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INTRODUCTORY NOTE: MORE RESEARCH, BETTER INCLUSION

NOTA INTRODUTÓRIA: MAIS INVESTIGAÇÃO, MELHOR INCLUSÃO

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In publishing this issue under the title “Inclusion of Persons With Disabilities. Policies, Practices, Research and Narratives”, the *Lusophone Journal of Cultural Studies* (LJCS) becomes, indeed, the first Portuguese journal on social sciences to dedicate one of its issues exclusively to the inclusion of persons with disabilities (PWD). Thus, it is an important milestone as it contributes to constructing a fairer and more inclusive society for PWD. If nothing else justified the timeliness of this publication, it would be enough to remember that historically accumulated knowledge shows beyond doubt how and how much PWD have been socially discriminated against, rejected and despised. For this issue’s edition, it is worth mentioning that the Communication and Society Research Centre’s directors and editors were inspired by Articles 8 and 27 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD; Convenção Sobre os Direitos das Pessoas com Deficiência, 2006). The particular purpose of this issue is to contribute to a better social awareness of disability, help combat stereotypes and prejudices, and promote the rights of PWD. The rights of PWD, which, since 2006, following the promulgation of the convention by the United Nations, have officially become a human rights issue — the right to respect, dignity, choice, freedom, work, schooling, starting a family, among others.

When we discuss the need to promote the inclusion of PWD, we can refer to Arnold Van Gennep (1981), to his concept of the rites of passage to analyse how the processes of inclusion of PWD tend to occur in the different social spaces, work, education or leisure. These spaces, where several contradictions, paradoxes and dualisms show that losing the status of socially excluded persons based on disabilities, does not necessarily lead to gaining the full status of socially included persons. That means effective inclusion is still to be achieved. People remain in the so-called “liminal status”, in a state of social suspension, in a limbo of vagueness and ambiguity, perpetually placed between inclusion and exclusion, as Robert Murphy, Alain Blanc, Michel Calvez and Charles Gardou, and others have argued. As such, the production of scientific knowledge is fundamental to understanding the factors that interact in social spaces where inclusion meets exclusion. In essence, these factors stem from socially established beliefs that place PWD at the margins of the production of so-called proper social relations. Such factors drive the expression of cultural antagonisms between disability and "normality", equally prevalent in the arguments stakeholders use about the presence and participation of PWD in those spaces. In the liminal status, people are hidden from the remaining members of society, in what Victor Turner (1990) calls "structural invisibility", so they are easily disposable. In an ambiguous situation, persons with disabilities are the target of exclusionary social attitudes and practices, as their liminal status makes them symbolically invisible. In other words, as Ravaud and Stiker (2000) state, they are "neither truly alive, nor truly dead, nor truly excluded, nor truly included" (p. 2). In short, they are in transit between exclusion and inclusion because hypothetically, they may either return to the previous state of exclusion or be effectively included.

Hence, social research on disability can contribute to the inclusion of PWD and to improving their quality of life for multiple reasons. As such, it should be disseminated to communicate theories and findings of interest to academics, regulators, journalists, activists, policymakers, professionals in organisations of and for PWD, including PWD themselves. That is the strategic approach of this issue of LJCS. It is intended to promote the dissemination of scientific knowledge against the backdrop of challenges related to disability. Ultimately, it is about contributing to abide by the principles of the CRPD towards a more inclusive society, respectful of human rights. This dissemination strategy involves reaching out to stakeholders engaged with disabilities, individuals, families, (re)habilitation organisations and their professionals, including PWD, to raise social awareness of the challenges affecting them and the solutions to eliminate or mitigate those challenges. Furthermore, it aims at increasing awareness of the rights of PWD, as determined in Article 31 of the CRPD. It expressly urges the creation of scientific knowledge in this field. It should also contribute to the success of the millennium development goals, strongly linked to meeting the needs of PWD. The eight articles included in this issue serve these purposes outstandingly well.

