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Memory spaces and people with disabilities

ARTICLE

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Abstract

In the city of São Paulo, there are many cultural facilities and currently one of the challenges is to make them a compatible space for people with disabilities. Furthermore, attracting this demographic depends on several factors such as the organization of the institution, the accessibility of the spaces, and more. The objective of this study was to present a brief analysis of museums and memorials that by nature preserve cultural and social importance in the city of São Paulo and that serve people with disabilities. Qualitative bibliographic research was carried out and verified that São Paulo has few spaces that include narratives of people with disabilities in their exhibition material and safeguard their memories.

Keywords: Memory. People with disability. Cultural spaces. Accessibility.

Espaços de memória e pessoas com deficiência

Reusmo

Na cidade de São Paulo existem muitos equipamentos culturais e atualmente um dos desafios é torná-los espacos compatíveis às pessoas com deficiência. Ademais, a captação deste público depende de vários fatores, tais como a organização da instituição, acessibilidade, entre outros. Assim sendo, o objetivo deste estudo foi apresentar uma reflexão sobre museus e espaços de memória que, por natureza, guardam construções de importância cultural e social na cidade de São Paulo e que contemplam pessoas com deficiência. Foi realizada uma pesquisa qualitativa do tipo bibliográfica. Por meio do estudo verificamos que São Paulo possui poucos espaços que compreendem narrativas de pessoas com deficiência em seu material expositivo e salvaguarda de suas memórias.

Palavras-chave: Memória. Pessoas com deficiência. Espaços culturais. Acessibilidade.

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Praticas

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1 Introduction

Museums and memory spaces are places that, by their very nature, are characterized as constructions of cultural and social importance in the city of São Paulo. In this sense, this article presents a reflection on facilities of this kind that cater for people with disabilities. Both memory spaces and museums are places that deal with issues of great relevance to the constitution of a people and their identity (MACHADO, 2009). Upon closer examination, it can be seen that there are few of these places that include certain narratives and themes, especially those linked to people in situations of vulnerability who make up the so-called minorities.

Considering the guidelines in the light of a new museology¹, memory spaces and museums have great relevance and the possibility of social transformation and resignification, whether through the way they disseminate their content to different audiences and how they act in the community, or through the choice of themes presented and worked on in such a way as to value certain narratives, subjects and stories. In this study, the number of museums, exhibitions and memory sites in the city of São Paulo were surveyed, followed by a brief analysis of what is presented in them. In addition, the number of institutions and their main themes were also assessed, with the aim of understanding whether they include narratives about people with disabilities.

Assuming that museums are spaces of great relevance and symbolic construction, it is important to consider that not being part of these spaces, or being part of them in a distorted way, can contribute to a lack of engagement and inclusion of certain social groups. An example of institutions that include such groups in a distorted way are those that exhibit the clothing/accessories of people who lived in a certain place and suffered from acromegaly, a rare disease characterized by the exaggerated growth of feet, hands and

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According to Duarte (2013), the New Museology is a broad concept created in the 1960s, a time when museum professionals and researchers began to question many points, the first being the identification of the museum as a contributor to the project and political ideal of cultural democratization, and the second, the election of the museum and its practices as a field of theoretical and epistemological reflection.

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other limbs. In these places, these objects are treated as rarities and as exotic elements, even though, deep down, they are part of a context that brings with it psychological suffering.

Speaking specifically of groups of people with disabilities, museum institutions still collaborate with a non-positive construction of these people, relating them to certain characteristics and often to pejorative allegories. In this sense, Martins (2017), taking Richard Sandell, explains that:

The discourse that the museum incorporates through exhibition practices or representation creates and generates social effects. Historically, museums have contributed to the development of negative impressions of disability, excluding and exposing reductive images of disability. Throughout the ages, people with disabilities have been represented to evoke negative ideas, to express feelings of fear, pity, punishment or supernatural character. They have thus been used as cultural objects and have not actively participated in the creative process of disability culture and its communication. This situation has corroborated the construction of social relationships between people with and without disabilities based on prejudiced and discriminatory cultural values (MARTINS, 2017).

