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Barriers to and facilitators of communication to care for people with sensory disabilities in primary health care: a multilevel study

Barreiras e facilitadores à comunicação no atendimento de pessoas com deficiência sensorial na atenção primária à saúde: estudo multinível

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ABSTRACT: Objective: Communication barriers are the main obstacle for people with sensory disabilities (visual and hearing) to access health services. This study aims to describe the presence of facilitators of communication of basic health units in Brazil and to verify its associated factors. Methods: Cross-sectional multilevel study, of 38,811 health units in 5,543 municipalities between 2012 and 2013, collected in the National Program for Improving Access and Quality in Primary Care (Programa Nacional de Melhoria do Acesso e da Qualidade da Atenção Básica - PMAQ-AB). The outcome was defined by grouping facilitators of communication (braille material; hearing resources; visual communication; accessible list of service; professionals to welcome users with sensory disabilities). The two levels were structured, using the variables: level I (contextual): macro region, population size, and GDP per capita; and level II (service): extended professional team (psychologist/social worker); service shifts; welcoming room; publishing of service hours; presence of physical access facilitators. Multilevel Poisson regression with hierarchical modeling was used in both stages. Results: The presence of facilitators of communication is small in Brazilian health units (32.1%). It is more frequent in the municipalities with a higher GDP (RP = 1.02, 95%CI 0.92 - 1.12) and population size (RP = 1.25, 95%CI 1.02 - 1.52). Conclusion: Welcoming users is the main access facilitator and should be the focus of initiatives to improve health care for disabled persons. Universal access with adequate services, removal of communication barriers and encouragement to properly welcome users must be promoted.

Keywords: Communication barriers. Primary health care. Disabled persons. User embracement.

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RESUMO: *Objetivo:* Barreiras à comunicação são principais dificultadores do acesso de pessoas com deficiência sensorial (visual e auditiva) aos serviços de saúde. Os objetivos do estudo foram analisar a prevalência e os fatores associados à presença de facilitadores à comunicação nas unidades básicas de saúde no Brasil. Métodos: Estudo transversal multinível sobre dados de 38.811 unidades de saúde de 5.543 municípios, entre 2012 e 2013, coletados no Programa Nacional de Melhoria do Acesso e da Qualidade da Atenção Básica (PMAQ-AB). Desfecho criado agrupando facilitadores à comunicação (material em relevo/braille; recurso auditivo; comunicação visual; listagem acessível de ações do serviço; profissional para acolhimento de usuário com deficiência sensorial). As variáveis de exposição do nível I (contextuais) foram: macrorregião, porte populacional e produto interno bruto (PIB) per capita. No nível II, (serviço) foram: equipe ampliada; modelo de atenção; turnos de atendimento; sala de acolhimento; divulgação do horário de atendimento; presença de facilitadores ao acesso físico. Utilizou-se regressão de Poisson multinível com modelagem hierárquica em dois estágios. Resultados: A presença dos facilitadores à comunicação é pequena nas unidades de saúde (32,1%), sendo mais frequentes nas unidades localizadas nos municípios com maior PIB (razão de prevalência — RP = 1,02, intervalo de confiança de 95% — IC95% 0,92 - 1,12) e porte populacional (RP = 1,25, IC95% 1,02 - 1,52). Conclusão: Ter profissional para acolhimento é o principal facilitador ao acesso e deve ser foco de ações para melhorar a atenção à saúde das pessoas com deficiência. Faz-se necessário promover acesso universal, com adequação de serviços, remoção de barreiras à comunicação e estímulo ao acolhimento do usuário.

Palavras-chave: Barreiras de comunicação. Atenção primária à saúde. Pessoas com deficiência. Acolhimento.

INTRODUCTION

Physical and sensory disabilities (auditory and visual) are the most prevalent disabilities both in Brazil and in the world, and population aging is directly related to the increase in these types of disabilities, because they are mostly acquired throughout life^{1,2}. The global prevalence of disabilities is 15.3% of the population; of serious disabilities, with a major impairment of daily skills, the percentage is 2.9%. However, among elderly individuals (over 60 years old), 10.2% report severe disabilities and need care³. In Brazil, the prevalence of self-reported disability was 6.2% (about 12.4 million people), increasing to 18.2% among the elderly. Visual disability was the most frequent one (3.6%), and hearing disabilities affect 1.1% of the population. The prevalence of both increases with age (11.5 and 5.2% at 60 years old, respectively)². This distribution of deficiencies is similar to the figures presented in other countries, such as in China⁴ and the United States⁵.