Although more diffuse and comprehensive, it is essential to highlight the importance of scientific knowledge in driving social change. All we need to do is observe the problems posed by population ageing (leading to an increasing number of impaired persons) and acquired disabilities stemming from social organisation risks, impacting the healthcare systems and the functional and bio-psychosocial rehabilitation processes. So to research in disability and to disseminate research results is to contribute towards the improvement of (re)habilitation policies and practices, assuming that, according to Robert Shalock and Miguel Verdugo's research, the promotion of quality of life for PWD is played out within the context of daily life. These authors are now proposing merging the quality of life and the support models. The purpose goes beyond rehabilitation to improving the quality of life through support from the living environment (family, professionals, organisations, administrations).

Furthermore, since disability is so deeply rooted in social systems, there is a myriad of issues requiring scientific research from a cultural and social or multidisciplinary approach. There is plenty of room to develop focused, comparative or longitudinal studies within national, regional or international scope, challenging the consolidation of partnerships of researchers from Portuguese-speaking countries, and Latin American countries and the European Union. We should add that this issue of LJCS focuses on the mobilisation of social researchers, advocating inclusive values towards identifying, understanding and explaining the difficulties and problems experienced by PWD. In addition to their physical, sensory and cognitive limitations, these persons live in social contexts governed by social rules that discriminate, devalue and exclude them. Rules produced and reproduced in the relationship between disability and "normality", that is, in the moments and spaces of interaction between PWD and their physical and relational social surroundings.

Each PWD is a unique being who may experience different causes and consequences of his/her situation, depending on the type and degree of disability and the concrete physical, organisational, and social environment of his/her daily life. That is why it is important that scientific knowledge also helps understand and explain how individual experiences add to the social construction of disability. Exclusion and discrimination of PWD are not just a result of the limitations posed by disability per se or of their class or socio-economic status. Exclusion and discrimination also stem from living and mobilising in environments that do not account for their physical, social, communicational or relational needs (transport, lifts, stairs, service desks, books, sign language, audio recordings...).

Social research must also analyse public social policies that directly or indirectly target PWD. It should do so considering their connection with the practices of organisations that promote inclusion. To understand and explain how they interact in reproducing and/or transforming the quality of life of PWD. These social research needs extend to analysing the processes, practices, discourses and strategies through which public and private agents apply the CRPD principles. The ensuing scientific knowledge is essential for understanding how disability is socially and politically (re)constructed. Thus, by bringing together governmental policies and organisational practices, the place of disability in society is strengthened, and the rights of PWD are acknowledged. Although we are going through a historical moment with a notorious slowing down of organised civic and citizen action, the social movements for disability, particularly in Portugal and Brazil, were determinant for creating, adapting and transforming almost all existing specialised organisations. Particularly in obtaining resources, developing the legal framework, and improving the physical or socially built environment. These movements' actions require extensive study in their multiple relationships with the State and society, their strategies and practices for action. Furthermore, as disability exists everywhere and in all known cultures, it is essential to find answers to questions: is there a culture of disability emanating from the various categories of PWD and disability in general or not? In other words, is there a culture of blindness or not? What about hearing or mobility impairments? Are they true cultures? Or are they just subcultures or counter-cultures? That sets the stage for investigating how definitions, treatments and life experiences of PWD are formed and vary according to the different cultures or subcultures within a given society or social environment.

The knowledge of social sciences is also fundamental for understanding physical and social barriers, why they persist and promoting a better redistribution of public resources for eliminating them. It is equally vital to promote rigorous and permanent knowledge on the qualitative and quantitative composition of the population with disabilities, on the impacts of new forms of defining disability, and on their measurement and implementation. In this regard, research is required to create valid and reliable measuring instruments and help solve the many problems inherent in data collection. Moreover, social research should be interested in studying the physical and social environments surrounding the lives of PWD. These are essential research to understand the different factors of the social construction of disability (e.g., the consequences of physical and environmental barriers, attitudes and dominant social representations, risk factors associated with urban and rural lifestyles and their prevention). As we know, such factors limit opportunities for the inclusion of PWD in accessing the education system and the labour market, among other relevant social roles and functions.

Social research can also provide insights into the consequences of the rapid expansion of so-called "assistive technology", which is designing and producing assistive devices that are changing the lives of PWD. It may also contribute towards improving these devices and understanding the factors regulating access to these devices, their impacts on daily life, and the social participation of people using them. On the other hand, social research in disability may also contribute towards solving problems related to the care provided by families to PWD, their impact on intra-family relationships, family activities for adapting to the situation, redistribution of roles and processes of family integration or disintegration. Social research may support the action, communication, structuring and organisational design of organisations working in disability and their relations with the State, families, PWD and other stakeholders in their environment.

