

Deafness in the Brazilian care policy: a genealogical analysis

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Abstract *Deafness can be understood from the clinical-therapeutic and the socio-anthropological perspectives. The study aims to perform a genealogical analysis of deafness; that is, an analysis of the practices of knowledge and power in Brazilian health policy. This is a qualitative, documentary study based on the theoretical assumptions of Foucault. Researchers selected 23 documents and conducted eight semi-structured interviews, which were also considered documents, with a non-probabilistic sample using the snowball technique. The genealogical analysis showed that health policies aimed at people with hearing impairment result from the power and knowledge relationships in the field of deafness, in which the medical-pathological discourse is seen as the real perspective, understanding deafness as a disability to be corrected. The socio-anthropological approach, which recognizes the deaf through the perspective of difference and the use of sign language, is a subject discourse that has not found space in health policy. The study highlighted the contradictions between the achievements related to the access to technologies and the propositions of the health sector, whose policy directs its actions exclusively to reach a listening standard, disregarding the multiplicity of deaf individuals.*

Key words *Deafness, Right to health, Health policy, Accessibility, Communication barriers*

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Introduction

From the 70s of the 20th century, the world has seen an increase in the discussion in defense of human rights, including people with disabilities, especially in the United States, Canada and European countries¹. The evolution and maturation of this movement led to important transformations, including the change of the term “disability”, which came to be understood as a combination between the injuries inflicted on the body and the barriers that prevent full participation in society. This definition was officially adopted in the United Nations Convention on the Rights of Persons with Disabilities².

Although this conceptual change in the “disability” category, which began to associate bodily limitations to environments with barriers³, has proven to be an important political strategy, and even triggered positive advances, it has not yet addressed some specificities. Based on this conception, it would be enough to include people who are deaf in the group of people with disabilities, but many deaf people do not see themselves that way⁴. They call themselves *Deaf*, being members of a *Deaf Community* and a cultural linguistic minority, as part of a group that makes use of a visual-gestural language – sign language, which is their main identity characteristic.

In turn, there are two coexisting truth regimes about deafness. A regime associated with the disability from the perspective of the biomedical model, which is centered on the deficit and on the teaching of speech, understanding it as the true speech.

Called by some scholars as a “clinical-therapeutic model”, this perspective understands deafness as an anatomical-physiological deficit that generates hearing loss⁵, which is understood as a pathological sign that raises efforts towards repair, thus generating an intense process of medicalization of deafness⁶. This is under the aegis of the same regime of truth which, as reported by Carvalho and Martins⁷, is that of a body in which something is missing and, therefore, the individual experiences situations of disadvantage and seeks the path of repair. As being deaf is understood as a disadvantage due to the difficulty in establishing communication and, in this perspective, it fits perfectly into the category of *people with disabilities*.

And there is a second perspective, which is focused on difference, centered on sign language, on the deaf community and culture, and which was called “socio-anthropological” perspective.

Most studies based on this perspective of deafness attribute the use of sign language to the development of an identity. Thus, sign language would constitute the deaf subjects and would allow them to share social experiences, beliefs, cultural values and would also favor the connection with the society as a consequence⁷⁻⁸.

Officially, there are 9,722,163 people with hearing impairment in Brazil, although it is not known exactly how many are sign language users⁹. A large international investigation showed that there were 1,700,000 sign language users in Brazil in 2007¹⁰. Although it may be outdated, this number shows that the number of people who use the Brazilian Sign Language (BSL) is not so insignificant to the point of being invisible to public health policies. Being included in the agenda of governmental priorities is not necessarily a quantitative parameter, but the asymmetries of power-knowledge that make up the social body.

Power is not a fact alone; power is, above all, “a mode of action of some over others”, which only exists associated with acts. According to Foucault¹¹

[...] It is a total structure of actions brought to bear upon possible actions; it incites, it induces, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their acting or being capable of action. A set of actions upon other actions¹¹ (p.243).

In this context, when the other involved in the action is the deaf, as subjectivity constituted as an individual-mode or as a group collective of subjection, over which power is exercised, this relationship has resulted in (linguistic, communicational and attitudinal) barriers, expressed by the denial of rights.

When these barriers are observed in the context of health, they result in a threat to a fundamental right. These obstacles are related to the difficulty in accessing information in sign language or other communication strategies, due to the professionals’ lack of knowledge about the reality of the deaf, their culture and rights and the lack of accessibility to services¹². In this context, they are denied the right to information and autonomy in making decisions about their own health.

However, there is a contradiction (or not), as the Brazilian Health System designed two policies involving people with hearing impairment throughout its history – the Brazilian National

Hearing Health Care Policy (PNASA)¹³, in 2004, and the Care Network for People with Disabilities (RCPCD)¹⁴, in 2012.

This Care Network was developed mainly aiming to expand access and qualify care, as a result of the Brazilian National Plan for the Rights of Persons with Disabilities - Living Without Limits, which was published in Decree No. 7.612/2011, and which intended to promote the full and equitable exercise of the rights of people with disabilities, through the development of policies, programs and actions.