Even today, it is possible to find figures and objects in museum spaces that represent people with characteristics that are different from those of a large part of the population and outside of something that has been constructed as socially accepted. Furthermore, this material is placed within a discourse of distortion of the humanity present there. Few museums, based on a discourse of cultural and social construction, focus on the historical trajectory of people with disabilities. In a different direction, however, it should be noted that, with the issue of inclusive education and accessibility policies, museum spaces have also undergone a process of reframing to attract different audiences and adequately serve the population previously excluded from cultural life, as Sarraf (2018) mentions:

The development of accessibility actions for people with disabilities and new audiences in cultural spaces and productions is a demand that is becoming increasingly present in the world of culture. Museums, theaters, cinemas, cultural centers and concert halls across the five continents, from the best known to the newly opened, have begun to consider people with disabilities, the elderly, families with babies and young children, people with serious illnesses and mental suffering as an important part of their audience; and, in order to ensure that these people are welcomed and remain loyal, these places have begun to propose new ways of designing spaces, communication and mediation strategies that make their offerings more equitable (SARRAF, 2018, p. 26).

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In the city of São Paulo, we have located two spaces that include narratives of people with disabilities, with exhibition material that takes into account their needs and importance, and which also safeguard related heritage. They are the Museum of Inclusion, which is linked to the State Secretariat for People with Disabilities, and the Dorina Nowill Memory Center, which is part of the Dorina Nowill Foundation for the Blind. These spaces also cater to the public and have educational services and collections.

Many museums have collections that cover art languages, different technologies, inventions, the economy, artists and historical figures, education, general and Brazilian history, anthropology, religion, intangible heritage, science, biology, among others. All of these sites have extremely relevant themes when it comes to the cultural, social and educational development of the city and the history of its population. However, if we consider the number of people who live in the city of São Paulo and all the surrounding population concentration, it is clear that the existence of only two institutions that contemplate narratives of people with disabilities represents an insignificant number.

2 Methodology

This study has a qualitative approach and is bibliographical. With regard to this type of research, Gil (2004, p. 44) mentions that it "is developed based on material that has already been prepared, consisting mainly of books and scientific articles". Specific references from the fields of museology and heritage education were used, as well as statistical data and information from two databases, SISEM-SP and Museum Platforms - IBRAM, repositories that have a survey of museums and memory spaces both in the state of São Paulo and in Ibero-America. The year of the search was 2023, with no time frame established.

3 Results and Discussion

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1-3.1 PEOPLE WITH DISABILITIES

The National Household Sample Survey (PNAD) for the year 2022 showed that Brazil has around 18.6 million people with disabilities, which represents 8.9% of the population (BRASIL, 2023). According to the same study, the region with the highest number of people with disabilities is the Northeast, with around 10.3% of the total, while the Southeast has 8.2% of that percentage. Gomes (2023) also mentions that the disabled population also has the least access to formal employment and education and, consequently, the least access to income. These figures indicate that the country's disabled population is a long way from social inclusion. Faced with this, the fact that we only have two institutions that address the historical trajectory of this social group, facilities that are even located in a single region of the country and that present this historical journey in a fragmented way, may indicate even more subjective layers of invisibility.

The Brazilian Law for the Inclusion of People with Disabilities, Law No. 13.146 of 2015 (BRASIL, 2015), provides a series of guarantees for people with disabilities in its comprehensive chapters, including the right to culture and access to cultural goods in an accessible format. Furthermore, it is up to public authorities to work towards eliminating barriers to promoting access to all cultural heritage. Mobilization around the search for the realization of the rights provided for by law must be constant and must bring together social actors from the cultural sector and people with disabilities also linked to this area.

2-3.2 WHO HAS THE RIGHT TO MEMORY?

The Universal Declaration of Human Rights (1948) states that: "everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific progress and its benefits". This means that, regardless of physical, mental, sensory, class or racial characteristics, everyone has the right to access culture and the benefits it can bring. Fischer (1987) also states that Art is necessary for man, because, according to him, human beings yearn to make their individuality social, and this can say a lot about the need to guarantee rights that have been won, as well as about valuing people

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with disabilities and their history in the fight for inclusion. Let's remember that Art here is not just about an artistic language, but refers to a set of values and works that represent a people and their cultural and historical manifestations.

