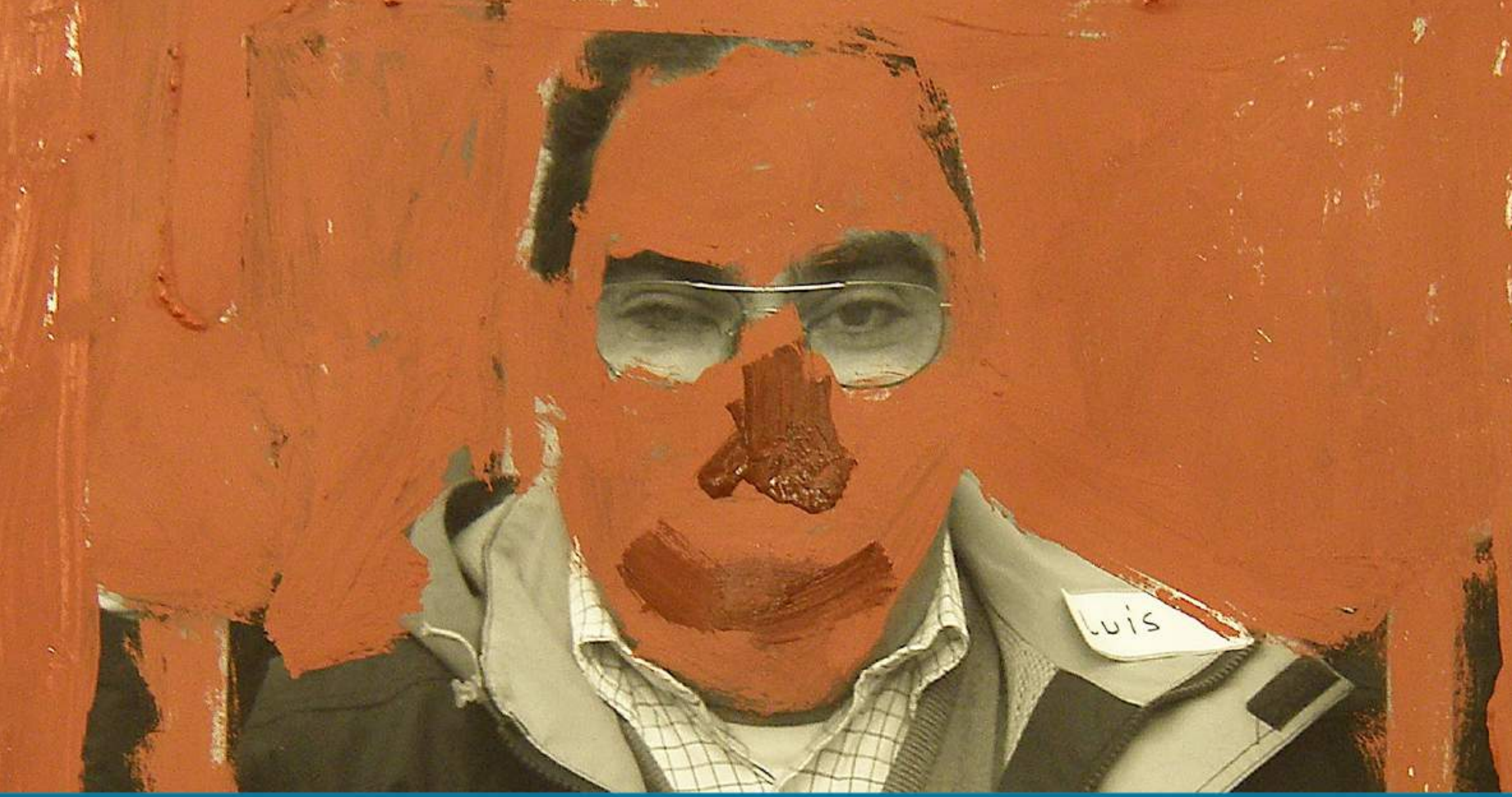

REPRESENTING DISABILITY IN MUSEUMS

IMAGINARY AND IDENTITIES

EDITORS
PATRÍCIA ROQUE MARTINS
ALICE LUCAS SEMEDO
CLARA FRAYÃO CAMACHO

CITCEM
CENTRO DE INVESTIGAÇÃO TRANSDISCIPLINAR
CULTURA, ESPAÇO E MEMÓRIA

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This important volume powerfully reveals the ways in portrayals of disability in museums, past and present, are implicated in the broader struggle for inclusion and equality. The rich, diverse and highly original contributions included here offer practitioners and researchers insights to stimulate and foster the emergence of more empathetic and ethical ways of representing difference in museums of all kinds.

RICHARD SANDELL
Professor of Museum Studies, University of Leicester

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INTRODUCTION

PATRÍCIA ROQUE MARTINS
ALICE LUCAS SEMEDO
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This e-book brings together a number of presentations submitted at the international meeting *Representing Disability in Museums, Imaginary and Identities*, promoted by the Transdisciplinary Research Centre Culture, Space and Memory (CITCEM) of the University of Porto and by the Directorate-General for Cultural Heritage (DGPC), with the support of Museu Nacional Soares dos Reis, on 29 May 2017. This meeting draws on the post-Doctorate research project entitled *A Representação da Deficiência nas Coleções dos Museus da DGPC: Discurso, Identidades e Sentido de Pertença* [The Representation of Disability in DGPC Museum Collections: Discourse, Identities and Sense of Belonging] (supported by a FCT Grant: SFRH/BPD/110497/2015), by Patrícia Roque Martins and hosted by the Department of Sciences and Heritage Techniques of the Faculty of Arts of the University of Porto and by the Directorate-General for Cultural Heritage. This research project aimed at intersecting different approaches to disability, both in the Portuguese case and international good practices, in particular disability studies, museum studies, art history, sociology, anthropology and art education.

Also, this meeting is an important contribution to CITCEM's internationalisation and research strategy developed within the research strand Education and Societal Challenges, specifically on the theme «Alterity in Us», which addresses issues of tolerance/intolerance, inclusion/exclusion, assimilation/discrimination. This approach aims at identifying alterities, analysing expressions of difference and interaction over time and space, and pinpointing memories and their respective traces. In addition to conference papers, a text by the workshop mediator Amanda Cachia is also included in this volume, broadening the scope of the discussion and make it more comprehensive and wide-ranging.

Although in recent years the representation of disability in museums has raised much interest among the academic community as a social group, disabled people are still sub-represented in museum narratives and overall this remains a subject touched upon with some caution by the cultural practitioners. The discussion about these issues has been regarded as an important way to better understand disability, showing, in particular, its potential to gradually counteract forms of oppression and exclusion of disabled people in the museum context. Integrating narratives on disability in museums' discursive practices seems to prompt their audiences to carry out deeper analyses on how through historic-artistic heritage the socio-cultural imaginary has been shaped and has influenced the attitudes and social values towards disabled people. The ways disability is represented in museums show how identities and specific social categories were assigned to this social group, being conducive, over time, to discriminatory and exclusion practices. In this sense, the social function of the museum also refers to ways to deal with these shortcomings and has significant impacts both on the cultural approach to disability and on the construction of more positive identities which aim for the inclusion of disabled people in today's society.

