




The right to accessible cities: the perceptions and wishes of people with Down Syndrome in Brazil and Portugal

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Abstract. The present investigation arises from the belief that nothing can be discussed about inclusive public spaces without questioning the exclusion of people with the most diverse types of disabilities from such spaces. However, accessibility is far from being a recurring theme in public urbanization policies and in academic debate environments. In this investigation, the focus is on people with Down Syndrome (DS). When choosing to discuss the desires and perceptions of people with DS about urban accessibility, an even more invisible path is traced. In fact, the few studies that discuss the inclusion of people with disabilities (PwD) in participatory decision-making processes regarding the feasibility of accessible urban spaces are focused on people with physical disabilities. Interviews with 34 people with DS, 18 in Brazil and 16 in Portugal, revealed people full of ideas and willingness to intervene and break the silence about accessible cities. Refusing the label that is socially placed on them as eternal children, the interviewees demonstrated that they understand the centrality of urban spaces in the search for social justice. Narratives showed that people with DS ask for putting into practice the social model of disability in decisions related to urban accessibility. In other words, it is urgent to problematize barriers – whether architectural or attitudinal – so that the centrality of accessibility is not exclusively based on the bodies and cognitions of PwD, but on their perceptions and wishes.

Keywords: Accessibility, Down Syndrome, Social Model of Disability

1 Introduction: Accessibility, urban mobility and inclusion for people with DS

The present investigation arises from the urgency of denouncing the academic silence on issues involving the right to cities of people with disabilities (PwD) [1]. It is based on research whose main objective was to discuss the desires and perceptions of people with Down Syndrome (DS) about urban accessibility. When choosing to focus on people with DS, an even more invisible path is traced. This happens because the few studies that discuss the inclusion of PwD in participatory decision-making processes regarding

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the feasibility of accessible urban spaces are focused on people with physical disabilities [2]. The concern to address the issue of accessibility for people with cognitive disabilities is justified by the fact that few academic studies turn their attention to these individuals, who do not even have a place of enunciation [3]. As such, people with cognitive disabilities' social invisibility refers to the metaphor of an "asylum without walls" [4].

Among the different cognitive disabilities, I chose to focus on people with DS, since they, in most cases, additionally have motor difficulties that compromise their mobility [5] [6] and have phenotypic characteristics that make their disability visible and easily identified by other people [7]. In general, people with cognitive disabilities tend to have more problems related to motricity and mobility than people without disabilities, and, in the case of individuals with DS, such problems are aggravated by the fact that they tend to present greater recurrence of obesity than most of the population [8]. In addition to architectural barriers, people with DS also seem to have to face attitudinal and communication barriers that end up hampering their mobility. These barriers appear because of the unpreparedness of transport service providers, such as bus or taxi drivers and bus changers. These professionals, most of the time, are not trained and do not know how to deal with the demands of people with cognitive disabilities [9] [10]. Therefore, in this paper, I first contextualize the right to cities for PwD by raising the centrality of urban mobility, namely in the case of intellectual disability. In the following section, I present the research methodology applied, based on interviews, including methodological specificities in relation to interviewees with DS. Next, the results cover perceptions and wishes that emerged from the analysis. Finally, in conclusion, I focus on the main issues raised by people with DS in relation to inclusive cities, that is attitudinal barriers.

2 Right to cities for people with disabilities

A study carried out in Brazil with people with DS [11] points out that such people yearn for autonomy. To seek this autonomy, at least in part, it is essential to discuss the attitudinal and architectural barriers that they have to face in order to occupy urban spaces. In other words, urban mobility is central so that we can think about the right to the city for PwD. In my fieldwork in Portugal, I had the opportunity to attend a debate on accessibility promoted by the Portuguese Association of Parents and Friends of People with Mental Disabilities (APPACDM Coimbra)¹, in partnership with the Faculty of Architecture of the University of Coimbra. At this event, it became clear that for people with intellectual disabilities, urban mobility and architectural and attitudinal barriers are obstacles capable of depriving them of a full life. All the expert speakers (architects, psychologists, occupational therapists, among others) were unanimous in emphasizing the importance of listening to people with intellectual disabilities so that urban spaces can truly be accessible. This was confirmed by a video from the APPACDM Coimbra, where people with mental disabilities express what they want to change in urban spaces

¹ The debate was entitled "INLUCITY- The architecture and spaces of inclusion" and was held in the Convent Room of the Convent of São Francisco in Coimbra- Portugal on April 9, 20195.