When using the word inclusion, we have to empirically start from the assumption that exclusion exists, i.e. that something is outside, does not participate, does not enjoy. According to Veiga-Neto and Lopes (2011, p. 122), "excluded refers to those who, in some way, are discriminated against by the state and/or society". This statement problematizes much of what many museum spaces face, not only in terms of accessibility, but also in terms of their content and environment, as well as what is determined and authorized to be part of the museum and to have the right to memory. In this context, we also make use of the concept of exclusion mentioned by Aidar (2002) and which has been imported into museology:

> Fundamentally, the concept of social exclusion refers to the processes by which an individual, or a group of individuals, find themselves with limited access to the instruments that constitute social life and are therefore alienated from full participation in the society in which they live. The main areas where this alienation can occur are those related to three levels: 1) exclusion from political systems, resulting in the loss of rights; 2) exclusion from labor markets and social assistance networks, resulting in the loss of resources; 3) exclusion from family and community links, resulting in the deterioration of personal relationships (AIDAR, 2002, p. 54).

This concept of exclusion, created in the UK by the Workers' Party, doesn't necessarily only apply to museum structures (AIDAR, 2002). When we analyze concepts of exclusion and place them in examples from practical life, we see that each one carries with it many forms of suppression. We have therefore chosen to use some of them to look at symbolic representations and cultural constructions of people with disabilities, which indicate that these people are often marginalized from processes of identity construction and social memory.

By briefly reviewing what has traditionally been considered relevant in museology, we can see that there are many forms of exclusion practiced in museum spaces, in different countries around the world and in different historical periods. Some moments are marked by the presence, in spaces reserved for memory and contemplation, of only people from

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the elite, while in others, the narratives witnessed in these spaces refer to personalities linked to the economic and social power of a given era. As Tolentino says, quoting Walter Benjamin:

Walter Benjamin (1994) says that we need to brush history against the grain, because the past as we know it is not in fact what it was. It is a construction. It is the narrative of the victors, of the hegemonic and dominant classes in their triumphal procession. We therefore need to listen to the echoes of the voices that have fallen silent. The echoes of voices from the limbo of oblivion, but which resist being heard. It's the same with cultural heritage. It needs to be brushed against the grain. We also need to make the voices it has muted resurface (TOLENTINO, 2019, p. 147).

It is important to bear in mind the role and power that institutions exert over the construction of memory and identities, and also over people's historical relationships, in order to analyze how they actually judge and preserve the cultures that are part of the same nation. Bourdieu (1989), in The Symbolic Power (p. 12), also makes an analytical and practical contribution to the formation of culture, describing the situation and the macro behaviors that determine society and showing how they manifest themselves within institutions. This panorama is not confined to schools, but is also present within other public and private institutions. The new museology has the potential for a more democratic cultural construction, involving the diverse voices that make up a country's population, as well as a certain "duty" in this regard. At this time, many museums began to invest in new guidelines for serving audiences that had previously been excluded from museum spaces, such as people with disabilities, people with social vulnerabilities and other groups, especially the These spaces are now being pushed towards institutional socially marginalized. involvement and commitment, so that they can fulfill an agreement with the so-called social transformation, as Machado (2009) states:

This means that if museums fulfill the function of maintaining culture and dominant social relations, they can also contribute to their transformation by seeking possibilities to build, within the contradictions and limits of the capitalist system, educational proposals and situations that favor the construction of social relations aimed at a different type of society (MACHADO, 2009, p. 11)..

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It is more important than ever that the narratives perpetuated by history and museums change and take into account the fulfillment of social rights, including all people and giving them the opportunity to enjoy and participate in these spaces.

3-3.3 THE CITY OF SÃO PAULO AND MEMORY SPACES

The city of São Paulo is considered one of the largest in South America, with 11,451,245 inhabitants, and is located in the most populous state in Brazil (IBGE, [2023]). On the website of the State Museum System (SISEM-SP), it is possible to see the number of registered sites, filtering by city, for example. The sites are not necessarily linked to state bodies and, unfortunately, not all of them are on the register. An example of this is the Dorina Nowill Memory Center, a private, non-profit institution, which, however, does not appear on this website, as well as other reference memory centers.

There are 314 cultural sites registered on the São Paulo State museum registration platform (SISEM-SP), 65 of which are in the city of São Paulo. If we include the greater São Paulo area, which includes a further 23 small municipalities, the number rises to 96 institutions and, if we add the Baixada Santista, which is made up of nine municipalities, this figure reaches 115 (SISEM, [2023a]). Thus, more than a third of the places dedicated to memory are concentrated in the region of the city of São Paulo and its surroundings.

