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The Social model of disability in Brazilian research within *sensu stricto* graduate programs

O modelo social da deficiência nas pesquisas brasileiras de pós-graduação *stricto sensu*

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Abstract: This paper analyses the presence of the social model of disability in academic research. Starting with the presentation of Disability Studies and the social model of disability, it follows to the discussion of the production of Brazilian thesis and dissertations with the aim of presenting in which academic contexts the social model is present, as well as analysing possible correlations between the adoption of the social model of disability and the valuing of the participation of people with disabilities in the scope of the research. Such production was characterized in terms of: distribution of studies per year; distribution of studies by type of higher education institution; distribution of studies by region; distribution of studies by field of knowledge; and characterization of studies between empirical and non-empirical. It is considered that conceptual discussions about the social model of disability and its ethical-political consequences are scantily present in national academic research. Only 32 of 196 studies retrieved referred, at least in an introductory manner, to this framework. Such presence, however, is perceptibly established in empirical studies; not only with regard to solid theoretical discussions, but, above all, with regard to the participation of people with disabilities and the recording of their experiences as a basis for the production of knowledge. Feminist Studies of Disability, knowledge as the second generation of the social model, are not yet incorporated by the Academy.

Keywords: Deficiência; Capacitismo; Pesquisa Acadêmica; Pós-Graduação

Introduction

This paper discusses Brazilian research at the *sensu stricto* postgraduate level that has focused on disability from the social model vantage point. The literature that seeks to record the social position occupied by these people in different times and cultures affirms the predominance of the denial of their ways of existing^{1,2}.

Following Barnes and Thomas³, before the 1980s the relevance of academic studies on disability was described by explanations emerging from the field of health sciences, such as medicine, and the professional interests related to it. In its assumptions, the medical model adopted by the health sciences was established from an organicist understanding, supported by the duality of the concepts of normality and abnormality¹ regarding disability. Such a model considers disability as an organic problem, caused by some disease or body limitation fixed in the functionality as “[...] the primary cause of social inequality and disadvantages experienced by the disabled, ignoring the role of social structures for their oppression and marginalization”^{4:2}. Once the limitation of organic cause was identified, a set of medical and welfare interventions began, aiming to cure the disability of the body, minimizing social disadvantages through normalization and/or behavioural adaptation, in order to promote their better functioning and social integration⁵.

The practices of normalization of individuals marked by the medical model also consisted in the institutionalization of people with disabilities, defining the specialized institutions as the most “appropriate” spaces for these people, succeeding so that they would be made socially invisible⁵. Therefore, the process of institutionalisation of people with disabilities contributed significantly to the construction of social conceptions of these individuals as unable to learn, dependent and immature. In other words, the emphasis given by the medical model to the limitations of people with disabilities has historically contributed to the dissemination of an ideology which considers this limit as the inherent cause of disability, reducing these people to a passive condition dependent on care.

The questioning underpinning the present article falls upon the conceptions about the person with disability which were widely disseminated by the medical model; in this model, commonly, these individuals are reduced to the organicity of their development, attributing to them the mark of disability, disregarding social aspects which constitute the conception of disability, as well as the social role played by these individuals in society. Thus, the conception of disability centred in the other as “different” and “unable” imputes a pejorative character to the multiple forms regarding diversity and human development. It is not about disregarding the biological dimension of disability and the

¹ We conceive the term “abnormal” as the set of expectations and cultural values rooted in society, which are conducive to the existence of distinction between individuals, because the conception that there is a supposed “normality” and “abnormality” is still present, these conceptions are imbued with an ideology that aims, many times, only to project on the subject positive or negative values depending on its audience.

organicity of its definition, but the individualization of this condition, which limits the full development of these individuals.

Aiming at changes in the concept of disability and denouncing the limits imposed by the medical model, a new model of theorization on disability started in the United Kingdom in the 1960's, called "Disability Studies". Setting up a new perspective on the debates and actions aimed at the public of people with disabilities, engaged in the fight for recognition and equality of rights, the social model was constituted as a field of action formed by the experiences of people with disabilities, in a movement formed by militants of the Movement for the rights of people with disabilities. The social model of disability engendered a new conception about disability⁶. Contrary to traditional medical approaches, "[...] it breaks the causal link between impairment and disability"^{7:547}, shifting the focus from the subject to social structures, which are limited "[...] in providing adequate services and adequately ensuring that the needs of men and women are taken into account within the social organization"^{2:48}.

The social model's premise anchors its explanation using the approach that regards disability as a reality founded on the economic and political structures of society; and people with disabilities are thus part of the oppressed social group⁸. According to Oliver⁶, the document called Fundamental Principles of Disability⁴, prepared in 1976 by the Union Physical Impairment Against Segregation (UPIAS), was the organization responsible for formulating a new conception of disability as a social phenomenon.