so that they can walk alone, focusing mainly on critical aspects in relation to public transportation. In Brazil, problems related to urban mobility are an important facet of the social exclusion of PwD. In fact, urban mobility presupposes that all means of transport must work in an integrated manner and be accessible to all people [12]. In addition to means of transport, urban mobility presupposes ease of walking movement by, and requires the user to enjoy the environments without receiving discriminatory treatment due to physical or intellectual characteristics [12]. If cities are the projection of society on a place, as emphasized by Henri Lefebvre in his book precisely entitled “The right to the city” [13], then, a lot can be understood about the values and interests of a society when we observe a city and who has the right to circulate and live in it. As stressed in literature, it is essential to discuss the right to cities of PwD [14]. Accordingly, the existence of laws that require accessibility is not sufficient. There is a need for political will and social demand for this right to become real. The lack of these two elements can prevent actions in the urban environment that are fundamental for the organization of an accessible city. Laws need to be changed by listening to the wishes and needs of PwD for a real accessibility in practice [15]. To speak of the right to the city, free circulation and the occupation of urban spaces by PwD, it is necessary to think of mobility and the infrastructure of cities as foundations on which the rights of these people as citizens should be supported [14]. Here it is important to emphasize that, mainly regarding people with cognitive disabilities, as it is the case of the people who participated in this research, attitudinal barriers must be considered as a third foundation, capable of even conditioning mobility and infrastructure [16]. When talking about infrastructure, however, it should be considered that accessibility is not only related to public structures. Commercial environments, for example, should, even by law, be spaces with adequate infrastructure for everyone. However, such spaces are examples of the type of place in which PwD often have difficulties in having their rights met. When individuals with a disability enters a retail environment, their greatest desire is to be seen as consumers, not as a problem to be solved and then removed from the store [17]. Finally, about attitudinal barriers, it is necessary to emphasize that they hamper mobility, such as in the case of the attitudes of public transport service providers or people who park vehicles on the sidewalks. Additionally, attitudinal barriers may reflect on purposely inaccessible physical structures so that PwD are not in some environments in which they are not welcome [11].

3 Methodology

Even before starting the description of the methodological procedures that were followed to carry out the empirical stage of the present research, it is essential to emphasize that I have always been aware that academics must carefully prepare themselves to have PwD as capable subjects to produce knowledge, given that these individuals often have peculiarities that make it impossible to use methods and techniques in the strict manner recommended by classic methodology books. Even knowing these methodological risks, I am convinced that when it comes to the fight for the inclusion of

PwD, it is fundamental to know with and not to know about [18]. In the investigation presented here, this question was carefully addressed, through the adequacy of methods and techniques to be used with people with DS. The data collection method was the interview. However, I did not follow a rigid protocol, leaving enough space for the specificities of each interviewee. The most important thing was to let the interviewees question me and take their time to feel comfortable with my presence and the interview. I interviewed 34 people with DS, 18 in Brazil and 16 in Portugal. In Brazil, the interviewees live in the city of Rio de Janeiro and in Portugal in Coimbra. The interviews revealed people full of ideas and willingness to intervene to break the silence about accessible cities. All survey participants were over 18 years old. I decided not to interview children because of the ethical implications that such a choice could bring and based on the assumption that perceptions about the city, mobility and accessibility in childhood may be different from the perceptions of an adult. In the interviews, only 3 questions were asked, which the participants answered freely and in a very long way. The questions were: What is an inclusive city? What are the biggest problems in public spaces? What would you like to find in public spaces? All interviews were recorded and transcribed. The results were analyzed using content analysis. The analysis categories were not previously created, having emerged from the field. In other words, the results are arranged in categories that were not predetermined with the literature review and were born from the interview analyzes themselves. The research participants were maintained as anonymous based on privacy requirement. In the presentation of the results, they are identified with fictitious names plus the place (Portugal or Brazil).

4 Results Analysis

4.1 Perceptions

In general, it is possible to affirm that the interviewees demonstrated that they understand the centrality of urban spaces for social justice. They stated, in different ways, that they realize that they do not have free circulation in the urban environment, which places them at the margins of society. The interviewees' statements corroborate what was pointed out by literature [16] in the sense that there is a social failure to guarantee the right to cities of PwD.

- *If I'm not on the street, and I'm not, I don't exist, do I?* (Felipe_Brazil)
- *You don't see many people with DS on the street. It hurts. It undermines our rights.* (Nuno_Portugal)

One of the most recurring complaints concerns transport systems. Many complained about transport, especially public transport, that was not made for them. They pointed out as the main issue the lack of care with the direction information, namely accessible information on itineraries and schedules. Respondents in Brazil also referred to the lack

of empathy and sometimes even the aggressive behavior of public transport drivers. This complaint did not appear in the interviews conducted in Portugal.

- How am I going to go everywhere if the bus wasn't made for me? Could it be easier to know where he's going? (Maria_Portugal)

- I realize that people. Especially the driver doesn't want me to be there. Of course, I have difficulty going up, it takes me a while, I'm chubby and slow (Fernando_Brazil).