The various approaches in the e-book's six chapters authored by scholars and researchers, cultural practitioners and activists, privilege transversal and multidisciplinary knowledge, highlighting singularities, understanding contexts and systems of relations, and confronting experiences of interpretation and dissemination of disability.

Although the perspectives of the authors differ, they all share one characteristic: the established relationship between the cultural meaning of disability and the historical process of social inequality. The authors highly emphasise the transformation of thought that incorporates discourse and social practices as being essential to counteract the negative narratives, both of the past and of the present, of the social phenomenon of disability. Some authors explore directly representation practices in museums and social exclusion issues found in the dynamic relationship between discourse and the formation of identities. Other authors stress the social role of the museum as an agent of change and consider that it has the potential to influence how society relates to disability, while others regard the history of disability as the starting point to interpret the contemporary meaning of the topic. The representation of disability is, therefore, seen as a vital demonstration of how the life experiences of disabled people have been portrayed, steering the role of museums towards the exploration of alternative ways of looking at disability.

The chapters in this e-book address three essential topics in the articulation between museums and disability: i) the representation of disability in museum collections; ii) the historic and social contextualisation of disability; iii) cultural accessibility.

In the first part, the chapter on *The Representation of Disability in DGPC Museums Collections: Discourse, Identities and Sense of Belonging*, Patrícia Roque Martins focuses her attention on a series of objects with different categories and chronologies found in Portuguese DGPC museum collections related to the topic at hand. The chapter *Re-framing Disability: Exhibiting Difference in the Medical Museum*, by Emma Shepley and Bridget Telfer, addresses research developed by The Royal College of Physicians in the United Kingdom, on the exhibition Re-framing Disability. The researchers worked with 27 disabled people researching their interpretations of a number of portraits from the 17th, 18th and 19th centuries representing disabled people. In the following chapter — *Down and Out and Disabled in the Middle Ages? Medieval Attitudes, Modern Assumptions and Public Dis/ability History* — Cordula Nolte offers an overview of the current research developed within the research group *homo-debilis* at the University of Bremen, in Germany, and examines the visual representations that report the story of disability from a Medieval perspective.

The second part covers the historical and social context of disability. The chapter *Framing Disability in Portugal: Historical Processes and Hegemonic Narratives*, by Fernando Fontes, looks into the cultural and social dynamics that form the narratives of disability and their impact on the living conditions and opportunities of disabled people, focusing in particular on the Portuguese case.

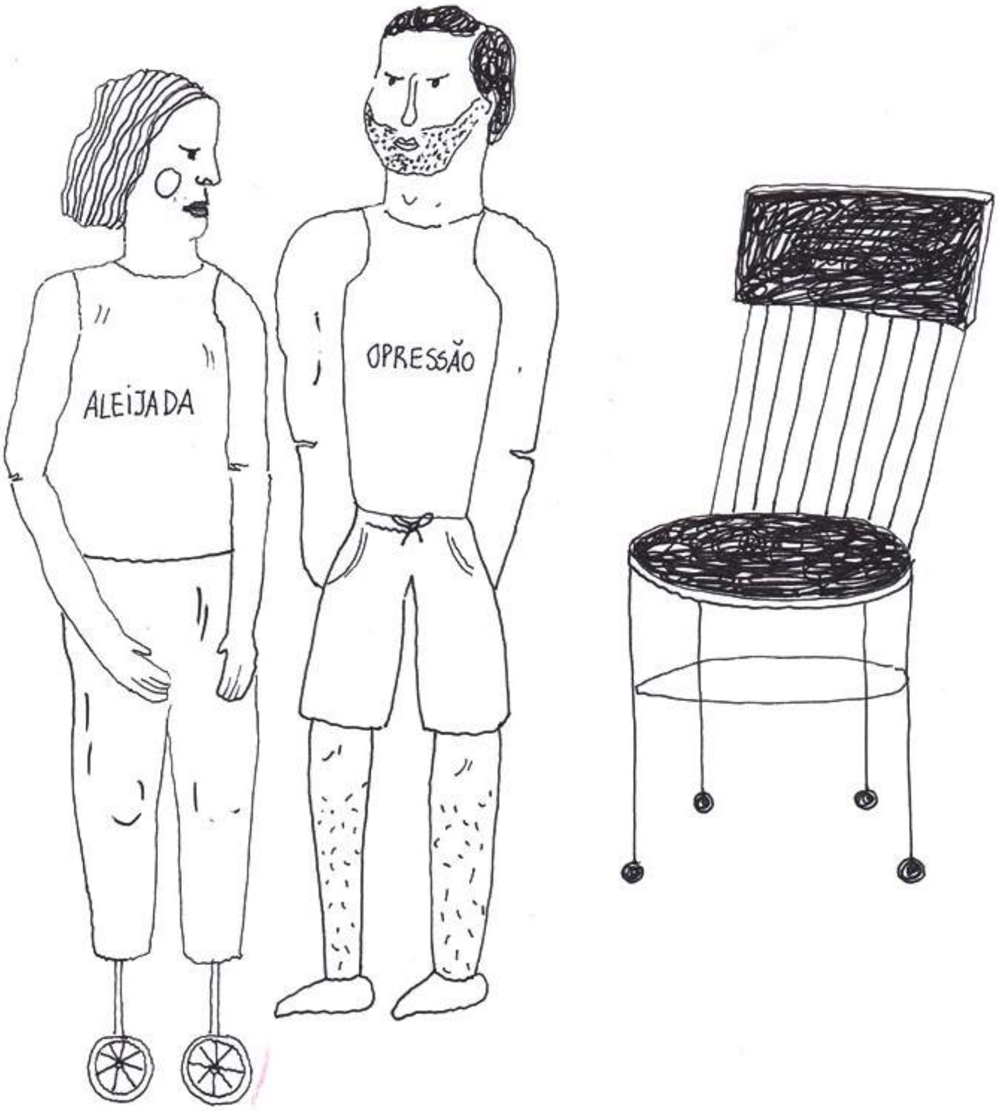
In the last section of the e-book, on cultural accessibility, the chapter *Collaborative Artistic Practices for Cultural Accessibility: Building Bridges Between Disability and Community*, by Amanda Robledo, contains a series of programmes and projects promoted by Spanish museums and art centres, namely by *The Tuya Foundation* and *Pedagogías Invisibles*, dedicated to disabled people at risk of exclusion. The chapter *The Politics of «Creative Access»: Guidelines for a Critical Dis/ability Curatorial Practice*, by Amanda Cachia, analyses the idea of «creative access» from the viewpoint of a curator who identifies himself as being a disabled person, offering instructions, recommendations and examples of exhibitions on art centres in the United States for the development of «dis/ability curatorial practice».