Martins et al.^{9:48}, highlights that the interpretation of disability is essential, because from it it is possible to minimize problems and outline solutions, also benefiting the field of scientific research, "[...] in which different conceptions mean different positions regarding the recognition and appreciation of the voice of people with disabilities". In line with the assumptions of the social model of disability, a research method emerges that aims, among other purposes, to develop studies carried out by people with disabilities, a research method called "Emancipatory Research", designed by the movement of people with disabilities. According to Barnes^{10:6} emancipatory research can be defined as "[...] the empowerment of people with disabilities through the transformation of the material and social conditions of research production", i.e., the use of the social model disability also means the acceptance by researchers and the scientific community that their production and the social and cultural environment that surrounds them may also, to a lesser or greater degree, reproduce situations of oppression experienced by people with disabilities⁹.

It is therefore essential to produce research concerning people with disabilities from the reports of their direct experiences, opinions and aspirations, so that they help researchers to understand their experiences from themselves, thus contributing, not only to the construction of a new vision of disability⁸, but also, “[...] to develop an appropriate policy response”^{11:252}, to the protagonists of the study and their main users or beneficiaries. In this sense, the social model of disability allows for a change in the hierarchical position between the researcher and the participant in the development of research that counts on the direct presence of the person with disability, in which this person ceases to be a spectator to become an active agent and interlocutor. their personal experience, their desires, needs, aspirations and above all, regarding the claim and guarantee of their rights. According to Barnes et al.¹¹, the participation of the social and political movement of people with disabilities in scientific research played a leading role in understanding the collective experience of disability, supporting studies that reflect on the problems involving the existence of these people both individually and collectively.

Considering the ethical-political and theoretical discussions presented so far, this article discusses the production of Brazilian theses and dissertations, with the objective of presenting the academic contexts in which the social model is present, as well as analyzing possible correlations between the adoption of the social model of disability and valuing the participation of people with disabilities within the scope of the research.

Method

The investigation of theses and dissertations was done without a defined time frame, covering the following databases: Higher Education Personnel Improvement Coordination (CAPES); Thesis and Dissertations Database, as well as in the Brazilian Digital Library of Theses and Dissertations (BDTD). We initially used the descriptor “Disability Studies” and its translation into Portuguese language “Estudos da Deficiência”, which resulted in a small number of research studies; as a second step, we began to use in addition to this descriptor, others related to the field such as: protagonism, person with disability, special education, inclusion, inclusive education, social participation, social movement, disability, narrative, oral history, emancipatory research, life story, exclusion, social inclusion, social model of disability and sociology of disability.

Based on the descriptors, after being crossed with the categories that we believe indicate a greater number of studies in the field, we identified 193 studies. In order to see if the selected studies dialogued with the researched theme, we read the title, followed by the abstract and when we were unable to obtain the information in these spaces, we resorted to the full text¹². We adopted as exclusion criteria for studies: duplicate research and studies that referred to the deficiency of non-human animals, nutrients, social or environmental aspects, metabolic aspects or the functioning of the organism (iron deficiency, immunological, etc.). In the mapping carried out, we found only 32 studies distributed between dissertations (20) and theses (12), corresponding to 16.6% of studies compared to the total recovered (193).

Initially, the depiction of the characteristics of the production was carried out based on the following categories: distribution of the number of studies per year; distribution of the number of studies per type of higher education institution (HEI); distribution of studies per region; distribution of studies per field of knowledge; and characterisation of the studies between empirical and non-empirical. After this process, the analysis of the empirical studies which had people with disabilities among the participants was deepened, considering: from which authors or documents the social model of disability is discussed; to what end the reference to the social model of disability is used; what is the position of people with disabilities in the studies.

Information analysis procedure

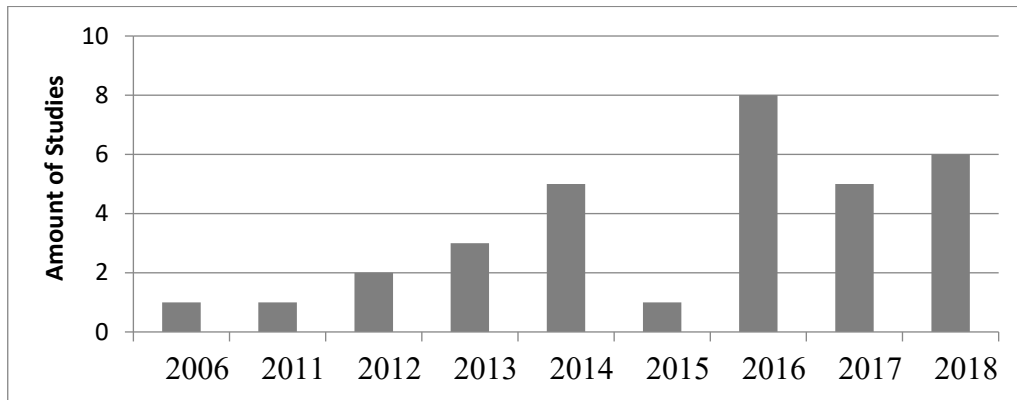
The different pieces of research were analysed qualitatively based on the investigation technique of the evidentiary paradigm, by Ginzburg¹³. Through the evidential paradigm, the author proposed a differentiated understanding of the phenomena, as aspects that previously went unnoticed, that is, the author valued the details of the documents, referencing their historical set. In this approach, the analysis focuses on explanatory and non-descriptive elements, seeking its origin and historical essence.