Disabled persons present more health needs which are not met^{6,7}, that is, they report greater difficulty in being able to solve health problems compared to non-disabled persons. Access to health services is also more difficult⁸. The barriers to this access can be classified into three categories: structural, financial, and personal/cultural⁹. These barriers do not compromise access only for disabled persons, but they tend to be more severe for this portion of the population^{10,11}.

People with hearing disabilities report barriers to communication as the main obstacle to health accessibility, both in relation to the interaction with health professionals and to the information available in the service¹². The main complaints reported are: communication problems during clinical examination and anamnesis; difficulty in understanding the prescription, which interferes with drug safety; lack of information on the best form of non-verbal communication for deaf patients; difficulties in the waiting room and for scheduling appointments¹³.

People with visual disabilities also have great difficulty in accessing health services. Barriers to communication, physical access, information (materials written in an inaccessible format) and attitudinal barriers were mentioned by blind or partially sighted people, such as lack of respect or concern in relation to the doctor's thinking that patients are not capable of caring for their own health¹⁴. Elderly people with visual disabilities, when compared to elderly people with no disabilities, had more comorbidities and conditions secondary to diseases (such as diabetes, systemic arterial hypertension and stroke), greater limitation of activities of daily living, such as walking, preparing meals or taking medications, in addition to greater restriction of their social life¹⁵.

Health professionals also realize that the access of population with sensory disabilities is more complex, reporting greater difficulty when caring for people with limited communication and visual disabilities than when caring for those with reduced mobility or cognitive disability¹⁶. Both users and professionals report the need for training and continuing education of the health team to reduce barriers to communication¹⁷, increased awareness and knowledge, the empowerment of disabled users and the creation of public policies to improve health care¹⁸.

The literature is very consistent in relation to the barriers to physical disabilities that hinder access to health units¹⁹⁻²¹. Nonetheless, there was no population-based study focusing on barriers to communication in primary health care services, which is a preferential gateway into the health care network. It is also assumed that the contextual variables, linked to the municipality in which health units of the referred studies are inserted, can influence the accessibility of services, given that primary care services are organized and offered by municipal health systems. Based on the above, the aims of the present study were to describe and analyze the facilitators of and barriers to access for using primary care services by people with sensory disabilities (hearing and visual).

METHODS

DESIGN

A cross-sectional and observational study was carried out, with a multilevel analytical approach, based on data from Cycle I of the National Program for Improving Access and Quality in Primary Care (*Programa Nacional de Melhoria do Acesso e da Qualidade da Atenção Básica* – PMAQ-AB) and contextual data from the municipalities.

SETTING

In 2011, Brazil implemented the National Program for Improving Access and Quality in Primary Care (*Programa Nacional de Melhoria do Acesso e da Qualidade da Atenção Básica* – PMAQ-AB), whose main objectives were to expand access and improve the quality of primary care²². The external evaluation of the PMAQ-AB was conducted in a multicenter and integrated manner by independent Education and Research Institutions, with direct monitoring by the Brazilian Ministry of Health. Cycle I of the PMAQ-AB took place between 2011 and 2013 throughout the Brazilian territory. The external evaluation instrument of the first PMAQ-AB cycle was organized into three modules:

- Basic Health Units (Unidades Básicas de Saúde UBS)
- Primary Care Teams;
- Users of primary care services.

In the present article, information from module I was used.

DATA COLLECTION

Data were collected *in loco* in all Brazilian UBS, between May and December 2012, with a standardized and previously tested instrument, using portable computers (tablets). The team coordinator responded to the data collection instrument, which was checked by the external evaluator. External evaluators, who collected the data, underwent a one-week training based on the field manual prepared by the Department of Primary Care (*Departamento de Atenção Básica* – DAB) of the Ministry of Health²³.