Finally, *Uncovering Hidden Stories in Museums: a Path Toward Visibility, Diversity and Inclusion*, by Ana Carvalho, reflects on the topic of representation of disability in museums, recalling the topics discussed at the international meeting and addressing future issues on this matter. In the presentations *The Identity and Representation of the Person with Disabilities*, by Lia Ferreira, and *Microaggressions Represented in Identity and Imaginary of Disability in Museums*, by Hélia Filipe Saraiva, their role as mediators of the international meeting was transferred to the production of texts that separate the above chapters. The live visual interpretations of the artists Dora Martins, Constança Araújo Amador and Joel Faria on the international meeting day are shown before each chapter.

The aim of the publication of this open access e-book is to increase scientific knowledge in museology and disability studies, more specifically in relation to issues concerned with identity, discourses and representations, as well as their impact on the contemporary problems of social exclusion. This book is, therefore, a useful tool for museum and disability practitioners, students and researchers, and people interested in this topic. Moreover, it takes an international approach, bringing together a number of research works and practices conducted in some parts of the world. Its purpose is to also disseminate information on the Portuguese context, informing both about the cultural history of disability and the researchers who have studied this subject and the international views that have emerged on the subject in Portugal.

I

THE REPRESENTATION OF DISABILITY IN MUSEUM COLLECTIONS



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THE REPRESENTATION OF DISABILITY IN DGPC MUSEUMS COLLECTIONS: DISCOURSE, IDENTITIES AND SENSE OF BELONGING[1]

PATRÍCIA ROQUE MARTINS*

Abstract: The basis of this chapter is the post-doctorate research «The Representation of Disability in DGPC Museum Collections: Discourse, Identities and Sense of Belonging» being conducted at the Department of Heritage Studies of the Faculty of Arts, University of Porto, and at the Directorate General for Cultural Heritage (DGPC). This text is essentially about the problem of disabilities and social exclusion, focusing particularly on the relation between the social role of museums and the fight against social inequality. At the same time, it will look further into issues related with the way disability is represented in DGPC Museum Collections and its impact on the discourses in museums, addressing every possible avenue for building more positive and innovative narratives. The issue of disability will be analysed as a social phenomenon, questioning the creation of identities and social categories that support the discrimination of disabled people, and thus limiting their social participation. It starts out from the idea that the public cultural narratives of disability — usually anchored in negative and depreciatory meanings —, create misconceptions about the reality of disabled people. While those meanings limit the way society relates to disability, they nevertheless lead to the actual identity

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[1] Assignment co-financed by the European Regional Development Fund (ERDF) through the COMPETE 2020 — Operational Programme Competitiveness and Internationalization (POCI) and national funds by the Fundação para a Ciência e a Tecnologia (FCT) under the POCI-01-0145-FEDER-007460 project.

distancing of this social group. In this sense, this chapter addresses the importance of museums as essential spaces for communicating ideas that may lead to social transformation and to a change of attitudes towards disability.

Keywords: disability, social exclusion, identity, museums, representation.

INTRODUCTION

The slogan «Nothing about us without us» is often used by disability rights groups to express the conviction that disabled people should be wholly part of the decisions related with their lives and of the issues that affect them as a social group. One of the main aspects to support this idea will necessarily depend on a reflected approach on how disabled people have been represented over time and have played an active role in the matters that concern them. Such approach has the power to change categories and the usual perceptions about the representations of disability in a more positive way.

This is the core aspect of the post-doctorate research project, currently in progress, entitled «The Representation of Disability in DGPC Museum Collections: Discourse, Identities and Sense of Belonging», funded by the Foundation for Science and Technology through the call for individual post-doctorate grants, having CITCEM and DGPC as host institutions. This research project stems from the idea that the issue of disability within museums is much more than just issues of physical access and communicative and educational interaction. It argues that although the elimination of barriers or provision of educational activities for disabled people can make access easier, it nevertheless does not solve the main problem that inhibits their lives, such as the lack of social participation. It is in line with the view that museums play a preponderant role in the identity construction of disabled people. It also assumes that museums are able to change the mainstream ways of thinking publicly about disability, thus contributing toward social transformation by suggesting new ways of looking at this social group.

Indeed, despite the current anti-discrimination policies issued by the European Community, aimed at creating equal opportunities for disabled people, Portugal continues to present significant data with regard to the limits imposed to their social participation[2]. These limits go beyond the removal of physical barriers and communicative interaction in the access to public, cultural and leisure facilities, relating to cultural issues attached to the social meaning of disability. It is therefore based on the idea that cultural values based on prejudice and sketchy attitudes regarding this group continue to prevent them from being fully included in society, thereby contributing to their discrimination and social exclusion.

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[2] PINTO, 2012; PORTUGAL, 2010.

The theoretical basis of «The Representation of Disability in DGPC Museum Collections: Discourse, Identities and Sense of Belonging» rests on the social model of disability, in particular on its resolve to tackle disability as a human rights issue, highlighting the ways in which cultural representations strengthen negative attitudes and shape everyday social practices. Moreover, it also rests on the concept of «disabled identity», considering disability as an alternative culture that needs to be recognised, promoted and celebrated. This concept is intended to help enhance a more positive approach to disability and to the acceptance of social diversity. Consequently, it seeks to dissociate itself from the negative values attached to the topic of disability.

In this sense, this research project aims to study the representation of disability in DGPC museum collections, the purpose being to explore new ways of looking collectively at disability. It therefore draws on the legacy of the historical-artistic heritage to generate a deeper understanding of how the identity of disabled people has been socially constructed. With this in mind, it is also expected to help museum staff so that they can better understand the topic in question, and to open new avenues for new museum practices that promote various perspectives and voices in the presence of the same artistic object, creating places of knowledge, acceptance and enhancement of the cultural identity of disabled people.

DISABILITY AND MUSEUMS: HOW CAN THE TWO COEXIST?

In an article dated 1991, Hunt sought to draw attention to how disabled people were publicly represented in the media, more precisely on television, in the press and in advertising, through the use of negative stereotypes:

> *Disabled people have identified ten commonly recurring disabling stereotypes in the mass media. These include: the disabled person as pitiable and pathetic, as an object of curiosity or violence, as sinister or evil, as the super cripple, as atmosphere, as laughable, as her/his own worst enemy, as a burden, as non-sexual, and as being unable to participate in daily life. These stereotypes are particularly evident on television, in the press, and in advertising*[3].

The very notion that the symbolic representation of disability rests on a number of negative stereotypes has not raised much controversy among researchers in disability studies. This idea stems from the evidence that the social imaginary on the identity of disabled people is indicative that there are relations of inferiority *versus* superiority vis-à-vis a standard of normality. Several authors have noted that the representational referents of disabled people are arranged publicly as a group of people segregated

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[3] HUNT, 1991: 45-48.

from society, in a kind of «a whole homogenised by its inadequacy, incapacity and low self-worth»[4]. This idea can also be found in the representation of disability in history, art history, archaeology and ethnography. The collections in several museums actually contain objects that address this topic, enabling a deeper understanding of how disability has been interpreted over different periods of time and social contexts.