From this context, a question arises: Are these policies aimed at the population of people with hearing impairment respecting their singularities? In other words, when something is developed aimed at this population, is there a consideration on the part of the population that uses sign language? Therefore, this article aims to carry out a genealogical analysis of deafness, investigating the practices of knowledge and power in the context of the Brazilian health policy.

Methodological route

This study refers to part of the analysis carried out in the study entitled *Noise and silence: a genealogical analysis of deafness in the Brazilian health care policy*¹⁵. This is a qualitative and documentary study, including a genealogical analysis, based on the theoretical assumptions of Michel Foucault. Genealogical analysis consists of showing the origin of power relations, as well as resistance, following the connections of events between historical facts¹¹. The study focuses on forces that are managed and that, in their interrelationship, produce facts that try to impose themselves as universal truth.

Foucault¹⁶ reports that there are also discourses of truth in the exercise of power, which emerge from it and, simultaneously, reinforce it.

*We should admit rather that power produces knowledge (and not simply by encouraging it because it serves power or by applying it because it is useful); that power and knowledge directly imply one another; that there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations*¹⁶ (p. 31).

It is relatively simple to identify the knowledge that presents itself as truth, as it is on the surface and circulates freely in the social body, subsidizing and reinforcing power. However, un-

derneath these powers, there is also knowledge, which is overshadowed and repressed, and associated with resistance, subjugated and inherent to every exercise of power. *Subjugated knowledges are, then, blocks of historical knowledges that were present in the functional and systematic ensembles, but which were masked, and the critique was able to reveal their existence by using, obviously, enough, the tools of scholarship*^{17:8}.

In order for the subjugated knowledge to come out of the shadow in which they were placed by the true discourse, and in order to identify the emergence of power relations, the genealogist must select documents where the events materialized. Details and facts that are ignored and not included as history, being neglected and rejected, are relevant to the genealogy¹⁸.

Thus, the researchers selected 13 normative documents and 10 informational documents (as shown in Graph 1) to carry out the genealogical analysis. The choice of documents was guided by the following criteria: 1) Federal laws and decrees that concern people with disabilities; 2) Federal laws and decrees related to deafness and sign language; 3) Directives of the Ministry of Health concerning people with disabilities; 4) Directives of the Ministry of Health on People with Disabilities directly related to deafness; and 5) Publications by the Federal Government (Secretariat of Persons with Disabilities and the Ministry of Health) related to persons with (hearing) disabilities of an informative and/or evaluative nature. In addition, the researchers carried out eight semi-structured interviews, which were also considered as documents (Graph 2). Thus, the selected sample was non-probabilistic using the snowball technique, in which the initially selected subjects suggest other participants. The inclusion criterion was to be sociopolitically involved in some phase of the development of health and/or education policies aimed at people with disabilities, such as leaders of social movements, managers, representatives of rehabilitation services, members of councils and committees who shared information on the topic through oral history.

From a temporal point of view, the genealogical analysis of deafness in the context of health policy considered the creation of the Unified Health System (SUS) in 1988 as a starting point, as well as the policies aimed at people with hearing loss that were developed as a result.

This study was approved by the Research Ethics Committee of the School of Medical Sciences at Universidade Estadual de Campinas (FCM/

UNICAMP) (CAE No. 51771815.2.0000.5404; Opinion No. 1.468.353) and carried out in accordance with Resolution No. 466/2012. The participation was voluntary and all participants signed the Free Prior Informed consent.

Results and discussion

Practices of knowledge and power about deafness in Brazilian health policy

When the SUS was developed, the Ministry of Health (MS) began to implement the first actions aimed at people with disabilities in the following decade. With regard to hearing loss, specialists, especially otorhinolaryngologists and speech-language pathologists from a university center focused on the oral approach, provided advice to the federal government

From the end of the 19th century until the middle of the 20th century, the oral approach was the privileged pedagogical approach in deaf education, being incorporated by speech-language pathologists as a therapeutic approach throughout history. Associated with the discourse of

a truth that understands deafness from a clinical-therapeutic perspective, the objective of this approach is to integrate the deaf child to the hearing society, through the development of the oral language¹⁹.

The following illustrates the participation of these specialists at the Ministry of Health (MOH) in the 1990s.

(...) there were two advisers: an otorhinolaryngologist, who performed surgeries Bauru, and that woman (...) who was a speech-language pathologist, and she is responsible for the table. She was in favor of the oral approach and oralization, and the otorhinolaryngologist assisted us to include cochlear implants in the directive. So, she developed the table with her group (from the Universidade de São Paulo-USP/Bauru). Afterwards, we met with the Brazilian Society of Speech-Language Pathology and Audiology, which made some recommendations, and we took it out of the hands of otologists and otorhinolaryngologists. But the table was developed by speech-language pathologists (Manager nº 2 of the Ministry of Health).

As a result of the work developed by this team, especially by the Speech-Language Pathologists, the table reported above is the “Table of Proce-

Chart 1. Normative and informational documents related to people with (hearing) disabilities.