VARIABLES OF INTEREST

The variables of the block related to accessibility to users with visual and/or hearing disabilities, decreased vision and/or hearing or those who cannot read were used. The outcome was created using the variables of the question of the PMAQ external evaluation instrument: "Does the health unit guarantee accessibility to users who cannot read, have reduced vision and/or hearing or visual and/or hearing disability?" the PMAQ external evaluation instrument. The following variables were grouped: presence of material with embossed characters, braille or embossed figures; auditory resource (sound); visual communication (signage by text, drawings and figures) indicating environments or UBS services; listing (scope) of service actions so that disabled persons have access; and existence of a professional to welcome users with visual or hearing disabilities. All questions had categorical answer options "yes; no; do not know/did not answer". After adding the facilitators, the variable was dichotomized into having no facilitator or having one or more facilitators.

The choice for joint analysis of barriers to auditory and visual communication was due to the low frequency of specific facilitators for each type of sensory disability.

The exposure variables of level I related to the contextual characteristics of the municipalities were macroregion, population size and gross domestic product (GDP) *per capita*, which were collected in the official secondary database of the Brazilian Institute of Geography and Statistics (*Instituto Brasileiro de Geografia e Estatística* – IBGE). The base year for information on population density, population size of the municipality and GDP *per capita* was 2010.

At level II, the variables related to the UBS, selected in an exploratory way, were extended professional team in Primary Care; care model (traditional and Family Health Strategy (FHS)/parameterized); service shifts; welcoming room; publishing of service hours; presence of facilitators of physical access (pavement in good conditions, non-slip floor, regular floor, access ramp, handrail and absence of carpet). The minimum professional team is comprised of a doctor, nurse and a licensed practical nurse, and the extended professional team can count on several other professionals, such as psychologists, social workers, nutritionists, physiotherapists, among others. For the present study, we considered an extended professional team with a psychologist and/or social worker. Regarding the care model, they were divided into the traditional model (UBS, with the largest population enrolled) and FHS/parameterized (units that have a FHS or are parameterized to work along the lines of this care model). All variables were collected in the external evaluation of the PMAQ-AB.

BIASES

In order to avoid information and measurement bias, the same instrument for data collection was used by all external evaluators. The evaluators also counted on the presence of a field supervisor.

STATISTICAL ANALYSIS

The data were analyzed using the Stata 11 and SPSS 20 software. Analyzes of the absolute and relative frequencies of the studied variables were performed. Multilevel Poisson regression²⁴⁻²⁶ (*xtpoisson* command, with *re* subcommand for random effects)²⁷ was used to obtain the gross and adjusted prevalence ratios with the respective 95% confidence intervals (95% CI) and 5% significance level. The modeling used was hierarchical²⁸ in two stages: Model 1 (only the contextual variables in the adjustment within the block itself); and Model 2 (the contextual variables with p < 10% of model 1, plus the UBS level variables). Deviance, Akaike information criterion (AIC) and Bayesian information criterion (BIC) parameters were used to analyze the adjustment of models. The theoretical model used was adapted from Donabedian²⁹ (Figure 1).

ETHICAL ASPECTS

Research was carried out in accordance with the principles of the Declaration of Helsinki and the guidelines and standards for research involving human beings of Resolution No. 446/2012, of the Brazilian National Health Council (Conselho Nacional de Saúde – CNS). For data collection related to external evaluation, the PMAQ was submitted to the Research Ethics Committee of Universidade Federal do Rio Grande do Sul, approved on March 13, 2012, registration No. 21.904.

RESULTS

A total of 38,811 UBS from 5,543 municipalities were assessed, reaching 99.6% of Brazilian municipalities. The most prevalent facilitators of communication were professionals for welcoming users (21.1%); availability of a list of accessible services for disabled persons (10.8%); and design of health services (8.6%). Hearing aids and materials available in braille were found in less than 1% of services. Even when grouping the facilitators to create the outcome, only 32.1% of the UBS had one or more facilitators of communication (Table 1).

The Southeastern and Southern macroregions had better results (presence of at least one facilitator in 39.0 and 36.3% of the units, respectively), as well as the municipalities with the highest GDP and population size (more than 500 thousand inhabitants). In relation to health units, having a welcoming room, a psychologist and social worker and publishing of service hours were also more associated to the presence of facilitators of communication (Table 1).



UBS: basic health unit.

Figure 1 Analysis model for sensory disability (visual and hearing).