In museums studies, some research work has focused on the problem of the representation of disability in museums. For example, Delin's study *Buried in the Footnotes: the representation of disabled people in museum and gallery collections*[5] has investigated evidence within UK museum collections that relates to the lives of disabled people, both historical and contemporary. The author concludes that the topic of the representation of disabled people in UK museum collections has been overlooked in museum discourses and practices, thus confirming its social impracticability and identity dissociation[6].

Following this project, the Norfolk Museums & Archaeology Service developed the project *Hidden Histories: Discovering Disability in Norwich's Museum Collections* with the purpose of revealing the «hidden histories» that would reflect the experience of living with a disability, depicted in their varied collections in Natural History, Social History, Military History, Archaeology and Contemporary Art. Overall, the project hoped to help change the lives of disabled people and the personal and social perceptions of disability[7].

The research project *Rethinking Disability Representation in Museums and Galleries*, developed at the Research Center for Museums and Galleries, of the University of Leicester, was coordinated by Dood and Sandell and worked with nine partner UK museums to bring together a number of social actors formed by disability activists, artists and professional of the cultural sector. The project grew from the analysis of a selection of historical sources that included disability-related narratives and testimonials of disabled people. Its purpose was to create different interpretative exhibitions to generate a deeper and more reflective understanding of the issue. Overall, this project found that the museums, through explanatory and educational practices, are conducive to the exploration of social issues insufficiently discussed publicly, as they convey ideas that are capable of contributing to social transformation and change of attitudes[8].

Another example is the research developed by the academic Rosemarie Garland-Thomson. Her work focuses on feminist and disability studies and she has contributed to the analysis of how the disabled body is represented in literature and visual arts. She focuses on how public cultural narratives on disability limit the way disabled people are

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[4] FERREIRA, 2007: 4-5.

[5] DELIN, 2002.

[6] DELIN, 2002: 84.

[7] TOOKE, 2006.

[8] DODD *et al.*, 2008: 10.

seen by the Other, and relates them with the emergence of new «public images» and their potential for shaping more positive and innovative narratives[9].

Also, the doctoral thesis by Diana Walters *Attracting Zealots: Responses to disability in museum collections and practice in the early 21st century* found that disability is a key area for future research on museum collections. The author considered that many of the existing museum collections can open the way for the creation of promising dynamics and challenges related with more sensitive issues on the history of disability, attitudes and contemporary practices[10].

THE CONCEPT OF DISABILITY CULTURE

Another aspect that has often been pointed out by several researchers dedicated to the study of disability is the concept of «disability culture». This emerging concept appears in literature as a positive factor in the human diversity of disability, contrary to the «tragic perspective» and «negative perspective» that the topic raises[11]. The consolidation of the concept of «disability culture» is indeed based on the idea that the attitudes, values and prejudices that sustain social oppression perpetuated throughout the lives of disabled people can be challenged through the notion of a common culture among disabled people.

The concept of «disability culture» therefore appears as a way of generating awareness to the issues of representation, identity and social activism, proposing ways of criticising the reason why some ideas on disability were developed and continue to persist. This concept recognises that the cultural imaginary socially established around disability is one of the main obstacles to valuing the social status of the disabled person. It considers that this cultural imaginary must be deconstructed to make room for the social change necessary to improve the way how their lives in society.

One of the problems that has been pointed out in the analysis of the «disability culture» concept is the lack of acknowledgment of a specific identity and culture of disabled people. This has been pinpointed as one of the main causes for this group to be socially excluded, as its collective identity is disregarded, thus giving rise to other forms of oppression other than the structural and access barriers to physical, social, and cultural spaces, also limiting their social participation[12].

Silverman argues that identity is something not always guaranteed to people surrounded by others who are different to them, and can generate unstable feelings related to the sense of belonging and filiation. This is often due to social factors that lead to

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[9] DODD *et al.*, 2010.

[10] WALTERS, 2007: 353.

[11] BARNES & MERCER, 2010: 187.

[12] BARNES & MERCER, 2010; LAWSON, 2001; PARSON, 2012.

the lack of opportunities, to ongoing negative stereotypes and to barriers that make it difficult for each individual to develop positive self-esteem[13].

The study carried out by Hall also suggests that thought should be given to the analysis of the identity issue of disabled people around the problem of how «difference» is represented. When the author poses the question: «Does visual language reflect a truth about the world which is already there or does it produce meanings about the world through representing it?»[14], he considers that the process of representation is formed by «shared values» that are produced around a specific social group in a specific place and at a specific time, through concepts, images, objects or feelings, thus forming the cultural imaginary of humanity on the same matters.

According to Hall, the representation system contains two key aspects: «language» and «discourse». They both define, to the «Other», the concepts, ideas or feelings that lead to the production of meaning. It is this meaning that bonds with power, regulating conducts, constructing and defining identities, and the ways in which some subjects are represented, reflected on or practiced. In this sense, the representation of a specific social group results from the meaning produced, while having at the same time an important role in the construction and transmission of that meaning through practices that are part of the «circuit of culture»[15].

Indeed, the identity of disabled people has been constructed from a representational system about the meaning of the «Other», based on hierarchical relations of superiority *versus* inferiority, in which society imposes itself on the individual. This being the case, Ferreira concluded that, in the case of disability, collective identity is not constructed autonomously by the disabled people themselves. On the contrary, these people «realise» their difference as is defined by the «Other», based on negative aspects, leading to their marginalisation and exclusion. In other words, the author believes that the identity of disabled people is, in fact, a «non-identity»[16].

EXPLORING THE DGPC MUSEUM COLLECTIONS

The DGPC is a central service under the direct administration of the Portuguese State responsible for ensuring the management of the country's cultural heritage and for developing and implementing the national museum policy. The DGPC is responsible for the management of fifteen national museums situated in Coimbra, Lisbon, Porto and Viseu[17]. The museums' collections are varied and extensive, ranging from the pre-history

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[13] SILVERMAN, 2010: 58.

[14] HALL, 1997: 223.

[15] HALL, 1997: 223.

[16] FERREIRA, 2007: 6.

[17] The fifteen national museums are: Casa Museu Dr. Anastácio Gonçalves, Museu Nacional de Arqueologia, Museu Nacional de Arte Antiga, Museu do Chiado – Museu Nacional de Arte Contemporânea, Museu Nacional de Arte Popular, Museu Nacional do Azulejo, Museu Nacional Machado Castro, Museu Nacional dos Coches, Museu Nacional de

period to the present day and covering very different areas: archaeology, ethnography, furniture, design, painting, sculpture, photography, musical instruments, clothing, and written documents.

The methodology first used to develop the research project «The Representation of Disability in DGPC Museum Collections: Discourse, Identities and Sense of Belonging» was based on a research in the online *Matriznet* collective catalogue, also under the supervision of the DGPC, among other entities[18]. This platform is considered to be the largest repository of information on the collections in Portuguese museums, and is, therefore, an important work instrument for professionals who deal with heritage and museums and also for students. The *Matriznet* allows for cross searches in the museums' collections, for instance, pertaining to a certain author, type or historical period, and offers three levels of research — simple, oriented and advanced.