On the *website* of the Brazilian Institute of Museums (IBRAM), the data and navigation format were out of date, but the portal provides an analytical panel, which, however, provided different information to that presented by SISEM-SP. For example, the register of museum spaces in the state of São Paulo, according to the information provided by IBRAM, includes places that are open, under construction, closed and extinct, which brings the total number of institutions to 748. However, in this source, it is not possible to filter the data by city in the state of São Paulo, but the table (Figure 1) allows you to report and *download* the data, providing information such as: of the 643 open sites, 308 say they do not have accessibility, 42 did not inform, eight have handrails and ramps and eight have

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exclusive parking spaces for the elderly. This information speaks to people with disabilities and vulnerabilities, but accessibility ends up revolving around more physical/architectural aspects, which does not guarantee the enjoyment and interaction of people with sensory disabilities, such as deaf or blind people.

Temática do Museu • Nome do Museu • Status * Download Redefinir filtros 41.4% Sim Aberto Fechado Em implantação Corrimão nas escadas e rampas -8 Extinto Vaga de estacionament exclusiva para idoso 0 100 200 300 400 500 600 700 50 100 150 200 250 300 350

Figure 1 - IBRAM analytical framework

Source: Museusbr ([2023]).

To find out some more data, we turned to the website of the Register of Ibero-American Museums, which showed that there are 3,013 registered institutions in Brazil (REGISTRO DE MUSEUS IBERO-AMERICANOS, [2023]). Of all the countries that make up the register and were part of the mapping, Brazil has the highest concentration of institutions of this nature. Still using data from the register, we can see that in the Southeast region of the country, where the city of São Paulo is located, there are 1,191 mapped sites. This region is made up of four states and is the second smallest in the country, according to the Brazilian Institute of Geography and Statistics (IBGE, 2023).

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4-3.4 MUSEUM OF INCLUSION

Currently, the Museum of Inclusion, located in the city of São Paulo, is a museum unit belonging to the State Secretariat for People with Disabilities. It was inaugurated in 2009 as the Inclusion Memorial and its mission is to "preserve, research and communicate the memory of the struggle of the social and political movement of people with disabilities in the state of São Paulo and its resonances in Brazil" (SISEM, [2023b]). The museum's long- and short-term exhibitions feature documents and records linked to the social movement of people with disabilities and the struggle for recognition of their rights. In addition to the leaders of the social movement of people with disabilities, most of whom are people with disabilities, the site also promotes discussions and actions linked to museum narratives and social inclusion. Its material collection includes materials covering all types of disability. The space has architectural, communication and methodological accessibility.

This place also stands out for its material collection, which contains audiovisuals, manuscripts, photographs, documents and oral memorials of people and events surrounding the inclusion and visibility of people with disabilities. In addition, from the outset it relied on the participation of people with disabilities to create a space to honor and raise awareness of the experiences of people with disabilities. This museum unit is currently temporarily closed to visitors, but it still represents an important archival reference for research into the movement for the social inclusion of people with disabilities and its resonances in the country.

5-3.5 DORINA NOWILL MEMORY CENTER

The Dorina Nowill Memory Center is part of the institutional heritage of the Dorina Nowill Foundation for the Blind. Its mission is to present the history of the struggle of blind and low-vision people in Brazil and around the world, as well as the life story of the educator Dorina Nowill, who lost her sight at the age of seventeen. The institution, which today bears her name, was created by her and some friends in 1946 under the name Fundação para o

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Livro do Cego no Brasil (FLCB) and, from the outset, had the intention of supporting the educational and social development of visually impaired people in the country.

Among many important actions that mark the institution and the history of the educator, we can highlight, in 1953, the creation of the so-called Braille classes² in the state of São Paulo, a project created and led by educator Dorina Nowill, who set up rooms for teaching the Braille system in state schools, which eventually evolved into pedagogical support rooms for children with disabilities. The educator also served as national secretary for people with disabilities for about 12 consecutive years, as well as holding positions at the United Nations (UN) and as President of the World Blind Union.

Institutionally, Dorina helped to create the first rehabilitation service for visually impaired people in the country and, through partnerships, automated the entire printing process of the Dorina Nowill Foundation for the Blind's Braille Press, which today is one of the largest in Latin America (NOWILL, 1996). The educator died at the age of 91, in 2010, and left, in addition to the institution that bears her name, a huge mark on the imagination and memory of blind people who were able to study in this country using books printed by the Dorina Foundation.