In the sphere of social research, it is possible to analyse the processes of primary socialisation of children (in cases of congenital disability) and secondary socialisation in the case of adults (disability acquired through an accident or illness) or in the case of the elderly (disability due to ageing). It may also investigate the effects of these processes on the interaction of these people with the family, belonging and reference groups and social and organisational institutions. Research contributions that address the increase in longevity are also relevant. Contributions to understand and explain, for instance, the social consequences of the medical science in prolonging the lives of people suffering from severe illnesses and chronic and disabling injuries, who live individually and socially limited lives. In other words, research on demographic and epidemiological issues is required, especially to learn about the geographical and social distributions of the multiple types of disabilities and the incidence or prevalence of disability by age, gender and ethnicity.

Moreover, many further issues related to the PWD's health care might interest social scientists studying health care systems, namely those related to how PWD use health care or how they are welcomed and treated in health care organisations. Cultural and social studies focusing on disability may also draw upon research focusing on victims and victimisation and violence processes affecting PWD, especially women. As research on the strategies and practices of the criminal justice and investigation system responsiveness to criminal actions and their impacts, namely regarding the factors causing impairment.

However, investigating through traditional social research methodologies is not enough. Researchers should favour emancipatory methodologies, ensuring the participation of PWD in the research that concerns them, in line with the motto of the internationally recognised Movement for Independent Living: "nothing about us without us". This movement showed how damaging the individualistic and biomedical approach to disability was and highlighted the importance of examining the experience of disability as perceived individually and collectively by PWD. When developing support or rehabilitation programmes, the interests and wishes of the individual are obviously of the utmost importance in establishing the plans. However, to assess the changes deriving from the implemented plans, we need to measure them objectively. That requires the participation of professionals or family members.

As the articles published here demonstrate, disability is above all a social and cultural issue, not a biomedical issue affecting a small part of the population, converted into a social minority, but one of the leading social phenomena of today, affecting societies as a whole. Considering the diversity of content in the papers published in this issue, we believe we live in a new era in the interaction between the disability domain and the scientific and social domains. Compared to the recent past, this era can be defined by growing scientific attention to disability issues and increased social attention to the problems of PWD. There are several signs of a consistent evolution in that direction. Still, this era is full of contradictions, ambiguities and ambivalence considering the continuous segregation, exclusion and low quality of life of PWD.

Despite this evolution, the truth is that, including the most developed countries, in cultural studies, including sociology and the social sciences at large, attention to disability as a scientific object took a long time to develop. In the Portuguese speaking countries, including Portugal, the scenario is still quite bleak, with disability issues far from integrating social scientists' agendas. In fact, Portuguese speaking countries are lagging far behind countries such as the United Kingdom and France. In the United Kingdom, Disabled People International has been fostering cultural and social studies on disability for at least 30 years. It follows a theoretical model (social model), providing some practical guidelines to be developed to address the needs of PWD. The same in France through the activities of the Maison des Sciences Sociales du Handicap of the École des Hautes Études en Santé Publique. In Portugal, for instance, even though there is a state organisation dedicated to disability (Instituto Nacional para a Reabilitação, I.P.), there is no social sciences journal disseminating knowledge on this field. Apparently, neither other Portuguese-speaking countries have any formally established group (institute or university research centre) permanently investigating disability issues within the cultural or sociological studies. In fact, reviewing the literature on disability issues in Portuguese speaking countries, we can conclude that few researchers in these countries are permanently interested in the cultural and social issues of disability. We urgently need more and more research, as urgently as we need more and more inclusion. Through this issue of LJCS we are doing our part.

So, through an approach focusing on the critical theory of society, Michtelli Agra and Valdelúcia Alves da Costa, in "Inclusive Education Policies and Pedagogical Practices in Public Schools: Experiences in Brazil", analyse the implementation of public policies on inclusive education and the experiences of school inclusion of students with visual impairment in a public school in Niterói, state of Rio de Janeiro (Brazil). Its core objective is characterising the experiences on pedagogical praxis with visually impaired students in an inclusion context. Overall, the results of this paper aim at demonstrating that school inclusion of students with disabilities, to be effectively inclusive, requires a "collective political-pedagogical commitment from teachers, administrators and family members in favor of public schools" (p. 21).