Studies were categorized as to: number of studies per year; number of studies per higher education institution (HEI); degree of title and administrative dependence; studies by region; studies by field of knowledge; studies by subject area; characterization of the studies regarding the method (empirical or non-empirical), the participants (presence or not of participation of people with disabilities) and the topics addressed.

Results and discussion

Next, we present some graphs that illustrate the mapping of this production in relation to research intended to be based on the social model of disability or on *Disability Studies*.

Graph 1. Distribution by amount of publications/year of studies.



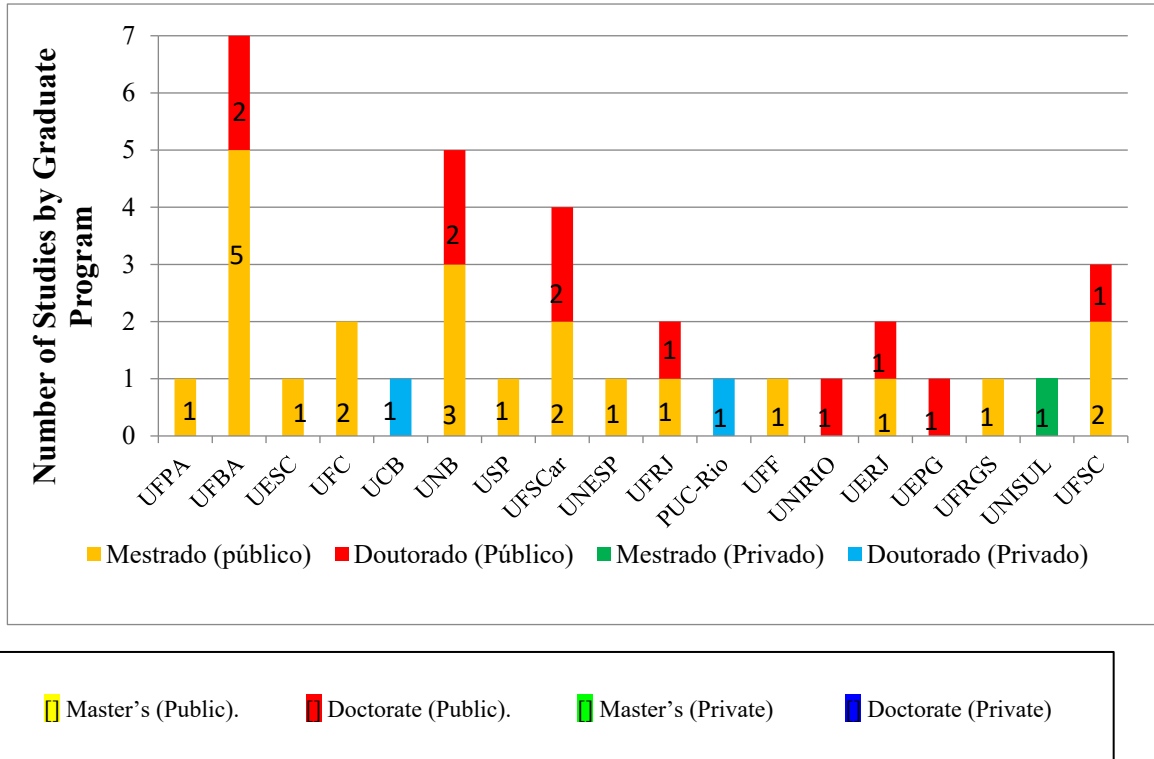
Source: Prepared by the researchers based on studies 384 available at the Capes¹⁴ Theses and Dissertations Database and the Brazilian Library of Theses and Dissertations¹⁵.

The years 2006, 2011 and 2015 reflect the scarce expressiveness of studies, containing only one publication for each year. From 2012 to 2014, we observed a growth in the number of publications, with greater amplitude in the years 2016 and 2018, corresponding to fourteen studies, that is, 43.7% of the total published production. The years 2014 and 2017 have the same number of surveys, with five studies each, corresponding to 15.6% of these.