Normative documents (laws, decrees and directives) related to people with (hearing) disabilities			
N	Document	Year	Subject/Topic
1	Law No. 7,853	1989	This law provides for support for people with disabilities, their social integration, for the Brazilian National Coordination for the Integration of People with Disabilities (CORDE), in addition to establishing the jurisdictional protection of collective or diffuse interests of these people, disciplining the actions of the Public Ministry, defining crimes and providing other provisions
2	Decree No. 914	1993	This Decree establishes the Brazilian National Policy for the Integration of People with Disabilities and provides other provisions
3	Directive GM/MS No. 1,278	1999	This Directive approves the indication and contraindication criteria for cochlear implants in the form of Appendix I
4	Decree No. 3,298	1999	This Decree regulates Law No. 7,853, of October 24, 1989, provides for the Brazilian National Policy for the Integration of People with Disabilities, consolidates the protection rules and provides other provisions
5	Law No. 10,436	2002	This Law provides for the Brazilian Sign Language (BSL)
6	Directive MS/GM No. 1,060	2002	This Directive approves the Brazilian National Health Policy for People with Disabilities
7	Directive GM/MS No. 2,073	2004	Brazilian National Hearing Health Care Policy
	Portaria MS/SAS 587	2004	Norma regulamentadoras para a implantação e funcionamento das Redes Estaduais de Atenção à Saúde Auditiva.
8	Directive MS/SAS No. 587	2004	This Directive establishes regulatory standards for the implementation and operation of State Hearing Health Care Networks

it continues

Chart 1. Normative and informational documents related to people with (hearing) disabilities.

Normative documents (laws, decrees and directives) related to people with (hearing) disabilities			
N	Document	Year	Subject/Topic
9	Decree No. 5,626	2005	This Decree regulates Law No. 10.436, of April 24, 2002, which provides for the Brazilian Sign Language (BSL) and Article No. 18 of Law No. 10.098, of December 19, 2000
10	Social Agenda - Citizenship rights for people with disabilities	2007	This document aimed to present the priorities defined for the Social Agenda of People with Disabilities during President Lula's Government
11	General Comments of the Convention on the Rights of Persons with Disabilities	2008	This document aimed to support legislative advisors and consultants of federal and state representatives and senators, managers and technicians, political, union and social leaders and each person, with or without disability, with regard to the Convention on the Rights of Persons with Disabilities
12	Decree No. 186	2008	This Decree approves the wording of the Convention on the Rights of Persons with Disabilities and its Optional Protocol, signed in New York, on March 30, 2007
13	Decree No. 6,949	2009	This Decree promulgates the Convention on the Rights of Persons with Disabilities and its Optional Protocol, signed in New York on March 30, 2007
14	History of the Political Movement of People with Disabilities	2010	This book tells the history of the social movement of people with disabilities in Brazil, as well as the public policies and main actions carried out by the Brazilian Government
15	Decree No. 7,612	2011	This Decree institutes the Brazilian National Plan for the Rights of Persons with Disabilities - Living Without Limits
16	Directive MS/SAS No. 793	2012	This Decree establishes the Care Network for People with Disabilities in the scope of the Unified Health System
17	Guidelines for Attention for Neonatal Hearing Screening	2012	These Guidelines guide multidisciplinary teams for the care of hearing health in childhood, with a focus on Neonatal Hearing Screening, in the different points of care of the network
18	Convention on the Rights of Persons with Disabilities	2012	It aims to promote the content of the Convention on the Rights of Persons with Disabilities to all Brazilians, in compliance with the provisions of the Convention
19	Brazilian National Plan for the Rights of Persons with Disabilities - Living Without Limits	2013	It presents the goals and actions divided by plan axis - access to education, social inclusion, health care and accessibility - in order to disseminate information and serve as a tool for the implementation and inspection of public policy
20	Hearing, physical, intellectual and visual rehabilitation instruction from a Center Specialized in Rehabilitation (CER) and qualified services in a single modality	2013	Complementary document to the directives and also serves to support municipal and state managers with regard to the organization of points of care, especially rehabilitation services regarding the physical structure, equipment, professionals (categories and quantitative), as well as premises for the exercise of practices of care
21	New Comments on the Convention on the Rights of Persons with Disabilities	2014	This document assesses the measures taken by the Government towards compliance with the prerogatives of the Convention on the Rights of Persons with Disabilities, which was ratified by Brazil in 2008
22	Brazilian National Plan for the Rights of Persons with Disabilities - Living Without Limits	2014	It reports the historical context that led to the development of the plan; the actions of each of the four axes; and the management and monitoring processes of the Living Without Limits Plan
23	General guidelines for Specialized Care for People with Hearing Impairment in the Unified Health System (SUS)	2014	The document guides professionals on aspects related to cochlear implant surgery and bone-anchored hearing aids, such as clinical and audiological assessments, follow-up and speech-language rehabilitation, surgery and pre- and postoperative follow-ups and criteria for indications and contraindications

Source: Authors.