For our research, we chose to use the simple level of research, entering some key words related to disability in the search engine to find objects in the DGPC museum collections that may be related to the topic. As a first step, we entered commonly used words such as disabled, disability, visually impaired, physically disabled, motor disability, hearing impaired, blind, blindness, sight, deaf, deafness, hearing, paralysis. Out of these keywords, «blind», «blindness» and «sight» returned results, allowing us to locate some objects associated to blind people or to episodes from the Bible that tell the story of healings by saints and divine punishments. Other keywords, in particular those that include the word «disabled» or «disability» failed to return any object connected to the topic. Nevertheless, we were able to see that both the words «disabled» or «disability» are used in the texts that describe the inventory, to refer to defective objects (*deficiente* in Portuguese can refer to «defective» or «disabled») as a result of their execution or state of conservation.

No object was found using the words deaf, deafness or hearing to refer to a disability, being used only for metaphorical purposes. This finding is indicative of a possible under-representation of the topic of deafness in the objects in the DGPC museum collections, of both deaf people as authors/producers of objects or as portrayed subjects. Perhaps it is because deafness has little impact on the viewer, compared to the visual or motor impairment, it is not explored as much over the centuries and in the societies represented in the DGPC museum collections. We nevertheless believe that there may be objects made by deaf people, even though there is no information about it in the inventory's information materials.

As we soon realised that we had to enter other words in the simple search in the inventory to reach a larger number of objects, in a second step we chose to enter

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Etnologia, Museu Nacional Grão Vasco, Museu Nacional da Música, Museu Nacional Soares dos Reis, Museu Nacional do Teatro e da Dança, Museu Nacional do Traje.

[18] Cf. <http://www.matriznet.dgpc.pt/MatrizNet/Home.aspx>.

depreciative words, or words no longer used, in particular dwarf, crippled, needy, paupers, beggars, wooden leg, mentally retarded, madmen, crazy, paraplegic, amputee. The search using these words returned objects connected to the topic of disability, showing that the names of the objects or the information materials related thereto are framed within unpleasant and insulting terms.

From all the objects from the DGPC museum collections regarded as having some sort of relation with the topic of disability, we are able to see how they are distributed across the several museums, as shown in Table 1. Some objects are from different periods and locations, ranging from pre-historic times to the present day, covering diverse areas such as painting, sculpture, photography, musical instruments, ideotechnic artifacts, utensils, documentary collections, etc. The Museu Nacional de Arqueologia (MNA), the Museu Nacional de Etnologia (MNE), the Museu Nacional do Azulejo (MNAZ) and the Museu Nacional do Teatro e da Dança (MNTD) stand out for the number of objects recognised by the search engine. As for the Museu Nacional dos Coches (MNC) and the Museu Nacional de Arte Popular (MNAP), we were unable to find any objects related to the topic. Since the Palácio Nacional da Ajuda, another monument also managed by the DGPC, has some objects of interest that relate to the topic, we chose to include it in the study.

Table 1. Distribution of objects across the DGPC museums[19]

MUSEUM	n.º of objects
Casa-Museu Dr. Anastácio Gonçalves	1
Museu do Chiado – Museu Nacional de Arte Contemporânea	8
Museu Nacional Grão Vasco	10
Museu Nacional de Arqueologia	30
Museu Nacional de Arte Antiga	18
Museu Nacional do Azulejo	22
Museu Nacional de Etnologia	24
Museu Nacional de Machado de Castro	3
Museu Nacional de Soares dos Reis	5
Museu Nacional do Teatro e da Dança	22
Museu Nacional da Música	5
Palácio Nacional da Ajuda	10

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[19] The number of objects in each museum is not final, so a more thorough study is needed for the removal or introduction of them.

THE REPRESENTATION OF DISABILITY IN DGPC MUSEUM COLLECTIONS

On a timeline, the interpretative reading of all the DGPC objects begins with the MNA collection, which includes a vast number of objects from the Iron Age to the Greek-Roman times. These objects represent the so-called «dwarfs» linked to the worship of the god Bes, that is, short stature male figures. God Bes was considered one of the most popular deities of ancient Egypt, especially in the Lower Period and Greek-Roman times[20]. An example is shown in Fig. 1.

Fig. 1. *Statue of Bes*, Unknown Author, VII-IV B.C. Lower Period. Museu Nacional de Arqueologia
Source: <http://www.matriznet.dgpc.pt/>

This museum's collection also includes another object, the «Statue of Vulcan», from the 1st century A.C. that represents another «very popular deity in the Roman period — the god Hephaestus/Vulcan» (Fig. 2).

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[20] ARAÚJO, 2001: 150.

Fig. 2. *Statue of Vulcan*, Unknown Author, 1st century A. C. Roman Period Museu Nacional de Arqueologia
Source: <http://www.matriznet.dgpc.pt/>

In Greek mythology, Hephaestus, the corresponding figure of Vulcan in Roman mythology, is considered a «handicapped» god because he was «shrivelled of foot» (he limped). This was seen as the cause of deep shame, as opposed to the ideal of physical and mental beauty of that period. As a result thereof, he was cast out from Olympus by his own parents, Hera and Zeus[21].

In the case of the god Bes, one can immediately recognise the representation of a body that deviates from the «normal» standard described in the *Matriznet* inventory records, in particular through the use of common expressions used in various instances, such as a «somewhat grotesque figure», «in a typical dwarf pose», with «short, bowed legs»[22].

As regards the «Statue of Vulcan», nothing in the description of this object indicates that it is of a physically «deformed» god, although this is plain for all to see. This idea brings us to the question of invisibility of an identity linked to disability, which is lost due to the lack of information in this regard. Besides being known as the god of

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[21] PEDRAZA, [s.d.]: 18.

[22] Cf. <http://www.matriznet.dgpc.pt>.

metalworking and crafts, the most relevant characteristic of Hephaestus/Vulcan is the fact that he has a limp, that is, a «physical mark of insufficiency, deformity, or functional diversity, as one would say today»[23]. This object, which represents a popular god known for being «lame», lacks this information in its description in the *Matriznet* inventory[24].

In fact, the importance of the representations of Bes and the «Statue of Vulcan» in the DGPC museum collections has to do with the fact that these objects mark the initial course in history of how the atypical human body is depicted in the cultural imagination of the western world, despite there being a number of different records on disability over time. As Barnes argued, the origins of the oppressive and discriminatory culture towards disability stems from ancient Greek, the influence of which was crucial to the construction of the base thought of Western culture[25].

For example, since ancient times the Roman aristocracy or the members of European monarchies used short people as their pets and for their entertainment[26]. This is quite evident in the painting by Portuguese artist José Conrado Roza, of 1788, «La mascarade nuptiale», and serves as a kind of cubicle of curiosities of the new world by presenting a number of «court dwarfs».

The myth of Hephaestus/Vulcan is also considered as being «a paradigmatic representative and refined expression of exclusion found in ancient Greece, and an inaugural patron of the forms of oppression, exclusion and cultural discrimination» shown by a god, who, because he has an atypical body, was cast out by his own parents from Olympus, besides being unable to maintain his marriage with the goddess of love, Aphrodite on account of his disability[27].

