease, so that everybody knows how to identify it and seek out health units as soon as possible. Students of Medicine, Dentistry, Nursing and Social Service are invited to participate as volunteers advising children in schools.

CONCLUSION

In addition to the struggles already fought and conquests already obtained by Persons Affected throughout its 27 years of existence, in favor of people afflicted by Hansen's disease, the daily actions that the movement implements focused on health policies, by means of the dignified social attendance that it supplies to people involved with Hansen's disease, should also be considered of great importance. Each call received and advised by Telehansen®, each forwarding and successful social accompaniment, each new volunteer interested in contributing to the cause for the elimination of Hansen's disease and each individual that discovers in the Social Movement for Reintegration of People Afflicted by Hansen's Disease, a new hope to build the milestones that will reconstruct their life, already shows us the size of this endeavor.

It is exactly in this direction, that we identify, within Telehansen®, its characteristic as a facilitator for users in the exercise of their civil, political and social rights. For this reason, this report could be considered to be inconclusive, in case we had not had the opportunity to make a brief analysis in respect of this peculiarity attributed to the service. For such, we will again make use of the data set out in graph 5 that shows the questions made by callers to the Telehansen® attendance.

If temporarily, only for the purpose of this analysis, we ignore the data considered unproductive in terms of advice/guidance about Hansen's disease, we will discover that more than 77% (seventy seven percent) of the calls received by Telehansen®, obtained a reply pertinent to the role for which it is intended. Even in the cases in which the question was directly connected to the functioning of Persons Affected, taking into account that the focus of action of the social movement is to contribute to the formation of Citizenship of the people afflicted by Hansen's disease, Telehansen® had, during 2008, a good average productivity.

As for the 23% (twenty three and percent) of unsatisfactory contacts, we will include, in Persons Affected's 2009 plan, investments for the training of the Telehansen® attendants so that they may learn attendance techniques and strategies capable of obtaining information from even the most reticent callers. In this manner we will be able to considerably reduce this percentage.

Even so, with the intention of better illustrating the productivity obtained by Telehansen® during the period from April to December 2008, the table below was prepared that shows an overall summary of the axes in which the subjects that were covered in each call are distributed. It is from this table that we can visualize in a more evident manner the diversity of the demands that reach the Telehansen® service.

TABLE 5 – Summary of calls advised/attended by Telehansen®

QUESTION	No Of CALLS RECEIVED	LEGEND:
Law no 11.520	948	OTHER SUBJECTS THAT INVOLVE HANSEN'S DISEASE
General information about Hansen's disease	746	
Non stated/hoax	727	DIRECT QUESTIONS ABOUT THE HANSEN'S DISEASE PATHOLOGY
Administrative questions	425	
Other social questions	258	
Personal contact	172	UNPRODUCTIVE
Referred from attendance units	134	
Social Security advice	104	QUESTIONS RELATED TO THE FUNCTIONING OF PERSONS AFFECTED
Questions about Persons Affected	99	
About external/theater activities	98	
Denouncement of lack of medicines	89	ATTENDANCE DONE BY THE PERSONS AFFECTED SOCIAL SERVICE
On reactions to the disease	87	
On campaigns	55	
On symptoms of the disease	53	
Complaint from health professionals	49	
Doubts of medication	46	
Wrong number	38	
Fax signal	36	
Request for informative material	35	
Press advisor	32	
Doubts on exams	31	
Denouncement about bias	28	
On the Health Truck	27	
Scheduling in interview	13	
Questions about other diseases	12	
TOTAL: 4342 CALLS		

Source: Own preparation.

Considering everything that was presented above, we find a base to resume the initial argumentation of this conclusion about Telehansen® as a means of access by the users to civil, political and social rights. This statement may be justified starting from the construction of the following premise:

- **CIVIL RIGHTS:** are potentialized when the user is stimulated to occupy spaces of social formation, such as professionalization, culture, leisure, amongst others, and participate in the mobilizations and campaigns in favor of people afflicted by Hansen's disease. The great relevance in exercising this right is in the fact that there in a not so distant past this population suffered from the most varied kinds of social segregation.

The compulsory isolation measure was a sanitary policy that, although it had been adopted to avoid the transmission of the disease, ended up representing an arbitrary violation of the rights contained in the Universal Declaration of Human Rights of 1948, in especial article XII: *“No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honor and reputation. Everyone has the right to the protection of the law against such interference or attacks”*. On the contrary, people were dragged from their homes which were burned, removed from their children and other family members to be kept in asylum colonies separated by sex and with their right to come and go denied.

Even after the discovery of the microorganism that causes the disease, this exile practice continued in the entire national territory, lasting years, leaving sequels that are still reflected in society. According to the Hansen's Disease and Human Rights handbook, from the Ministry of Health (2008): *“Many isolated people, upon leaving the hospital-colonies, could not reintegrate themselves into society, or were not received by their families and had to return to the place where they had lived the greater part of their lives”*. What was guaranteed to these subjects, even after the end of the compulsory isolation in Brazil and the destruction of the walls, was the daily exercise to try to represent and reconstruct themselves in society.

With the perspective of contributing to the deconstruction of this scenario, we identified in the attendances registered by Telehansen®, actions capable of encouraging the exercise of coming and going of people afflicted by Hansen's disease. Amongst them, the questions connected to the campaigns and external activities, receipt of denouncements, indication of attendance locations, etc.