Chart 2. List of respondents according to subject position and institutional place.

Oral history respondents	
Subject position	Institutional place
Deaf Leadership No. 1	Member of the National Federation of Education and Integration of the Deaf (FENEIS) and of the National Council for the Rights of Persons with Disabilities (CONADE).
Deaf Leadership No. 2	Member of the National Federation of Education and Integration of the Deaf (FENEIS) and of the National Council for the Rights of Persons with Disabilities (CONADE).
Manager of the Secretariat of Human Rights	General Coordinator of the National Council for the Rights of Persons with Disabilities (CONADE).
Manager No. 1 of the Ministry of Health	Member of the General Coordination of Health of Persons with Disabilities of the Ministry of Health
Manager No. 2 of the Ministry of Health	Member of the Health Technical Area for Persons with Disabilities of the Ministry of Health
Advisor of the Ministry of Health	Member of the General Coordination of Medium and High Complexity of the Ministry of Health and, previously, of the Health Technical Area for Persons with Disabilities of the Ministry of Health
Representative No. 1 of Rehabilitation Center	Member of the Advisory Committee on the Implementation of the Care Network for People with Disabilities
Education policy researcher and consultant at the Ministry of Education	Researcher from Public University

Source: Authors.

dures, Drugs, Orthoses, Protheses and Special Materials⁹, through which the first procedures for people with hearing impairment were included in the SUS. In academia, the speech-language pathologist and her group mentioned are known as a group that promotes the oral approach at USP Bauru.

This same group also provided huge contributions to the PNASA¹³, created in 2004, from differences in professional categories linked to rehabilitation, especially speech-language pathologists.

There was nothing organized and structured, but from this policy on, there was the possibility of enabling services such as Hearing Rehabilitation Centers. These Centers started to receive funding from the MOH to develop diagnostic and therapeutic care, screening and monitoring of hearing²⁰, benefiting many Brazilians, especially the elderly.

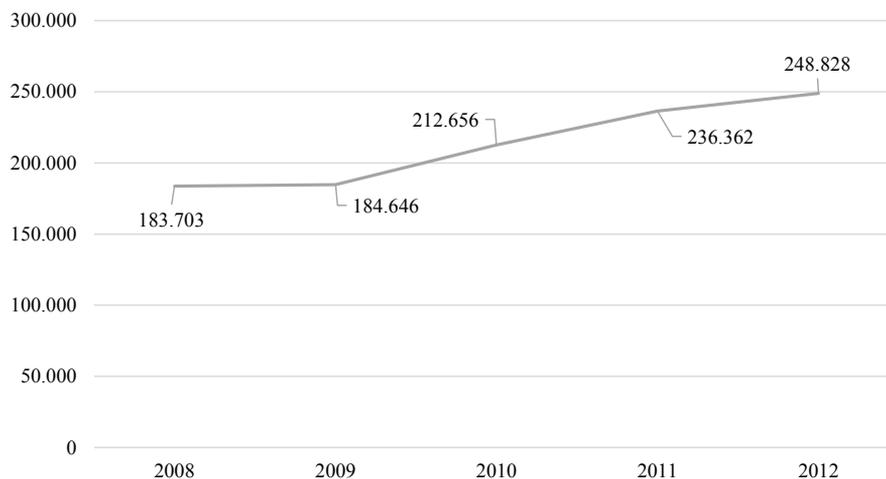
The policy also recommended actions that should be developed in primary care, such as: hearing health promotion, prevention and early identification, informational and educational actions, family guidance and referral to rehabilitation services¹³.

PNASA was a turning point regarding access to hard technologies²¹, which are capable of pro-

viding auditory stimuli to those who do not have this possibility. There are only a few health systems in the world that fully finance this type of resource. Graph 1 shows the growing evolution in the number of hearing aids provided in the period in which PNASA was in force, until the RCPCD replaced it in 2012.

The researchers investigated to understand the socio-historical context that resulted in the creation of PNASA and found that there had to be an opening in the governmental agenda so that the issue of auditory rehabilitation could be prioritized. This emergency condition was due to the presence of an advisor, who worked in the Technical Area of Health of Persons with Disabilities at the MOH, who, in addition to being a speech-language pathologist, had close ties with the Workers' Party (PT), the political party that ran the federal government at the time. Therefore, the focus on Speech-Language Pathology was present, not only in the MOH, but also within the Presidential Palace itself.

Thus, there was the political issue that was very important, since the advisor was from the workers' party and audiology was promoted for being represented in the government and in the ruling party. It does not mean that this was the only reason, but there were two important determinants: first, there



Graph 1. Approved amount of hearing OPM purchased with federal funding. Brazil, from 2008 to 2012. Information prior to 2008 was not available in DATASUS.

Source: Ministry of Health - Outpatient Information System of SUS (SIA/SUS).

was a technical advisor who, as part of the ruling party, could report the 'speech-language pathologist's claims' to the Government. (...) If you analyze the dates, it is possible to notice a very large (financial) increase during the administration in which (the advisor) represented the workers' party in the coordination (Manager No. 2 of the Ministry of Health).