Disability in the context of Western society over different times is marked especially by stereotyped and ideological representations, framed within an oppressive and discriminatory logic. As such, we find it important to list some of the objects of the DGPC museum collections that show the practical implications of being a disabled person, articulating them with the development of the concepts of vulnerability, frailness and dependence. In other words, that which Patrício named «the rupture and construction of a practical, political, social and cultural imaginary of the human being as self-sufficient», in which «what is missing is a fundamental element in the construction of the human being and its place in the world»[28].

This is particularly evident in how disabled people relate with the world of work, showing their inadequacy to act as a productive force in a social context of classes. These

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[23] PEDRAZA, [s.d.]: 19.

[24] Cf. <http://www.matriznet.dgpc.pt>.

[25] BARNES, 1998: 59.

[26] GARLAND-THOMSON, 1996: 2.

[27] PEDRAZA, [s.d.]: 10.

[28] PEDRAZA, [s.d.]: 14.

expressions can be found in some objects of the DGPC museum collections through the representation of disabled people begging, and in the texts of the *Matriznet* inventory prepared by museum staff that describe and explain the nature of each object. These are various objects from various periods in time that tell the stories of real disabled people, or show ways of representing them using characters types. The latter are part of the cultural imaginary on disability throughout the history of art.

In the documentary collection of the MNTD, for example, the photograph entitled «José Carlos dos Santos (actor)», from the 19th century, depicts the actor wearing sunglasses because of his blindness (Fig. 3). The information given is that although the actor went blind in 1877 and then retired, he continued to perform. While this description suggests that he was unable to work because he was retired, on the other hand it shows that, in reality, he continued to work even though he was blind. In this case, his blindness caused him to stop working, as was the customary way of dealing with disability in the context of a «practical-political-social-cultural»[29] imaginary, leading him to drop out of the labour market. Nonetheless, in bucking this trend, the actor continued to work, namely in the play «The Blind man's Sister»[30].

Fig. 3. *José Carlos dos Santos* (actor), Unknown Author, 19th century. Museu Nacional do Teatro e da Dança
Source: <http://www.matriznet.dgpc.pt/>

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[29] FERREIRA, 2007.

[30] Cf. <http://www.matriznet.dgpc.pt>.

Begging was also regarded as one of the main ways of life of disabled people and can be seen in various representations in various objects of the DGPC museum collections. The object «Crippled beggars», of the plastic art collection of the MNE, from the 20th century, by Rosa Ramalho, represents that condition both on a plastic level and in its title, as well as in the legend «give some money to the crippled» (Fig. 4). The use of the adjective «crippled», often used to represent disabled people, also helps to trigger feelings of pity and inferiority. Moreover, the inventory record describes this object as representing «two anthropomorphic figures», i.e., something with a more or less human shape, also dehumanises disabled people[31].

Fig. 4. *Crippled beggars*, Rosa Ramalho, 20th century. Museu Nacional de Etnologia
Source: <http://www.matriznet.dgpc.pt/>

Another example is the «Azulejo», by an unknown artist, from the 18th, whose description in the inventory record states that it is «perhaps of a beggar», since it depicts a «male figure, […] bent over a crutch, with no left arm, and with a wooden leg» (Fig. 5). The clothing and the surroundings of the figure in no way suggest that this is a begging situation. In fact, the figure's demeanour is rather dignified. This, then, contradicts the comment in the inventory record, which assumes that because the person being represented has a disability, he is a beggar[32].

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[31] Cf. <http://www.matriznet.dgpc.pt>.

[32] Cf. <http://www.matriznet.dgpc.pt>.

Fig. 5. *Tile*, 18th century. Museu Nacional do Azulejo
Source: <http://www.matriznet.dgpc.pt/>

The painting by José de Almeida e Silva, «Van Rouge», dated 1932 (Fig. 6) and the photograph by J. Marques «Canto e Castro in 'Divine Words'», dated 1964 (Fig. 7) demonstrate how the representations of disability have often been constructed around visual and descriptive narratives that clearly serve to typify and ridicule disabled people. These cases refer specifically to the representation of people with intellectual disabilities. In the case of the painting «'Van Rouge' of Santiago», this person actually existed and is described in the *Matriznet* inventory record as a real «character type» that inspired the author to represent the «madman» or the «drunkard».

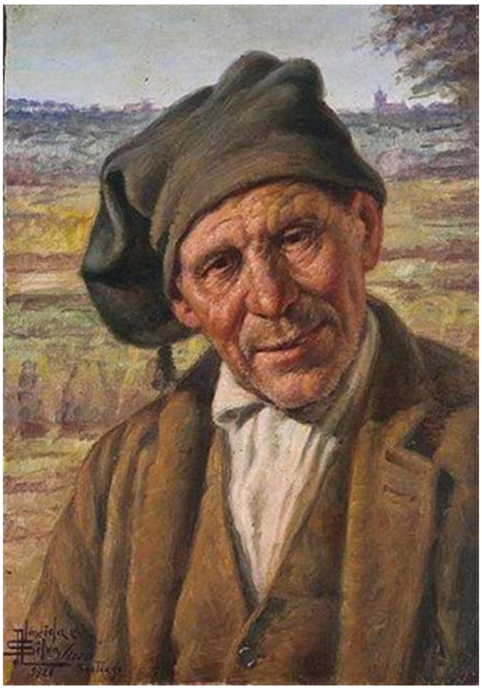

Fig. 6. *«Van Rouge» of Santiago*, 1932. Museu Nacional Grão Vasco
Source: <http://www.matriznet.dgpc.pt/>

The photograph «Canto e Castro in 'Divine Words'» portraits one of the scenes of the play «Divine Words», in which a person with an intellectual disability appears on stage. This is a disturbing picture in that the character is lying down in a wooden cot-like structure, on two wheels, with his legs bent at the knees, in a not so human pose. The *Matriznet* inventory record corroborates this approach by describing that the scene depicts the «[…] actor Canto e Castro imitating the mentally retarded Laureano […]»[33]. As we can see, these are two concrete examples of how disability is used to trigger feelings of mockery, through stereotyped characterisations that ultimately bar the development of more positive characterisations of people with intellectual disabilities.