With regard to the academic degree of the author and the number of published research, we have the following distribution:

Most studies are concentrated on master's research with representation of twenty productions; the doctoral research papers correspond to twelve studies. Thus, of the amount of 32 productions, 62.5% are characterized in dissertations and 37.5% in theses. According to Bueno¹⁶, the justification for the lower incidence of theses may be in the smaller number of doctoral programs in the country and by the academic training time that this level demands. In addition, we can infer that the lower number of defended theses may mean discontinuity of the deepening of studies on this theme.

Graph 2. Distribution of research by higher education institution (HEI), academic degree and administrative dependence.

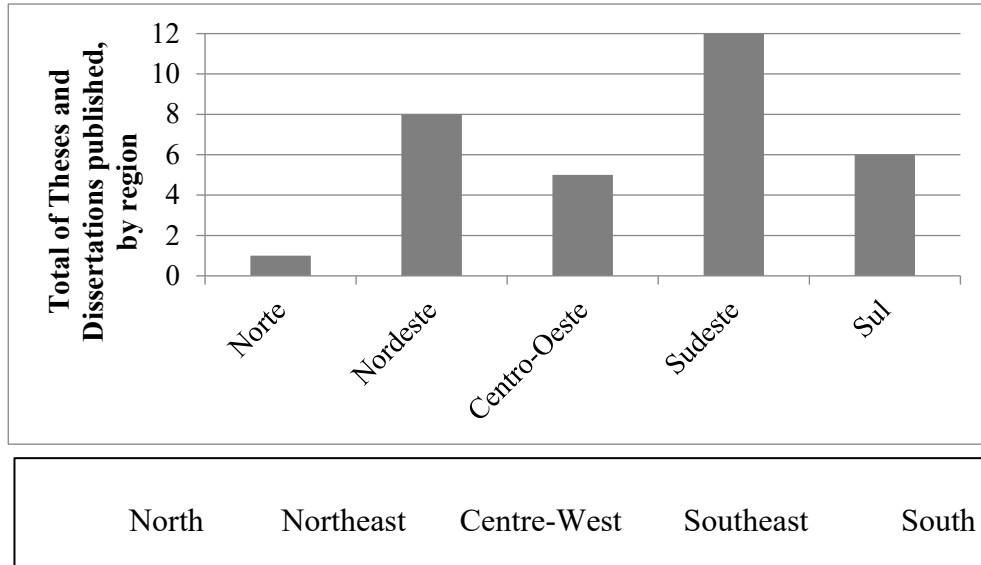


Source: Prepared by the researchers based on studies available at the Capes¹⁴ Theses and Dissertations Database and the Brazilian Library of Theses and Dissertations¹⁵.

Of the eighteen higher education institutions that produced studies on the theme that we propose to investigate, only three are private institutions. The expressive majority of the studies was developed in federal universities (nine institutions, with 50% of the productions). In sequence, the state universities, which constitute five institutions, making up 27.7% of total studies.

Next, we will present the distribution of theses and dissertations published distributed by region:

Graph 3. Distribution of published research by region.



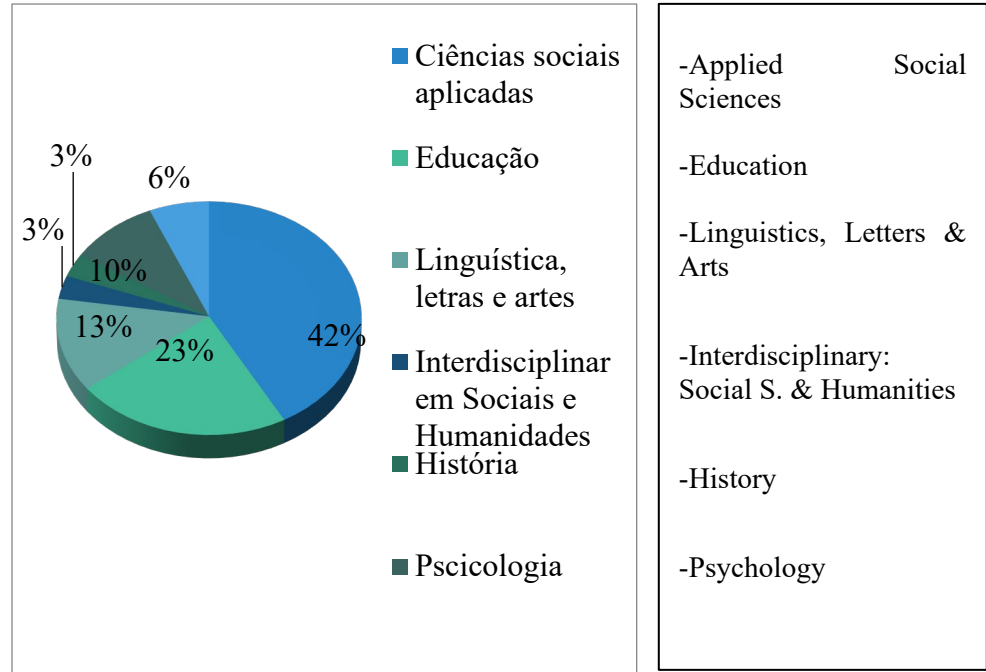
Source: Prepared by the researchers based on studies available at the Capes¹⁴ Theses and Dissertations Database and the Brazilian Library of Theses and Dissertations¹⁵.