The following article: "French Support and Work Assistance Establishment and Social and Professional Integration of Workers With Disabilities in Rural Areas. The Example of Habert (Savoie, France)", Meddy Escuriet, Mauricette Fournier and Sophie Vuilbert focus on the process of professional inclusion of a group of people with mental disabilities and/or intellectual disabilities in one French support and work assistance establishment located in a small rural and mountainous village in the Alps. According to the authors, this experience offers PWD compensation for their work. It is a therapy that promotes satisfaction with life and feelings of usefulness, social recognition and opportunities for independent living and community participation. The authors conclude that despite the professional inclusion being set in a rural environment in a rough territory and geographically distant from urban centres because the institution provides personalised mobility support, the geographical isolation may be a driver of professional social and spatial inclusion.

In "Inclusive Education Policies and Pedagogical Practices in Public Schools: Experiences in Brazil", Jaciete Barbosa dos Santos and Jenifer Satie Vaz Ogasawara, drawing on the critical theory of society, especially the studies of Adorno, reflect on the paths of inclusive education. Despite social and political advances, in Brazil and many countries worldwide, they are still surrounded by physical, social and behavioural barriers that limit and cause multiple challenges to the educational process of PWD. Their path is still permeated by much precariousness, evident in the unavailability of resources and essential accessibility services and in the persistence of beliefs and attitudes that hinder the dignified educational inclusion of PWD. The authors conclude that creating a genuinely inclusive school requires looking beyond the specific needs of PWD. In other words, inclusive education also depends on the education systems' formation of individuals committed to valuing human diversity and accepting it unreservedly. Without this education, the inclusive school will only be a formal plan. The practices of discrimination, marginalisation and segregation will persist, and according to the authors, "we will be increasingly exposed to barbarism, resulting from a pseudo-formation/semi-formation that still prevails in most institutions" (p. 63).

The article that follows is "Professional Inclusion of Down Syndrome Workers in the City of São Paulo: Personal Achievement, Productivity, and Social Relationships in the Work Environment" by Ricardo Casco, Patrícia Ferreira de Andrade, Cintia Copit Freller, Gabriel Katsumi Saito and Roberta Cruz Lima. In this article, the authors introduce the results of a survey conducted in 2018, based on a sample of 20 young workers with Down syndrome. According to the authors' analysis of a set of dimensions related to the process of professional inclusion of the young people in the sample, it is possible to conclude that they are successfully included in the organisations' relational and work systems. The proof of this lies in the levels of satisfaction with work and the adequate performance of activities and tasks they undertake.

The article entitled "Effectiveness and Efficiency in Associations of Parents and Friends of the Disabled Persons From Minas Gerais" by Sérgio Sampaio Bezerra reveals some characteristics and portraits of the actions of the Associations of Parents and Friends of Disabled People in Minas Gerais (Brazil). These characteristics and portraits were drawn from the perspective of their managers, considering the three dimensions of these organisations' mission: offering services, improving the quality of services and defending the rights of people with intellectual disabilities. The author developed a laborious and careful methodological process and anchored in the principles of systemic analysis and using various statistical analysis techniques. He analysed the data from a random sample of 199 Associations of Parents and Friends of the Exceptional people aiming to measure the effectiveness and efficiency of these organisations' networks in Minas Gerais. The results obtained may, somehow, be considered surprising considering the heterogeneity of the network regarding the differences among the organisations in it, especially considering their location, size and variety of services provided to people with disabilities. In fact, unlike what might be expected, the statistical analysis results point to the network homogeneity. Hence, the author could not construct a quantitative explanatory model to understand the differences in the effectiveness and efficiency of the network organisations' actions.