		Facilitators of communication	
		Yes	No
		n (%)	n (%)
Facilitators of communication	Professional for welcoming users	8,195 (21.1)	30,616 (78.9)
	List of services for DP	4,200 (10.8)	34,611 (89.2)
	Visual communication of health services	3,336 (8.6)	35,475 (91.4)
	Hearing resources	148 (0.4)	38,663 (99.6)
	Braille	83 (0.2)	38,728 (99.8)
	One or more	12,464 (32.1)	26,346 (67.9)
Facilitators of communication (outcomes) Gross Domestic Product*	1 st tertile	3,426 (26.5)	9,521 (73.5)
	2 nd tertile	3,933 (30.3)	9,026 (69.7)
	3 rd tertile	5,105 (39.6)	7,799 (60.4)
	Up to 5,000	757 (31.9)	1,617 (68.1)
	5,001 to10,000	1,099 (29.3)	2,647 (70.7)
Population size	10,001 to 50,000	4,980 (28.5)	12,497 (71.5)
(inhabitants)*	50,001 to 100,000	1,613 (31.5)	3,503 (68.5)
	100,001 to 500,000	2,392 (36.8)	4,112 (63.2)
	More than 500,000	1,623 (45.2)	1,970 (54.8)
	Northern	685 (21.3)	2,525 (78.7)
Macroregion*	Northeastern	4,063 (27.8)	10,574 (72.2)
	Central-Western	770 (28.5)	1,936 (71.5)
	Southern	2,293 (36.3)	4,021 (63.7)
	Southeastern	4,653 (39.0)	7,290 (61.0)
	No professional	8,483 (28.5)	21,252 (71.5)
Extended professional team*	Psychologist or Social Worker	1,834 (41.4)	2,599 (58.6)
	Psychologist and Social Worker	1,879 (47.1)	2,109 (52.9)

Table 1 Bivariate analysis of facilitators of communication and the socioeconomic conditions of the municipalities and the characteristics of basic health units, Brazil, 2012.

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		Facilitators of communication			
		Yes	No		
		n (%)	n (%)		
C	Traditional	804 (18.2)	3,612 (81.8)		
Care model"	FHS/parameterized	9,228 (33.8)	18,041 (66.2)		
Walasming to suck	No	Facilitators of communicationYesNon (%)n (%)ional804 (18.2)3,612 (8meterized9,228 (33.8)18,041 (4o7,700 (26.8)21,065 (7o7,700 (26.8)21,065 (7s4,711 (47.4)5,223 (5)o550 (74.0)193 (2619,488 (79.7)2,417 (2)26,946 (70.6)2,888 (2)33,264 (54.6)2,712 (4)51,301 (48.8)1,366 (5)13,625 (83.6)710 (16)221,602 (66.3)10,991 (3)31,119 (59.5)763 (40)o5,169 (22.9)17,364 (7)	21,065 (73.2)		
welcoming room"	Yes	4,711 (47.4)	5,223 (52.6)		
Facilitators of physical access*	0	550 (74.0)	193 (26.0)		
	1	9,488 (79.7)	2,417 (20.3)		
	2	6,946 (70.6)	2,888 (29.4)		
	3	4,797 (62.4)	2,888 (37.6)		
	4	3,264 (54.6)	2,712 (45.4)		
	5	1,301 (48.8)	1,366 (51.2)		
Service shifts*	1	3,625 (83.6)	710 (16.4)		
	2	21,602 (66.3)	10,991 (33.7)		
	3	1,119 (59.5)	763 (40.5)		
Publishing of	No	5,169 (22.9)	17,364 (77.1)		
service hours*	Yes	7,295 (44.8)	8,982 (55.2)		

Table 1. Continuation.

 $^{*}\chi^{2}$ and p < 0.05; DP: disabled persons; FHS: Family Health Strategy.

In the multilevel analysis, the cities in the Southeastern region (PR = 1.67, 95%CI 1.48 – 1.89) and the Southern region (PR = 1.50, 95%CI 1.31 – 1.71) had a higher prevalence of least one facilitator to access, as well as the municipalities with the largest population size (PR = 1.32, 95%CI 1.06 – 1.65) and with the highest GDP (3^{rd} tertile) (PR = 1.12, 95%CI 1.01 – 1.23), when compared to the other categories (Table 2).