Regarding the development of studies in the set of theses and dissertations broken down by region, we can observe that the highest incidence of research is located in the Southeast region with 12 studies, totalling 37.5% of all production. Next, we have the Northeast region with eight studies, the South region with six studies, the Centre-West region with five studies and the Northern region with only one study.

According to Silva¹⁷, in recent years there has been a process of decentralization of research from the Southeast-South axis, regions with extensive tradition and scientific development. The expansion of graduate programs in the various regions of the country led to an increase in the participation of researchers in scientifically less traditional locations. Therefore, we can infer that this process has occurred, among other variables, through a movement of dialogue and collaboration between researchers aimed at expanding the country's scientific production¹⁸.

Below is presented the distribution of Theses and Dissertations by research area:

Graph 4. Distribution of research by field of knowledge.



Source: Prepared by the researchers based on studies available at the Capes¹⁴ Theses and Dissertations Database and the Brazilian Library of Theses and Dissertations¹⁵.

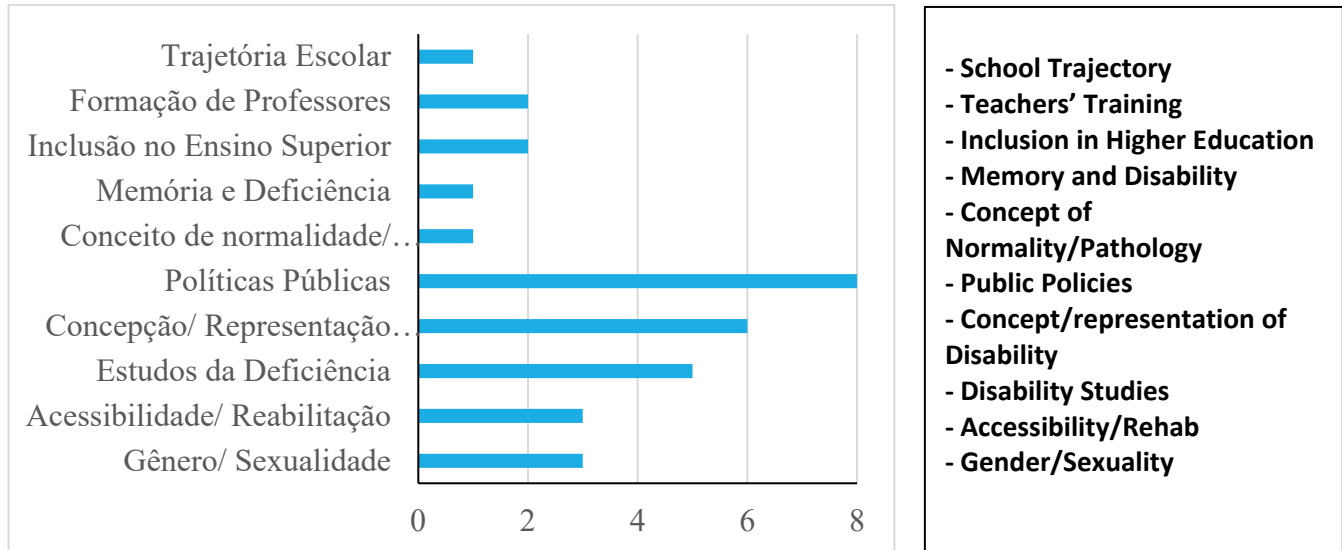
It may be observed that the highest concentration of studies falls within the field of knowledge of Applied Social Sciences, corresponding to 42% of the total research; the areas which make up this field refer to the field of Law, Sociology, Anthropology, among others. The studies present in this field are consistent with an approach which aims to understand the overall development processes of people with disabilities in a process of “[...] critical questioning, in which, [...] the conceptual, theoretical, explanatory and practical dimensions are considered of vital importance”^{19:137}.