Fig. 7. *Canto e Castro in «Divine Words»*, 1964. Museu Nacional do Teatro e da Dança
Source: <http://www.matriznet.dgpc.pt/>

Another way of representing disability in the DGPC museum collections is found in biblical themes, as a mystery to be solved or a means of divine deliverance. Disability is easily directed to highlighting the importance of a medical diagnosis and of the cure. For example, the «Ex-voto» objects, in particular the painting by an unknown painter, from between the 18th and 19th centuries, which states in its legend that «Marianna d'idade de 7 mezes. Sega de bexigas» (Mariana, aged 7 months. Blinded by chickenpox) (Fig. 8), and the painting of «Saint Cosmas and Saint Damian», by Garcia Fernandes, 1525-1531, representing the amputation of a gangrened leg and its replacement (Fig. 9). The description of the altarpiece representing Queen Isabel, «Rainha Santa Isabel», dated 1540-1550, by an unknown artist, states that it was used as an «offering from an uncle to his crippled

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[33] Cf. <http://www.matriznet.dgpc.pt>.

niece after she was cured» (Fig. 10). The are other representations of disability in the DGPC museum collections that refer to the healing power of saints, for example, Saint Lucia, who is holding a platter with two eyes that have the power to restore sight (Fig. 11), and the representations of the revelation of St. Raphael Archangel to Tobias, giving him the power to cure his father's blindness (inventory n.º 2362 and 2363)[34].

Fig. 8. *Ex-Voto*, Unknown Author, 18th-19th century. Museu Nacional de Arqueologia
Source: <http://www.matriznet.dgpc.pt/>

Fig. 9. *Saint Cosmas and Saint Damian*,
Garcia Fernandes, 1525-1531
Museu Nacional de Machado de Castro
Source: <http://www.matriznet.dgpc.pt/>

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[34] To know more about this objects cf. <http://www.matriznet.dgpc.pt>.

Fig. 10. *Queen Isabel*, Unknown Author, 1540-1550. Museu Nacional de Machado de Castro
Source: <http://www.matriznet.dgpc.pt/>

Fig. 11. *Saint Lucia*, Unknown Author, 15th century. Museu Nacional de Arte Antiga
Source: <http://www.matriznet.dgpc.pt/>

On the other hand, there are also some the objects of the DGPC museum collections that are related to the topic of disability but do not represent disabled people, yet were used by them. For example, the accordion, a musical instrument once known for being «less noble», since it was often associated to the representations of disabled people who begged. One other musical instrument, the «Cravo Antunes» (harpsichord) (inventory n.º MM372), from the collection of the Museu Nacional da Música is, today, one of the few examples of the Portuguese school of harpsichord making, and is from a shelter for blind women situated in a convent in Lisbon[35]. There is also a surgical instrument in the Museu Nacional de Arqueologia collection, called «probe or cataract needle», from the Roman period, used by ophthalmologists in cataract operations (Fig. 12).

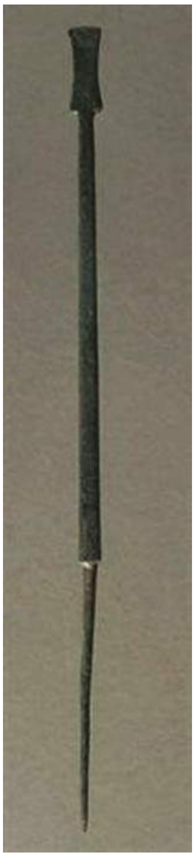

Fig. 12. *Probe or cataract needle*,
Unknown Author, Roman Period
Museu Nacional de Arqueologia
Source: <http://www.matriznet.dgpc.pt/>

These objects are clear examples of how the nature of disability was represented in the Portuguese museum collections throughout art history by stereotypes and negatives ideas. Nevertheless, this can be an opportunity for DGPC museums provide new insights into their collections, exploring the stories of life, habits and cultural meanings associated with disability. The DGPC museum collections contain essential objects that can lead to new identity constructions of disability and to the change of their social and cultural imaginary. These disability-related objects also breathe new life into the social

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[35] To know more about this objects cf. <http://www.matriznet.dgpc.pt>.

role of these museums, enabling the creation of meaningful educational projects on the social inclusion of disabled people, taking into account the discourses and practices that represent disability in the historical-artistic heritage.

CONCLUSION

The research project «The Representation of Disability in DGPC Museum Collections: Discourse, Identities and Sense of Belonging» can help generate novel interpretations within the current paradigm of disability. As in so many international collections, so too do the DGPC museum collections contain objects that concern stories of disability. How these objects have been exhibited, the messages they convey and the meaning they disclose to the public have not yet been fully analysed and explored, nor have the disabled people had any control over the public interpretations made about them.

As with any objects in a museum collection, these disability-related objects are shown to the public through their description, information and interpretation, which will inevitably influence and promote paradigms about disability. By the same token, the invisibility given to the existing representations of disability and the lack of alternative meanings strengthen models of naturalisation of the messages that the objects embody, with consequences in the way the public opinion thinks about this subject.

With this in mind, the research project «The Representation of Disability in DGPC Museum Collections: Discourse, Identities and Sense of Belonging» aims to be a means to deconstruct prejudices and stereotypes, addressing new ways of looking at the national historical-artistic heritage, and contributing to a better understanding of the way and the reason why disabled people are excluded from society. In this sense, it aims to achieve maximum impact in the collective transformation of the Portuguese culture. It seeks to create opportunities to generate new public images about disability, disrupting the dominant representations that contribute to social transformation. This is expected to facilitate the awareness of museum staff in the issues of representation and its cultural impact, and to make them feel more motivated and confident to develop projects with groups of disabled people and the public in general. In particular, producing a broad range of perspectives on objects of their collections that represent disability, establishing connections between their historical past and their present lives.

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[No title]

RE-FRAMING DISABILITY: EXHIBITING DIFFERENCE IN THE MEDICAL MUSEUM

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BRIDGET TELFER**

Abstract: The Royal College of Physicians' *Re-framing Disability* exhibition explored a group of rare 17th-19th century portraits depicting disabled men and women from all walks of life, many of whom earned a living exhibiting themselves in public. The prints formed the centre of the award-winning exhibition led by the responses of 27 contemporary disabled participants from across the UK who discussed the prints and their relevance to their own lives. The exhibition toured from 2011-15 and aimed to build on academic literature in addressing the lack of representation of disabled people in museums. This paper outlines the development and outcomes of the project as an example of best practice in using the social model of disability in museum displays and the later work of the Royal College of Physicians museum as a partner in the University of Leicester Research Centre for Museums and Galleries' acclaimed collaborative disability performance projects *Cabinet of curiosities: how disability was kept in a box* (2014) and *Exceptional and extraordinary: unruly bodies and minds in the medical museum* (2016).

Keywords: Disability, museums, history, portraiture, social model.

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INTRODUCTION

On 14 February 2011 the Royal College of Physicians of London (RCP) launched an exhibition entitled *Re-framing Disability: Portraits from the Royal College of Physicians*. It was displayed at the RCP's headquarters in Regent's Park, London until 8 July 2011.

The exhibition showed a group of 17th-19th century portraits from the RCP's museum collections. They featured disabled men, women and children, many of whom exhibited themselves to earn a living. Some, such as conjoined twins Chang and Eng. Bunker (1811-74) are still well-known today and others, like professional artist Thomas Inglefield (b1769) born without legs or hands, and Henry Blacker, «the tallest man who ever exhibited in England» in the 1750s — are forgotten[1]. Appendix 1 lists the historic prints and the individuals portrayed.

The exhibition's interpretation of these portraits was led by academic research and responses from 27 disabled people who were invited to be filmed, photographed and interviewed in group discussions. The exhibition comprised of the historical prints, contemporary photography, a film, audio commentary and a catalogue (see Fig. 1).