In relation to health units, those that published their service hours (PR = 1.56, 95%CI 1.49 - 1.63) and those that were part of the FHS (PR = 1.50, 95%CI 1.38 - 1.62) had better results. In order to have an adequate physical structure, with the five facilitators to physical access — pavement in good conditions, non-slip floor, regular floor, access ramp, handrail and absence of carpet — (PR = 1.41, 95%CI 1.19 - 1.68) and with a welcoming room (PR = 1.28, 95%CI 1.22 - 1.35) were also associated to the presence of facilitators of access to communication (Table 2).

Table 2. Multilevel analysis of the presence of facilitators of communication in health units in Brazil in relation to the socioeconomic conditions of the municipalities and the characteristics of basic health units (UBS), 2012.

		Adjusted analysis ^a		Adjusted analysis ^b					
		PR	95%Cl		р	PR	95%CI		р
	1 st tertile	1				1			
GDP	2 nd tertile	1	0.92	1.09	0.99	0.98	0.90	1.07	0.63
	3 rd tertile	1.12	1.01	1.23	0.03	1.02	0.92	1.12	0.76
	Up to 5,000	1				1			
	5,001 to 10,000	0.95	0.85	1.05	0.31	1.03	0.92	1.15	0.64
Population size (inhabitants)	10,001 to 50,000	0.94	0.86	1.03	0.19	1.05	0.95	1.15	0.36
	50,001 to 100,000	1.02	0.90	1.15	0.77	1.11	0.98	1.25	0.09
	100,001 to 500,000	1.11	0.98	1.26	0.09	1.18	1.04	1.33	0.01
	More than 500,000	1.32	1.06	1.65	0.01	1.25	1.02	1.52	0.03
	Northern	1				1			
	Northeastern	1.25	1.11	1.42	0.00	1.27	1.12	1.43	0.00
Macroregion	Central-Western	1.23	1.05	1.43	0.01	1.11	0.95	1.30	0.20
	Southern	1.5	1.31	1.71	0.00	1.28	1.11	1.47	0.00
	Southeastern	1.67	1.48	1.89	0.00	1.35	1.19	1.53	0.00
	None					1			
Extended professional	Psychologist or Social Worker					1.12	1.06	1.20	0.00
team	Psychologist and Social Worker					1.19	1.12	1.27	0.00
Care readal	Traditional					1			
Care model	FHS					1.50	1.38	1.62	0.00
Welcoming	No					1			
room	Yes					1.28	1.22	1.35	0.00
	0					1			
	1					0.85	0.72	1.01	0.06
Facilitators of	2					1.06	0.90	1.25	0.51
physical access	3					1.22	1.03	1.43	0.02
	4					1.36	1.15	1.61	0.00
	5					1.41	1.19	1.68	0.00

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		Adjusted analysisª				Adjusted analysis⁵			
		PR	95%CI		р	PR	95%CI		р
Service shifts	1					1			
	2					1.38	1.27	1.51	0.00
	3					1.45	1.29	1.65	0.00
Publishing of service hours	No					1			
	Yes					1.56	1.49	1.63	0.00

Table 2. Continuation.

^aModel 1: only contextual variables in the adjustment within the block itself; ^bmodel 2: contextual variables with p < 10% of model 1 plus the variables of the UBS level; PR: prevalence ratio; 95%CI: 95% Confidence Interval; GDP: Gross Domestic Product; FHS: Family Health Strategy.

There was an improvement in the adjustment parameters of the models: empty model (deviance = 51465.022 / AIC = 51469.02 / BIC = 51486.16), model 1 (deviance = 51270.934 / AIC = 51294.93 / BIC = 51397.73), and model 2 (deviance = 39918.484 / AIC = 39966.48 / BIC = 40167.09).

DISCUSSION

In Brazil, few UBS had facilitators of communication. Among the 38,811 health units evaluated by the study, the presence of professionals for welcoming users was an important facilitator of communication. On the other hand, hearing and material resources were available in less than 1% of health services. It is noteworthy that the best results were presented by the Southeastern and Southern regions, as well as by the municipalities with the highest GDP and the largest population. For health units, publishing service hours and the care model of the FHS remained associated to the presence of facilitators of access to communication.