Research in the field of Education represents 23% of the theses and dissertations studied here. The social model of disability applied to this field, questions and problematizes the structure in which the education systems are inserted in all instances and levels, straining the conceptions and concepts that permeate this space, such as normality and abnormality, historically used to classify students under the justification of their school failure or under the argument of their disability. In this sense, the social model presents a significant contribution to the field of education, enabling the change in its teaching and learning methods, also important and necessary to the field of Special Education, which aims at its core, the elimination of any and all barriers that limit the full development of people with disabilities, in order to transform the pedagogical environment so that everyone may learn.

The other fields of knowledge shown in the graph comprise mainly those studies in the field of human sciences, with few studies in the area of health.

Next, we will present the information on the distribution of studies by thematic field.

Graph 5. Distribution of studies by thematic field.



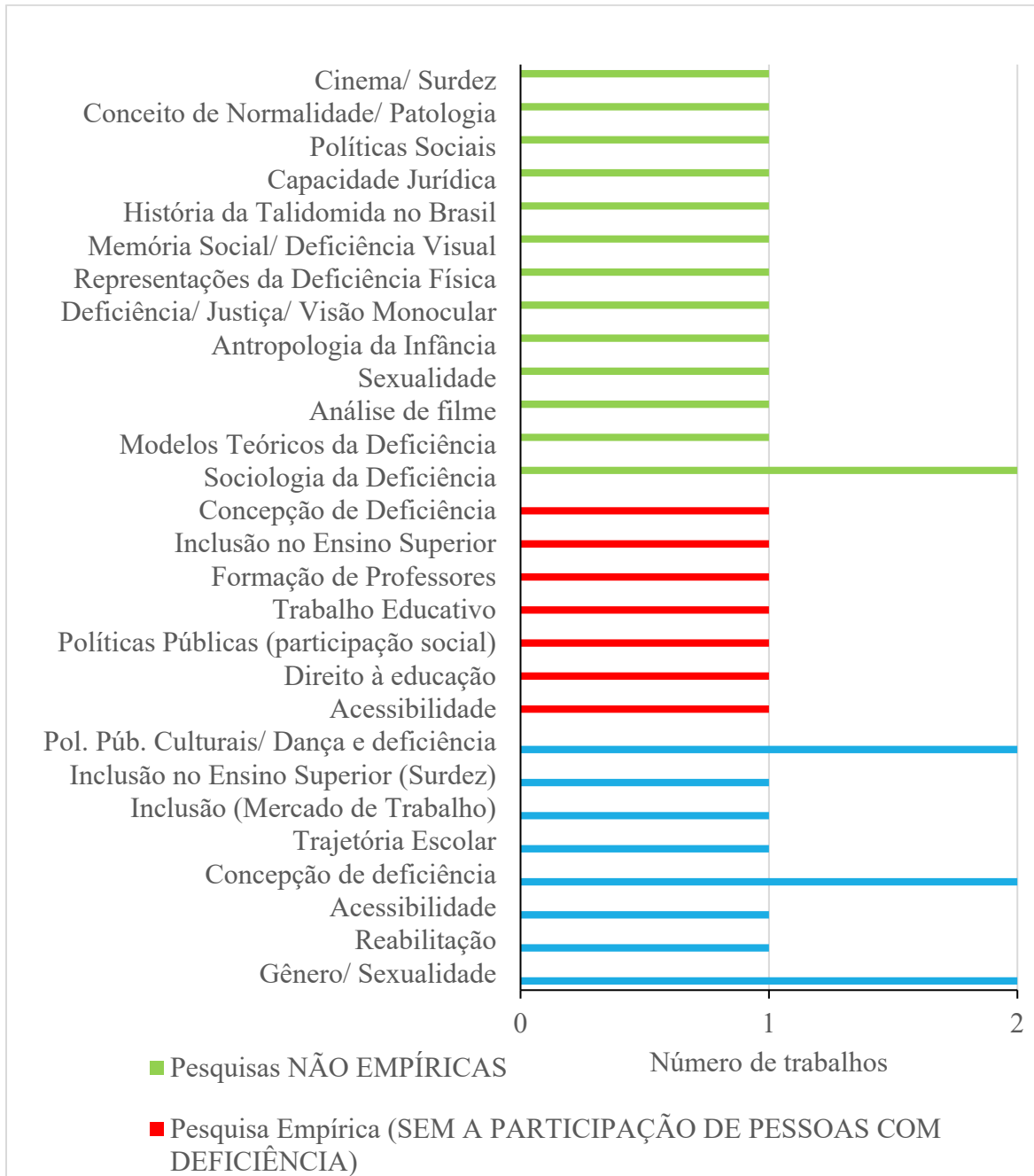
Source: Prepared by the researchers based on studies available at the Capes¹⁴ Theses and Dissertations Database and the Brazilian Library of Theses and Dissertations¹⁵.