This advisor, and the power relations in which she was involved, collaborated to develop a favorable scenario so that the "speech-language pathologist's claims" could be met, providing the necessary support to put into practice the proposals of the group that advised the MOH.

(...) the group of the speech-language pathologist helped to develop the directive, and all those directives (2,073/2004, 587/2004 and 589/2004) started to be developed with her (the speech-language pathologist from USP/Bauru) and the staff of the University of Bauru. She (speech-language pathologist) discussed a lot because she believed that this space was necessary in the SUS, and she understood the procedure and so did the ABA staff (Brazilian Association of Audiology) (Manager nº 2 of the Ministry of Health).

Although less expressively, the interviewees' reports show the participation of two institutional places - the Brazilian Association of Audiology and the Brazilian Society of Speech-Language

Pathology and Audiology, whose approaches were similar to the oral approach of the group of professionals from the university center.

In the midst of the historical facts that are characterized as an emergency condition of PNASA, it is necessary to question the knowledge about deafness that specialists, the scientific society and the technical consultants of the MOH use to support their practices. The following illustrates and reinforces the continued use of the clinical-therapeutic approach on deafness.

There was a discussion between the otologists, the otorhinolaryngologists and the advisors, it was a mess. (...) actually, the great discussion was about the use of sign language or oral language. There was such a discussion that when the Bill that instituted the Brazilian Sign Language in Brazil was submitted to the Coordination, the coordinator did not sign and was against this Bill. So, there was even greater confusion (...), but the Coordination did not change its mind. The MOH was against, but it won the dispute (the Bill was approved) (Manager nº 2 of the Ministry of Health).

At that time, in the early 2000s, there were disputes far beyond the field of health, such as in education, where the socio-anthropological approach on deafness resonated much more easily and sign language was introduced into classrooms. This approach, which can be understood

as part of a subjugated knowledge, did not get support in health, except for a still small part of speech-language pathologists, who would gradually incorporate this approach into their practices, thus adopting bilingualism as a work approach.

Bilingualism arises from the socio-anthropological approach on deafness, as a pedagogical approach that supports the exposure of deaf children to sign language in a school environment, so that it can be naturally acquired and as a first language. Simultaneously with the acquisition of this language, the approach promotes the learning of the auditory-oral language as a second language, in its oral and/or written modality.

The publication of a law – the BSL Law, enacted in 2002 –, which recognized the Brazilian sign language as another Brazilian language, put pressure on a set of practices defended by the health field, represented by specialists who directly influence the development of policies aimed at this discussion. In this context, it is not surprising that the MOH was against the bill that recognized Libras as the main means of expression for the deaf. This position was based on arguments that not only defended access to hearing repair technologies and the development of an oral ability, but also promoted the idea that sign language was an obstacle to language development.

(...) it was believed that everyone should be given a chance to speak and develop more and more and not be limited, since (experts said that) according to research, (...) when people acquired the sign language (...) they had more difficulty communicating (...) and acquiring speech. Thus, the idea was to include the cochlear implant, prostheses, and everything that could promote speech in the table of the SUS. (...) None of the specialists who advised the Ministry of Health were against the oral approach, so this decision was taken. There was also the following idea: the area of education was responsible for issues involving the BSL (...) and there was a concern that if sign language was established as an official language, it would not give oral approach a chance. And there is no sense in this idea, as the two approaches can coincide (Manager nº 2 of the Ministry of Health).

Therefore, PNASA is the result of knowledge-power practices guided by the truth regime on deafness, which has been understood as a true discourse for centuries. It was developed with a clearly defined target audience in mind: the *hearing impaired*; that is, people who do not listen, but who have to listen; people who don't speak, but have to speak. Anyone who does not meet

this policy, even if they have a hearing loss, is not a target of the policy. The health policy developed for *people with hearing impairment* reiterates a subject produced in the 18th century and assumes an excluding profile.

The development of PNASA was also a response against a knowledge that was gaining more and more space, which was evident with the approval of Law No. 10,436/2002. In addition to the policy itself, the field of health strategically delimits the territories that belong to it and to education.

In this way, all the necessary actions to normalize the *hearing impaired* subject are assigned to health, while the sign language is not included in health, as a prohibited territory through which sign language would not be allowed to pass. In order not to simply deny sign language, which would be politically incorrect, the health field reinforces that another field (education) is responsible for it.

Policies aimed at people with disabilities result in the inclusion of two types of subjects in normative documents: the *hearing impaired*, which is the responsibility of the health area, and the *deaf*, which is the responsibility of the education area. Thus, PNASA ended up reinforcing this binarity and individuals were forced to adapt to these norms, even if they wanted to transit through the two spaces.

This study does not criticize the SUS offering access to technologies capable of assisting oral abilities, as it should be noted that this access is a positive point to be valued in the Brazilian system. However, it should be noted that the policy does not recognize that there is a group of people who communicate through sign language within the segment of *people with hearing impairment*. There are many reports of deaf people who are sign language users and who are approached by professionals trying to convince them to undergo implant surgery or fitting a hearing aid to the detriment of sign language.