In the article "Thematization of Disability in Children's Literature – Perspectives on the Characters", Renata Junqueira de Souza and Sílvia de Fátima Pilegi Rodrigues analyse how people with physical disabilities are represented in six children's literature books. It is a relevant debate, given the goals of inclusion of children and young people with physical disabilities, where the objectives of the Brazilian national special education policy intersect with how children's literature publishers interpret these goals in their published works. The works the authors analysed depict the characters with disabilities in two different mindsets. On the one hand, the not very inclusive approach looks at disability through the lens of political correctness and stereotypes PWD. This approach represents them as subjects, both capable of heroic overcoming and accepting, pure and simple, the limitations of the situation they find themselves in. On the other hand, an inclusive approach looks at disability through a human diversity lens, treating disabled characters equally with non-disabled ones. In this approach, overcoming and accepting reality inspire the characters' interactions in the stories presented. The authors conclude that "it is relevant to analyse works that neither reinforce stereotypes placing the characters in conditions of subordination and/or inspiring pity, nor refer to disability as heroic overcoming, resignation and acceptance of destiny or divine will" (p. 135).

In the article "Professional (Re)Integration of Persons with Disabilities: Perceptions of the Contract Employment Insertion/Contract Employment Insertion+ Measures by Beneficiaries and Promoters", Neuza Cardoso Borges and Paula Campos Pinto question the Portuguese State's policy to promote the employability of people with disabilities and its results. Hence, the authors present and discuss

> the results of an exploratory and qualitative study on the measures known as contract employment insertion/contract employment insertion+ (CEI/CEI+), implemented in the region of Lisbon and the Tagus Valley. It examined the perception of three stakeholders — 16 male and female beneficiaries with disabilities, nine institutions promoting these measures, and seven non-profit organisations devoted to training and employment of persons with disabilities — to know their perspectives on the potentialities and limitations of these measures. (p. 139)

The authors conclude that, although the analysed measures positively affect the well-being of the people involved who consider them as good opportunities to show their professional skills, they do not solve the employment needs of people with disabilities successfully permanently. The article is closed with a list of recommendations, based on the testimonies of the stakeholders involved, that we consider a relevant contribution to the analysed measures' greater effectiveness.

Finally, in "Workers With Down Syndrome: Autonomy and Wellness at Work", Alex Sandro Corrêa, José Leon Crochick, Rodrigo Nuno Peiró Correia and Fabiana Duarte de Sousa Ventura describe how the professional inclusion of a sample of workers with Down syndrome impacted their quality of life. The impacts are manifold and can be observed at various levels: individual, social and affective relationships and expectations for the future. The authors report improvements in well-being, self-esteem and autonomy and other "achievements in the affective-social field (dating and friendships), in the family, economic and professional spheres, albeit with restrictions" (p. 157). Furthermore, employment also led to improvements in their feelings of worth, acceptance by others and projecting the future in the same way as other young people of the same ages.

The "Varia" section includes three articles. The first by José Ricardo Carvalheiro has the title "'The People Turn it Off and Go Out Looking for Fado' — Radio and the Fado Resistance to the Estado Novo in the 1930s". Essentially, the author seeks to identify the articulations of radio with Fado throughout the 1930s, a period marked by the rise of Salazarism in Portugal. These articulations might be considered the result of struggles for the domination of radio broadcasting among different actors, with different purposes and their own strategies. The second article, "World Out of Place: The Degradation Trajectory of Holiday Building From the Perspective of Bourdieusian Social Space" by Victor Lucena and Julieta Leite is, according to the authors, "a reflective analysis of the biographical trajectory of symbolic degradation of an emblematic edifice built in Recife (Brazil) — the Holiday Building" (p. 193). Finally, the "Varia" section includes Olga Estrela Magalhães, Clara Almeida Santos, Catarina Duff Burnay, Rita Araújo, Felisbela Lopes and Ana Teresa Peixinho's article with the title "Vaccination Against Covid-19 — An Analysis of Portuguese Official Sources' Digital Health Communication". In this article, the authors analyse and assess how the Portuguese State and the Portuguese health organisations communicate with their audiences through digital media in a time characterised by the health crisis caused by the covid-19 pandemic. They collected digital content published on five websites and four online social networks. This compilation was undertaken between the day the approval of the first vaccine was announced and when health professionals started administering the second dose. The results merely provide informative information, lacking the pedagogical content required to engage and empower the recipients.

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