Among the themes addressed in the studies, we observe the concentration on social policies, followed by the studies of Sociology. Themes in education and special education are also very present, with discussions still very rooted in the pedagogical field, such as teaching and learning processes, the conception of disability, teacher training, among others, taken by discussions from the perspective of inclusive education, which has as its principle including all students indiscriminately, regardless of their socioeconomic, ethnic, cultural origin or any disability, whether physical, cognitive or sensory.

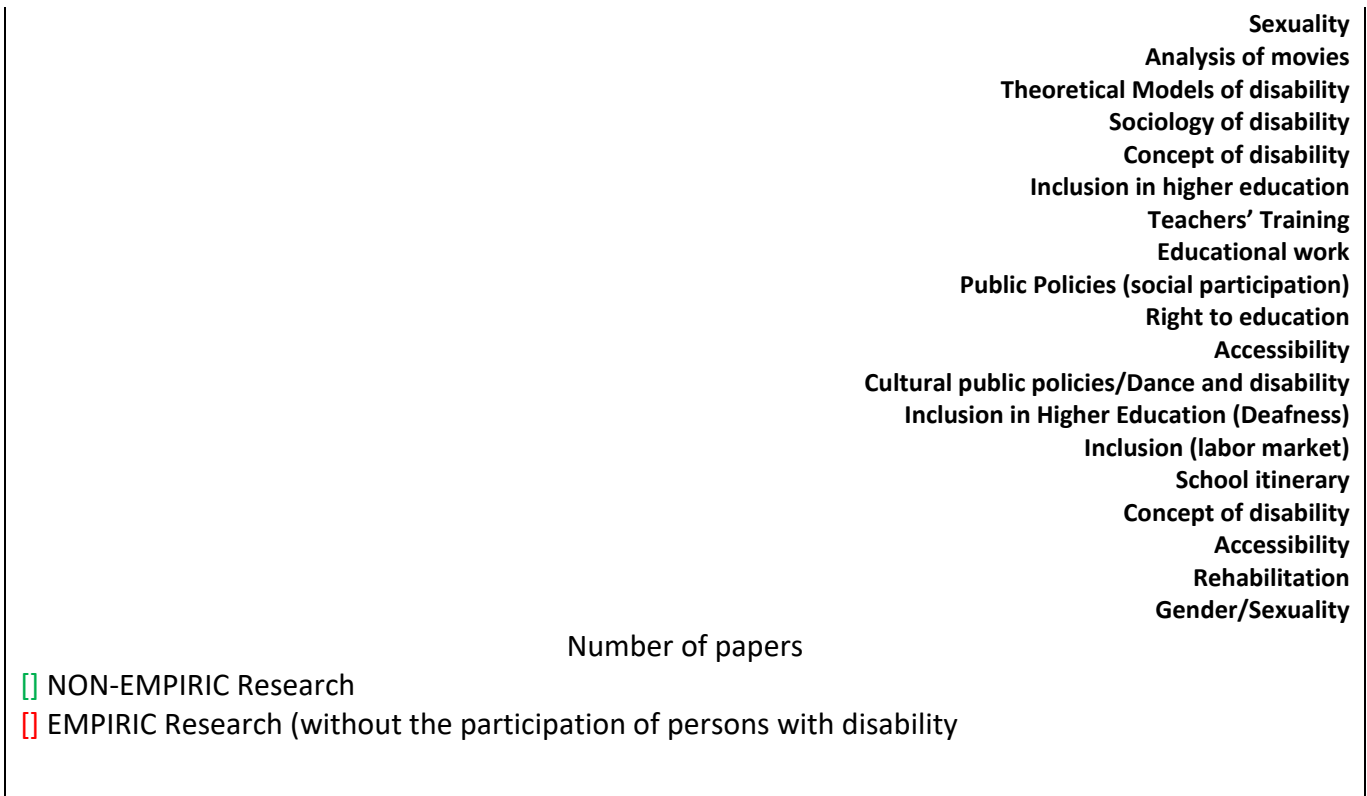
Furthermore, we can observe that the diversity of themes has been approaching in an insignificant way in the field of knowledge of Disability Studies, expressing scarce articulation between the researched areas, aiming at more complex perspectives of understanding society and the implications of the concept of human rights. aiming at understanding the “[...] silencing of the experiences of people with disabilities in favor of putting the structures of social oppression in plain sight”^{9:51} in the quest for a more inclusive society.

In graph 6, the studies are characterized regarding the method (empirical or non-empirical), as to the participants (presence or not of the participation of people with disabilities) and as to the topics covered.

Graph 6. Characterization of studies regarding the method, participants and topics addressed.