In the case of deaf adults, they must also have their right to choose respected, as they may be sign language users but may want to learn to speak; and they need to be respected and there must be services well prepared for their needs. However, it is wrong when they look for a service and this service immediately tries to convince them that they should no longer use sign language (Deaf Leadership nº 1).

Despite pointing out that PNASA was a policy created disregarding the multiplicity of deaf individuals, it must be recognized that it allowed for meeting a set of needs of a significant part of

the population. Despite this, the investment was disproportionately higher in hard technologies. On the one hand, hearing losses were being more identified and there was an increase in access to hearing aids; on the other hand, there was very little guarantee of comprehensiveness of care, as it often ended in the fitting of the device.

It should be noted that comprehensiveness is understood as something that can only be achieved through the knowledge of people's health needs, which concern their living conditions, access to all *health technology*²¹ capable of improving and prolonging life, to the creation of bonds between the user and the professionals, and to the autonomy in the way of living life.²²

One of the main criticisms refers to the failure to create mechanisms to ensure comprehensive care, such as to overcome difficulties in accessing therapeutic monitoring carried out by speech-language pathologists in order to promote language development, since this service focuses on the same services where hearing aids are provided, often far from people's homes.

The integration between the points of care, the guarantee of comprehensiveness and access for all citizens, with the allocation of rehabilitation services according to local reality and demand, are still goals to be achieved²³.

Therefore, the fragmentation of care is a challenge to be overcome not only with regard to people with disabilities, but in the entire health system. Thus, the SUS went through a process of reassessment of the organizational model, culminating with the adoption of Health Care Networks (RAS) in 2010 as the main strategy to achieve comprehensiveness²⁴.

The RCPCD was developed from the implementation of this new organizational model in Thematic Networks, which is reported by Louvison²⁵ as networks that provided greater discussion between those involved, but that do not face important structural problems.

As in the preparation of the PNASA, the Ministry of Health had the collaboration of external consultants and scientific societies for the implementation of the RCPCD; however, it also included a broader and more diversified group of professionals in the area – the *Advisory Committee on the Implementation of the RCPCD*.

On the other hand, although this committee including representatives of several universities and Rehabilitation Centers to prepare the policy was subdivided into Working Groups (WG), the "Hearing WG" did not have the same diversity of members, as shown below.

The (Hearing) WG was very homogeneous, mainly due to the high number of otorhinolaryngologists. The discourse was very similar and the group did not have great disagreements, as they were discussing a specific issue at the time, which was prosthetization. Therefore, rehabilitation (in this case, used as a synonym for therapy) was not being discussed at that time. For that group, the discussion of "rehabilitation" involved discussing technology, not rehabilitation models, which was never discussed as follows: "Now, we will discuss what is best for the deaf (...)". There was already a consensus in the group that, if the child was deaf, the protocol was to reach the diagnosis and have a prosthesis or implant placed (...). At some point rehabilitation would be discussed, but that moment never came because there were people with different backgrounds and I believe it would cause a lot of controversy. (...) In just a few times it was possible to add: "We must not forget that sign language also exists". This was not something to be discussed, it just seemed that: this issue is the responsibility of education (Representative nº 1 of Rehabilitation Center).

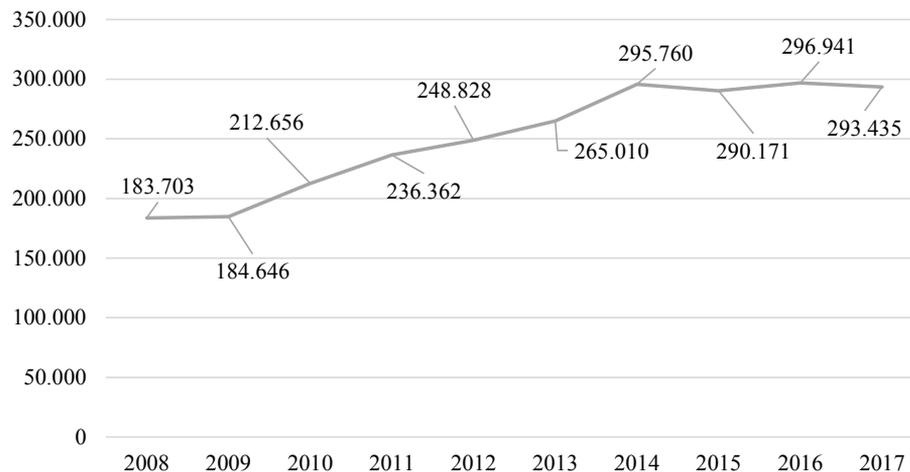
This Committee had the opportunity to advance in a discussion that the previous policy did not address, even with the presence of new social participants from other institutional places. By analyzing the guidelines of the new policy described in the Hearing, Physical, Intellectual and Visual Rehabilitation Instruction²⁶, prepared by the technical staff of the MOH together with these specialists who, at that time, were no longer restricted to the USP-Bauru group, it could be noticed that the content is quite similar to that of PNASA, with a few updates.