Founded in 2002, the Foundation's Memory Center considers the culture of visual impairment as historical heritage and presents people with disabilities as historical subjects. The site is accessible and welcomes visits from the general public. As well as learning about important parts of Dorina Nowill's life and work, it is possible to learn about the work carried out to date by the institution in favor of the social inclusion of blind and low-vision people³.

What is important to note, and which also applies to museum and educational contexts, is that the greater the political involvement and commitment of authorities to effective cultural change, the greater the possibility of adherence by other members of society and the greater the impact of change.

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² The Braille system is an embossed reading and writing system that enables reading through the fingers. It was created by Louis Braille in 1822 (ABREU; SANTOS; FELIPPE; OLIVEIRA, 2018).

³ Cf. Dorina Nowill Foundation for the Blind ([2023]).



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In the 20th century, the focus on human rights gained much more emphasis and the construction of identities continues to be linked to social issues. An important historical milestone was the International Year of People with Disabilities, proclaimed by the United Nations in 1981, which served to draw attention to the situation of people with disabilities around the world. The date was also a great symbolic milestone for international agreements to start thinking more and more about public policies for the *integration* of people with disabilities into social life.

It is worth mentioning that, as an official document created in 1994 and instituted by the United Nations (UN), the Salamanca Declaration made it mandatory for signatory countries to discuss issues related to the rights of people with disabilities, seeking to create public policies to guarantee these rights.

In view of the decisive social conquests that have taken place since the 1990s, with the establishment of public policies, of which there are a large number in Brazil, people with disabilities occupy a different social role. Placing them as people worthy of cultural heritage and memory shows a deep respect and alignment with a more inclusive, democratic, diverse and accessible future. Tolentino (2019) states that:

Do irom the beginning of the creation of IPHAN in the 1930s to the present day, the field of heritage has expanded and new voices, including those of resistance, have begun to claim the legitimization of their cultural references as important to the nation's memory and identity. Anchored above all in the anthropological concept of culture, which encompasses the whole complex of knowledge, beliefs, art, morals, laws, customs or any other capacity or habits acquired by man as a member of a society, the Brazilian state's conception of cultural heritage began to consider the set of knowledge, practices, expressions and products of the different groups and social segments that make up Brazilian society (TOLENTINO, 2019, p. 138).

Respect for different people and their distinct characteristics is a factor that marks the evolution of a nation. In many sectors of society, we see gaps, not just historical ones, but more affirmative actions to value and rescue the dignity of a section of society that unfortunately continues to have a curtailed existence. Thinking that museum institutions can and should recognize this struggle for the rights of people with disabilities makes us understand a statement by Rússio (1980) about museums and their rich potential to collaborate with the evolution of a society: "museums are children of the society that

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engenders them... and, like all children, they serve to help their 'parents' in their process of updating, recycling the world (p. 240)".

4 Final considerations

Throughout the course of this study, it was possible to see that both the city and the state of São Paulo have the largest number of museological cultural facilities. In the case of the city, it is also one of the only places in the country that has exhibition spaces dedicated exclusively to disseminating the trajectory and historical memory of people with disabilities.

Despite this, the information provided shows that there are still few spaces in the city that focus on the history of people with disabilities and the safeguarding of related materials, but this study highlighted two that play an important social role. The research also revealed the decisive role of public policies in guaranteeing access to cultural goods and the participation of people with disabilities in spaces that were not previously frequented. However, the challenge of expanding access and participation for these people is still present and urges us to mobilize such actions at a national level.

Furthermore, the presence of people with disabilities in these spaces is fundamental, because the strength of social movements has mobilized the field and the fight for the most diverse rights, an action that is still necessary in a society that is not culturally inclusive.

There are links between the fulfillment of human rights and the rights of access to museum spaces, since the excluded profile of society is the same as the one excluded from museums and memory spaces. By no means can the research be exhausted here, but it is necessary to deepen the construction of references, which unfortunately are still disorganized and not standardized in all regions of the country, especially in relation to data on museum institutions.

Humanity didn't get this far just because of the achievements and self-aggrandizing discoveries of a dominant elite. History proves that these have always been the exception

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in the human fabric. Reviewing history and including everyone who helped build it is a commitment not just to the past, but to the present and to building a future that is much more inclusive and democratic.

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