In some countries, especially in Brazil, the macroregional differences in health regarding access, use and performance of health services have well-discriminated scientific evidence. Well-structured and rational health systems are expected to have primary health care as a gateway to the entire population, regardless of the economic situation. However, it is known that macroregional inequities due to socioeconomic conditions and environmental characteristics related to health systems³⁰ also interfere with the use of health services. The Southeastern and Southern regions showed better results in the human development index³¹ and greater use of health services³². In contrast, the Northern and Northeastern regions with the highest percentages of care provided by the Unified Health System (SUS) had worse results. This reinforces the need to adapt these services to loco-regional realities with a view to reducing inequities³³.

There are differences between people with the same type of sensory disability, both for individual preferences and for individual limitations and capabilities. Not all deaf people will be able to communicate in Brazilian Sign Language or lip reading³⁴, just as not all blind or partially sighted people will use Braille. Some facilitators of communication, such as braille or embossed figures, may involve higher costs and logistics for the production of material, in addition to not reaching a large part of the visually disabled population, considering that people who lose their sight throughout their lives have less chances to use these methods³⁵. Thus, although the health guidelines provided by means of audio description or braille increase the autonomy of individuals in relation to self-care in health, this conduct has not been made available in health services. In a study conducted in Fortaleza City (Brazil), only 1.5% of the 204 people with disabilities interviewed (n = 3) reported having received guidance in braille³⁶.

The degree of information availability on the services offered also influences the use of these services and health equity³⁷. In the present study, we could notice that publishing service hours was associated to better results. Probably, teams that are concerned with information availability are also more aware of the need for facilitators of communication, especially professionals for welcoming users.

The decision of where to invest public resources to achieve better access to health must consider both the needs of users and the means that reach the greatest number of individuals³⁸. Simple measures, such as the list of services published so that disabled persons have access, or signs or drawings indicating the services available at the unit should be encouraged. The cost of making these improvements is very low when compared to the benefit that these actions can bring to people with hearing disabilities.

The presence of professionals to welcome users with sensory disabilities, which should be present in all health units, is reported in only 21% of services. This presence, in the authors' opinion, is the main facilitator of access and should be the focus of actions to improve health care for disabled persons. In a study on barriers to access, partially sighted people or blindness also pointed out individualized communication techniques and a welcoming attitude as effective measures for the quality of care¹⁴. Investing in professional training, enabling the human resources that already exist in the services, will bring great benefits for access and quality of care. This need for training and continuing education of the health team to reduce barriers to communication is also perceived by the professionals themselves¹⁷.

The limitations of this study are the impossibility of causal inference, in addition to the lack of specific questions for disabled users about facilitators of communication. Moreover, in the first cycle of the PMAQ-AB, health teams that voluntarily adhered to the program participated in it, which may indicate that these teams had better performance in relation to the outcome studied here. The PMAQ-AB also has among its inherent limitations the fact that it is an instrument of mixed responses, in which some items were self-reported, and others were assessed with on-site verification. The presence of this bias can limit the interpretation of prevalence, and the result can be overestimated. Therefore, considering these limitations, accessibility to users who cannot read, with a visual disability and/or hearing or visual and/or hearing disability may be even less.

Due to the comprehensiveness of the study, which is national in its nature, several interviewers performed the external evaluation. Although they received training, this procedure may have caused information bias in the study. The presence of the field coordinator double verified it and, therefore, granted quality to the data collected by the PMAQ-AB. In addition to these limitations, some important explanatory variables for the assessment of barriers to and facilitators of communication for the care of people with sensory disabilities in primary health care were not addressed.

The absence of disabled persons in epidemiological studies is a problem that has already been reported by other authors³⁹ and that must be overcome. The absence of indicators that assess the presence of specific facilitators, such as professionals qualified in Brazilian Sign Language is also a limitation of the study. On the other hand, this is a nationally based survey, which also considered contextual issues and brought barriers to communication to be discussed, which are usually neglected in favor of physical barriers. This discussion brings important contributions to improve health actions and guarantee access to health services for those who need it.

FINAL CONSIDERATIONS

The results found in research showed that most UBS in Brazil do not have the necessary communication facilitators to guarantee accessibility to people with sensory disabilities. The services that have the greatest physical accessibility are those with more facilitators of communication, possibly because they are better equipped units and are concerned with accessibility more widely.

Universal access with adequate services, removal of communication barriers and encouragement to properly welcome users must be promoted.

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