The guiding documents still focus on access to hard technology, describing in a very detailed way criteria related to evaluation; indication, selection and fitting of the device according to the age of onset, type and degree of hearing loss; periodic monitoring of the equipment in the individual's daily life, aiming at possible electroacoustic adjustments and offering guidance on the use and handling of the device.

Graph 2 shows the increase in access through the growing number of hearing aids provided from 2012, when the RCPCD was developed.

The documents also show the need for speech-language pathology therapy, but with no detailed guidance on this practice, reporting only that it should be guided by a "comprehensive rehabilitation", without further clarification.

On the other hand, countless pages are dedicated to hearing aids, while only a few lines are



Graph 2. Approved amount of hearing OPM purchased with federal funding. Brazil, from 2008 to 2017.

Source: Ministry of Health - Outpatient Information System of SUS (SIA/SUS).

dedicated to “speech-language pathology monitoring” and nothing is said about the different therapeutic possibilities of working with the deaf, including the use of sign language. This finding could have no significance if the power relations and knowledge-power practices that permeate the field of deafness were unknown.

It is quite relevant that rehabilitation has not been questioned and that there has not been an analysis of the therapeutic approaches that can be adopted in the Hearing Rehabilitation Centers. The MOH maintained the same posture and the same approach on deafness. If at that time the MOH avoided discussing this issue because it could cause a lot of “controversy”, it could be explained by being one of the spaces where the true discourse on deafness would resonate most.

On one occasion, this was questioned in the *Intersectorial Commission for the “Health of Persons with Disabilities” of the Brazilian National Health Council (CNS)*, which had a speech-language pathologist who works from a bilingual perspective as a member. The pressure reverberated into the “Hearing WG”, but it was quickly neutralized.

This was mentioned in a single meeting, in which the coordinator reported that she was going to participate in a CNS meeting, which would also include deaf users and would discuss the issue of sign language. Thus, there was a discussion in

the group that led to the following question: “Was it really necessary to discuss the sign language issue? After all, in fact, we only discuss technological features.” And the discussion ended like that, the issue was never discussed again. The coordinator probably attended (the meeting at CNS), but she did not report what was discussed at the meeting. The coordinator only mentioned this in one of the meetings, and this generated a certain surprise in the group, since the group included many otorhinolaryngologists, and they reacted like: “Sign language should be discussed by the education field, not us. Our field is health.” (...) And this was never discussed or addressed again (Representative nº 1 of Rehabilitation Center).

However, more recently there has been a change in the updated version of the *Hearing, Physical, Intellectual and Visual Rehabilitation Instruction*²⁷, which for the first time recognized the Law No. 10,436/2002 and suggested the need for the professional team, together with the family, to evaluate the possibility of including sign language in the therapeutic process.

The forces surrounding health policy are not pressured by the deaf movement, but by the category of rehabilitation professionals, more specifically by speech-language pathologists who promote bilingualism.

The demand of the rehabilitation center regarding the use of sign language in the therapeutic

process is actually a demand of professionals who work with therapy. It is a very frequent demand among speech-language pathologists and in the teaching of speech-language pathology, involving a discussion between those who defend the oral approach and those who defend bilingualism. This is the professional category that presents this issue to the General Coordination of Health of Persons with Disabilities (MOH) (Manager nº 1 of the Ministry of Health).

Disputes between professionals who promote the oral approach and bilingualism seem not only to give more visibility to sign language users within politics, but also to guarantee spaces for action. Regardless of the speech-language pathologist's approach, the two options always have a therapeutic character that aims to restore a standard, which is still not in the agenda of the social movement of the deaf.

However, the attempt to question the therapeutic work with the deaf in order to include sign language came from speech-language pathologists who promote bilingualism, and not from the deaf movement. This is explained by the fact that the deaf who are sign language users do not recognize themselves in this agenda and, therefore, do not put pressure on the MOH, as shown below.

There is very little pressure from the deaf movement on the General Coordination of Health for Persons with Disabilities and the health field in general. The demands of the deaf people's movements are focused on other issues, such as the desire to include sign language interpreters in health units, which resulted in the development of BSL Centers (Manager nº 1 of the Ministry of Health).

Cochlear implant surgeries that are also linked to RCPCD should also be investigated, especially because the therapeutic follow-up of users can be conducted in Hearing Rehabilitation Centers.

The *General guidelines for Specialized Care for People with Hearing Impairment*²⁸ make it clear that rehabilitation must be based on the oral method, excluding the possibility of simultaneous sign language.

In addition, the Guidelines add that Rehabilitation must take place in the patient's city of residence, aiming to overcome the geographic barrier that is often at the root of the discontinuity of care; but, on the other hand, it does not create concrete management mechanisms to allow this and for the longitudinality of care to occur.