Cinema/Deafness
 Concept of Normality/Pathology
 Social Policies
 Legal capacity
 History of thalidomide in Brazil
 Social Memory/Visual Impairment
 Representations of physical disability
 Disability/Legal/Monocular Vision
 Anthropology of childhood



Source: Prepared by the researchers based on studies available at the Capes¹⁴ Theses and Dissertations Database and the Brazilian Library of Theses and Dissertations¹⁵.

Within the category of non-empirical studies, 14 research studies were collected, corresponding to 43.75% of the total results and characterized primarily by literature review studies, documentary research and film analysis. The following stage encompassed video analysis (YouTube), analysis of soap operas and state of the art research, accounting for 1 study per item. The amount of research suggests a significant interest of Brazilian researchers regarding this field of knowledge of disability studies, having the contact of multiple areas of training and the interdisciplinary nature of their studies as enabler of the expansion of discussions on the social model of disability and the incorporation of these studies in the Brazilian academic landscape.

The 18 empirical studies correspond to 56.25% and were analysed differentiating the categories presence/absence of participation of people with disabilities.

The empirical studies that counted with the participation of the person with disability account for 11 researches, corresponding to 34.4%. Among the selected research, we highlight topics addressing the conception of disability, totalling 3 studies, followed by the topics on gender/sexuality with 2 studies and the topics of accessibility, rehabilitation, school trajectory, social rights, inclusion in higher

education and public policies, with 1 study for each theme highlighted. Regarding the characterization of the research participants, we observed in general a sequence of description that begins with the fictitious name (keeping the integrity of the participants), age, education, occupation, whether they live with other people, how long they have had disability (whether congenital or acquired) and, in some cases, whether they have any affective relationship. The analysis evidenced the participation of 29 women and 20 men, with ages ranging from 18 to 52 years.

Final considerations

It is key to remark the importance of the Brazilian public university in scientific production, promoter of research in various areas of knowledge, consolidating itself as a privileged locus of investigation and institutional support for the development of studies and the training of researchers^{16,20}.

The predominance of public universities in the production of Brazilian science and technology should result in greater investment in the sector instead of the budget cuts that have been occurring blatantly at present; the decrease of resources allocated to education at all levels has been a constant to each Brazilian government management. For Durham^{20:3}, “[...] as strange as it may seem, it is necessary again to insist and demonstrate the need for research for the development of the country and the importance of the public university as its cornerstone”.

With regards to the presence and appropriation of the social model of disability by the national academic production, it is possible to affirm that this conception is mostly listed, making up only the background of the discussions, most of the time. The radical approach implied in the social model of disability does not seem to have been fully appropriated in the theoretical argument or in the analysis and discussion of the results. It was mainly situated as a subsidiary historical element to the introduction of the discussion, being presented as part of a comparative framework, which also contained other conceptual models.

Related to the participation of people with disabilities in empirical studies, in most situations it is linked to discussions about their experiences in the general societal context. As a priority, the researchers used semi-structured interviews or interviews without a previously established script, in addition to the oral history or life history method, placing the persons with a disability as main interlocutors in their history. As for the topics investigated, the lack of studies on the subjective and/or

individual dimensions of people with disabilities calls our attention. According to Meletti²¹, it is common for those aspects related to the experiences of people with disabilities, to have their histories and perceptions of the world to be considered irrelevant, so it is not customary to take them as interlocutors or even document their experiences. On the contrary, such aspects concerning people with disabilities are commonly neglected.

Also, studies that had the participation of people with disabilities used the interface of Disability Studies and the social model of disability as a theoretical and methodological reference. In them, people with disabilities were understood and characterized as historical and social subjects, which allows us to affirm that the analyses employed were in line with the principles of the social model of disability, to the detriment of the “[...] individualistic approach, restricted to the body, that claims scientific neutrality and advocates normalizing actions, while labelling individuals as unfit and ignoring the social structures that impede social participation [...]”^{22:62}.

Additionally, we can see the use of the social model of disability keeping a highly positive correlation with the expansion of the field of understanding of social phenomena constituting the development of the disabled person, by the way of avoiding to restrict the reality experienced by these people to a mechanical relationship of organic cause. (impediment) and social effect (disability).

As a summary, we consider that conceptual discussions about the social model of disability and its ethical-political consequences are scarcely present in national academic research. Only 32 of 196 retrieved studies dealt, at least in an introductory way, with this framework. Such presence, however, is perceptibly established in empirical studies; not only with regard to more robust theoretical discussions, but mainly regarding the participation of people with disabilities and using the recording of their experiences as a basis for the production of knowledge.

In view of the above, we suggest that discussions regarding the so-called second generation of the social model, expressed in feminist disability studies, such as that carried out by Garland-Thomson²³, can be widely debated by the different areas of knowledge that are involved with the guarantee of the rights of people with disabilities, so that national academic research can benefit from the production of knowledge that has been carried out both by the social movement of people with disabilities and by researchers with disabilities.

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