The last statement is important because it is possible to see that the interviewee attributes the accessibility problem to his being overweight, a common characteristic of people with DS. The literature had already denounced that many people with DS blame themselves for their excess of weight, removing from society the duty to ensure accessibility [8]. Another question recurrently raised by the interviewees concerns the generalization of the needs of PwD. The literature had already pointed out that when talking about accessibility, it is common to consider only the needs of people with motor disabilities, especially wheelchair users [5]; [2]. It is essential to point out that the interviewees said that the architectural barriers exist, but they stressed that the attitudinal barriers are equally present and, many times, even more important.

- It is not a point of not being able to because there is an architectural barrier. The worst are the people, their attitudes. (Livia_Brazil)

Finally, I would like to point out that there were many references about the lack of mobility and accessibility in public spaces, but the lack of access in consumption environments was also recurrent. As seen in the literature review, it is very common for PwD to have difficulties in transiting in private service and retail environments [19].

- I don't think I can go into a store alone. It is difficult for me to understand the logic of the place. (Bruno_Portugal)

In the speeches about accessibility in consumption environments, for the interviewees it would be important to have the perception that such environments are ready to receive them. For them, this issue is an inseparable part of the right to the city.

4.2 Wishes

The most recurrently mentioned desire was to be heard. Respondents said that society sees them as children who cannot have their own way. The label of eternal children had already been pointed out by the literature as harmful and responsible for the attempt to legitimize the withdrawal of rights of people with DS [11].

- They think I'm a kid and so they don't let me talk about how I would like things to be. (Otávio, Portugal)

- I want the right to be heard about what politicians are going to do in my city. (Marcia, Brazil)

The last statement illustrates a very clear desire to participate politically in public power decisions. Authors had already pointed out the negligence with the participation of PwD in the elaboration of public policies [15]. Regarding public transport, as pointed out in terms of perceptions, namely transport not made for them, the greatest desire of the interviewees was that the signs of the bus lines were better. Thus, they believe they would have greater autonomy when moving around.

- The buses could be painted in different colors (Nuno_Portugal)
- Taking public transport is very difficult for me. There is a lack of clear information that we understand. (Pedro_Portugal)

It is important to note that in the interviews carried out in Brazil, the desire for the city to be safer was very common. They said that they are afraid of being mugged and that this fear is the main impediment for them to walk alone. Besides the violence factor, since none of the Portuguese interviewees referred to this issue, there is the view that the streets have architectural and attitudinal obstacles that should be eliminated so that people with DS could move autonomously. As the literature points out about PwD in general, access to culture is also difficult for people with DS. Museums were mentioned by respondents as places they would like to visit, but which are not accessible. They stated that it would be desirable for museums to be “freer spaces”, in reference to the fact that many times guided tours are not concerned with accessibility.

- Why do I have to see things in the museum in that order? I wish it was another one. (Nuno_Portugal)
- The information, when given previously, makes visiting museums much easier, but this is utopian. Nobody wants us in museums. (Marta_Brazil)

It is worth mentioning that this cultural distancing of people with DS also contributes to social invisibility. Having these people in society as someone who owns and is capable of producing knowledge and culture is fundamental in the fight for inclusion. In sum, it is possible to say that the interviewees want universal design to be put into practice:: (1) equal use for all people with diverse abilities; (2) flexibility in use; (3) simple and intuitive use; (4) accessible information; (5) error tolerance; (6) small physical exertion; (7) size and space for free movement (Kulyukin, & Kutiyawala, 2010).

5 Conclusion

It is important to begin these final considerations remembering that accessibility failures in urban environments can be considered endemic even if there are some attempts

at change [20]. In this research, narratives showed that people with DS require that the social model of disability to be put into practice in decisions related to urban accessibility. Such a model presupposes that the limitations are not in PwD (medical model) but in society, which is not prepared to meet the needs of such people [21] [22]. In other words, it is urgent to problematize barriers – whether architectural or attitudinal – so that the centrality of accessibility difficulties is not based on the bodies and cognitions of PwD, but on their perceptions and desires. Following authors who argue that understanding the social meaning of disability, as well as the parameters through which disability is socially constructed, symbolizes a primary challenge for disability researchers in any field of knowledge, new studies with this focus should be carried out [23] [24].

For people with DS, the main issues concern attitudinal barriers and relate to the fact that they are seen by society as “unproductive” and as “eternal children”. Therefore, it is cheaper and more comfortable to keep people with DS away from public spaces. Transmuting rights into favors, these people are increasingly on the sidelines, hidden in private spaces and far from any kind of perspective of inclusion. Finally, I believe it is quite emblematic to bring the answer given by one of the interviewees to the question: “What is an inclusive city?”

“A city where I am a person and not a disability.”

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