In this sense, both those who undergo cochlear implant surgery and those who conduct

a device fitting often have their care interrupted when they most need it. In this approach, the health industry that has the SUS as a large consumer market is the only part that does not take risks of having "losses", since the SUS is totally dependent on the suppliers. As shown in Graph 3, millions of Reais are invested annually in hearing aids from public funding.

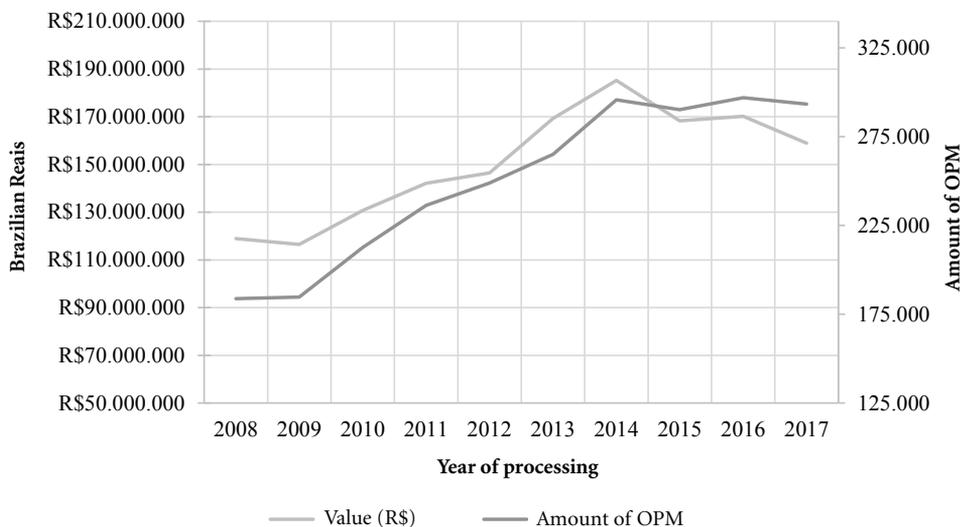
Of course, there is economic interest from a medical equipment business industry, which is also guided by the medical-pathological discourse of deafness. One of the deaf participants was convinced that the practices of professionals, especially doctors, are guided by a logic driven by economic interests.

The group and doctors, even some famous doctors, who make this policy do not accept sign language, what do these doctors want? They want money! (...) We need to be more respected, after all, we are human and we have the right to have our language too. Why can't the sign language be accepted too? (Deaf Leadership nº 2).

Although there are professionals who work guided only by this type of interest, the researchers do not believe that the knowledge-power practices exercised by professionals are exclusively for this reason, as it would be a very reductionist and unfair perspective. In order to analyze this issue, the researchers decided to turn to two intercessors, Deleuze and Foucault, who question the reasons why the exercise of power can be explained.

As for the problem you present – you see who explores, who makes a profit, and who manages, but power is something even more diffuse – I would raise the following hypothesis: even Marxism – and above all it – determined the problem in terms of interest (Power is held by a ruling class defined by its own interests). There is a question that immediately arises: how is it possible for people who are not so interested in power to follow power, link themselves closely to it, and beg a part of it? Perhaps in terms of investments, both economic and unconscious, interest is not the last word; there are investments of desire that explain that one can desire, not against their interest – since interest is always a consequence and is found where the desire places it – but desire in a deeper and more diffuse way than their interest²⁹ (p. 76).

This perspective leads us to the possibility that, when subjecting themselves to a medical-pathological approach, professionals actually desire a "cure" for deafness, through all possible resources. Ultimately, these desires are perfectly aligned with the interests of companies, which



Graph 3. Approved amount and values of hearing OPM purchased with federal funding. Brazil, from 2008 to 2017.

Source: Ministry of Health - Outpatient Information System of SUS (SIA/SUS).

are increasingly profitable due to the group of professionals in perfect harmony with them.

In addition, factors such as the daily exclusion experienced by the deaf in society and the distance in the teaching of professionals from the deaf population and their culture lead to a real lack of knowledge of their health needs, contributing to policy makers, as well as the advisory team, to adopt practices of knowledge power that are not in line with the comprehensiveness of health care.

Conclusion

The knowledge and power practices associated with deafness inevitably affected public policies, which are the product of one or several governments, impacted by numerous forces. In this study, it was possible to find that health policies - the *Brazilian National Hearing Health Care Policy* and the *Care Network for People with Disabilities* - were guided by a regime of truth about deafness that has been constituted as a true discourse for centuries and that does not recognize that the deaf person may have different characteristics, with different needs that may include or not access to technology.

Collaborations

NG Vianna, substantially contributes to the conception, design, analysis, data interpretation, paper writing and approval of the version to be published. MGG Andrade, substantially contributes to the design, analysis, data interpretation, critical review of the paper and approval of the version to be published. FCS Lemos contributes to the analysis and interpretation of data, critical review of the paper and approval of the version to be published. D Rodriguez-Martín, contributes to the analysis and interpretation of data, critical review of the paper and approval of the version to be published.

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