- **POLITICAL RIGHTS:** more directly related to the Telehansen®'s elucidative profile. Persons Affected is a self declared non political social movement and as such, uses alternative ways to act in the defense of the interests of the target public of Hansen's disease. It must be clear that, not recognizing to be a member of a political party, does not mean that the demand for and imposition of a presence in the front of governmental authorities on questions relating to Hansen's disease, should be done in a limited manner. To the contrary, it is exactly because it does not wear any political 'colors', that Persons Affected manages to simultaneously insert itself in the struggles of separate chains of thought, thus achieving, an ever greater range of entities, civil associations and other institutions that adhere to the cause.

In the past, people that were victims of compulsory isolation, also had their right to vote controlled. The sick that lived in the old colonies had to deliver their voting card to local managers to avoid any possibility of passing the disease to people considered healthy outside the colonies. In fact, to avoid any chance of contact with people who did not have the disease, the colonies had their own currency identified on one of its sides by "Lazarus's Hospice". No action could be performed without the supervision of the managers under the penalty of reclusion in the prison that also existed in the colonies. A real limited society, impeding people from exercising their citizenship.

However, the formation of Citizenship in Brazil is interpreted as a complex and historically defined process. Different from the logic described by Marshall (1967), here the social rights came in front, brought out in the middle of the suppression of political rights and reduction in civil rights caused by the dictatorship. The political rights, curiously arose in the military regime. But, for Carvalho (2008), a full citizen would be one who was the holder of all three rights. Those who had access to only one of these rights, would be an

incomplete citizen. Because of this, for the author, full citizenship in Brazil is an almost unreachable ideal.

Today, Persons Affected stimulates people afflicted by Hansen's disease to participate ever more in political decisions that involve the country. More than this, through Telehansen®, users are also invited to be present in the political demonstrations held by the movement in favor of the collective objectives of this population. By means of the Telehansen® attendance, information regarding political rights of citizens and what to do to access them is disclosed.

- **SOCIAL RIGHTS:** without doubt, these are the most discussed during attendance in Telehansen®. They represent the guarantee to education, health, leisure, work and Social Security in case of disease, old age, death of a supporting family member or involuntary unemployment. Social rights are also the largest victims of the changes that have occurred in the world economy. Social assistance, which should attend the “needy”, who lack the means for subsistence, is the most affected with the destructive consequences of capital. The degree of poverty of the population in general, increases ever more the number of people demanding help and social benefits, causing worries to the capitalist order. How to distribute help, without reducing the value of work? Assistance is often had as a generator of “dependency” and “abuse” of social resources.

In the case of people afflicted by Hansen's disease, all of the inheritance left by the negative effects of the disease, may respond to the various current causes that permeate the social dynamics of these individuals. Especially, the weakening of conditions for access to the job market and absence of representation in the Professional Work Booklet, expressed as a legal requirement for citizenship in Brazilian society. The majority of the people who left the old Hansen's disease colonies have not yet managed to qualify themselves professionally or have physical limitations that impede them from certain activities.

In the health area, the picture is also not very bright. Like all Brazilians, a person afflicted with Hansen's disease has the right to full time attendance by a team of health professionals who may help him in the cure, in the prevention of incapacities and

rehabilitation from the disease. This team should have a doctor, nurse, nurse aid, physiotherapist, community agents, occupational therapist, psychologist, social assistant and others. It also constitutes a right of the user, to know the disease that affected him and receive advice on the diagnosis and treatment that is being done. However, the conditions are pessimistic and there is a large lack of preparation in attendance by the public health units.

In relation to physically disability, it is up to the State to offer users the guarantee of access and accessibility: access to social rights to be respected as a member of society and accessibility to be able to move around safely wherever he/she wishes. It is worth noting that the duty of the State does not exclude the responsibility of the family, companies and society. It is for this reason that Persons Affected makes itself present.

Through Telehansen®, the dissemination of what the social rights of people afflicted by Hansen's disease are is frequently exercised. As well as this, it is through this channel that the help of someone who is not being accessible to the user is often requested. It is unnecessary to say that more than 50% (fifty percent) of the questions made via Telehansen®, are related to the absence or difficulties in accessing a social right by the individual. Within these directives offered via Telehansen®, we have Law No. 11.520, guidelines on the rights of the patient under the Single Health System - SUS, information on Social Security, disclosure of job vacancies for people with handicaps plus all the forwarding supplied by the Social Service.

The constitution of citizenship for people afflicted with Hansen's disease was and continues being a process that is constructed extremely slowly, in short steps. Recently, the social rights have received greater emphasis for these individuals. Especially with the new acquisitions and changes in Brazilian legislation to attend to these users. Even so, we have demonstrated how the social field is shown to be so fragile for these subjects. In this manner, to ensure qualified attendance to people, all the social movement volunteers, including the Persons Affected Social Service team, should make an effort to frequently update themselves on the laws, decrees, provisional measures, benefits, help, rights and duties, amongst other factors that are directed at the population attended by Persons Affected.

Certainly, the theoretical and empirical deepening made under the proposal for analyzing the reflections and questions made in this report, leads us to identify a reciprocal relationship between Persons Affected, as a social movement, and the formation of Citizenship of people afflicted by Hansen's disease. With all the measures than can be improved so as to ensure better results in its actions, the work that is done in Telehansen® presents itself as a social apparatus of great relevance in Brazil.

Without doubt, Telehansen® qualifies PERSONS AFFECTED's intervention in the political processes and in the analysis of problems in the public policies intended for people afflicted by the disease. It is as if it were an excellent sample of the strategies of public health, humanization, social assistance, human rights, information processes, communications and education amongst others. A service that may be interpreted in the words of Geraldo Vandré: *“Vem vamos embora que esperar não é saber, quem sabe faz a hora não espera acontecer”* (“Come, let us be gone, because waiting is not knowing, those who know make things happen, they don't wait”).

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