Acclaimed as «innovative»[2], «challenging and inspired»[3], the exhibition won the 2011 Ability Media International Visual Arts Award, created by Leonard Cheshire Disability «to identify outstanding creative projects that encourage a more inclusive world for disabled people». *Re-framing Disability* went on to tour ten venues across the United Kingdom and Ireland, culminating in a display at the Upper Waiting Hall of the Houses of Parliament, London in January 2015.

Fig. 1. The *Re-framing Disability* exhibition at the Royal College of Physicians, 2011
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[1] TELFER *et al.*, *eds.*, 2011: IX.

[2] SHAKESPEARE, 2011.

[3] LEONARD CHESHIRE, 2011.

PROJECT AIMS

«It is often taken for granted that disability is something visible… well you can't tell that about me, unless I'm having a fit»[4].

The *Re-framing disability* project tackled «largely uncharted territory in combining both historical and contemporary analysis of the prints by medical historians and disabled individuals»[5]. The relationships between medical science and the body; and between the scientific practitioner and the disabled individual have been defined by inequality and controversy historically and today, and the representation of disabled people's bodies, past and present, has been experienced as abusive and exploitative. *Re-framing disability* aimed to enhance public understanding of why and how disabled people were represented and understood in certain times and places, through research and the creation of a contemporary forum allowing disabled people control of their own histories and identities through discussion and debate. Appendix 2 lists the RCP's aims and outcomes for the exhibition in full.

The project consciously set out to «reduce the cultural invisibility of disabled people in traditional museum displays»[6] as a significant contribution to work by UK academics and museums in this area over the last twenty years which confirms that «very few museums display items relating to the lives of disabled people, or acknowledge the link when they do and even fewer consult disabled people when creating such displays»[7]. The situation has been slow to improve despite «more than 10 million people in the UK have a limiting long-term illness, impairment or disability»[8]. Disabled people are «under-represented within the arts and cultural sector workforce in all role types and levels of seniority»[9] and over a quarter of UK museums «currently provide no access information on their website for disabled visitors planning a visit» and thus potentially exclude up to 1 in 5 of the UK population from participation in their programmes[10].

THE ROYAL COLLEGE OF PHYSICIANS (RCP)

Re-framing disability also developed as a direct response to the collections and history of the RCP itself. Founded by King Henry VIII in 1518 to regulate and control the practise of medicine in London — the RCP is the oldest medical college in England. It retains its position at the heart of England's medical establishment despite five centuries of turbulent history. Today the RCP is a modern membership body with over 33,000 members and fellows in the UK and internationally, «spanning every career stage from

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[4] Allan Sutherland, *Re-framing disability* focus group participant (EVANS & ADAJI, 2011f).

[5] BOYD, 2011: 4.

[6] TELFER *et al.*, *eds.*, 2011.

[7] TELFER *et al.*, *eds.*, 2011: 5.

[8] TELFER *et al.*, *eds.*, 2011: 15.

[9] ARTS COUNCIL ENGLAND, 2018.

[10] VOCALEYES, 2016.

medical student to consultant» and now delivers examinations, training, conferences, and clinical audits amongst other roles[11]. Physicians today are «doctors — consultants, registrars and doctors in training — who work across 30 medical specialties[12]. They care for millions of medical patients with a huge range of conditions, from asthma and diabetes to stroke and yellow fever»[13].

THE RCP MUSEUM COLLECTION

The RCP has had five homes in London since 1518 and is currently based in a Grade I listed building designed by Sir Denys Lasdun and opened by HM Queen Elizabeth II in 1964 (Fig. 2). An acknowledged architectural masterpiece — the heart of Lasdun's modernist building is a theatrical glass and marble atrium. This ceremonial staircase hall was created as a showcase for the extensive and important collections of medical portraits, sculpture, decorative art and medical artefacts gathered throughout the RCP's history[14]. Britain's most eminent physicians line the walls, depicted by the leading portrait artists of their age including Sir Peter Lely, Cornelius Johnson, Sir Joshua Reynolds, Johan Zoffany, Sir Thomas Lawrence and Philip De Lazlo. The staircase hall also holds the RCP's temporary museum exhibitions on the first and second floors.

Fig. 2. Exterior, Royal College of Physicians, London
©Royal College of Physicians

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[11] ROYAL COLLEGE OF PHYSICIANS, 2018a.
[12] ROYAL COLLEGE OF PHYSICIANS, 2018a.
[13] ROYAL COLLEGE OF PHYSICIANS, 2018b.
[14] CALDER, 2008.

Out of public view, the museum holds a substantial, but little-known archive of prints and drawings. This collection contains over 5,000 portraits of scientists and medical personalities, with representations ranging from Hippocrates to 20th century practitioners. The collection remained largely unexamined until 2005 when professional museum staff were employed to audit, catalogue and transform the private art and medical collections into a publicly accessible museum. The museum was accredited by Arts Council England in 2008 and opened free of charge to the public in 2009 and remains so to date (January 2018).

By 2007, the small group of prints which form the basis of *Re-framing Disability* had been brought to light. They were a fascinating group of 17th-19th century portraits showing the faces and bodies, not of clinicians and scientists, but of disabled men and women of all ages, walks of life and professions.

We don't know when the group came into the RCP collections or who donated them. Archive records do not show them arriving together, so they are most likely to have arrived as part of other donated print collections, collected and presented by fellows with an interest in the field. The prints had never been researched or displayed since their arrival at the RCP[15].

RE-FRAMING DISABILITY — ORIGINS OF THE PROJECT

The significance of the prints and appropriateness of the RCP to explore their history was immediately apparent to the RCP's museum team, as was the decision that the resulting exhibition would not solely focus on the historical prints, but would be led by contemporary responses and insights from disabled people gathered during focus groups designed for open dialogue and debate.

The project was led by RCP staff member Bridget Telfer, audience development coordinator. Telfer drew on museum studies research from the University of Leicester's Research Centre for Museums and Galleries (RCMG) by Professor Richard Sandell and RCMG director Jocelyn Dodd whose publications *Buried in the Footnotes* (2004) and *Rethinking disability representation* (2006-8) directly inspired and influenced *Re-framing disability*. *Re-framing Disability* was also informed by the legacy of decades of work by artists, activists and authorities «to improve the marginalised view of disabled people» — project academic Julie Anderson cites the work of artists Chris Rush, Doug Auld, Riva Lehrer and the high-profile sculpture of the pregnant artist Alison Lapper by Marc Quin installed in Trafalgar Square in 2005 as having built public awareness in the preceding decades[16].

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[15] TELFER *et al*., *eds*., 2011: IX.

[16] TELFER *et al*., *eds*., 2011: 16.

It took Telfer two years to take the project from initial planning phases to exhibition opening. Critically the RCP was successful in gaining a Wellcome Trust People Award for £27,000 which allowed the recruitment of the team who could create the project. The disability-led organisation Shape Arts joined as a project partner. Shape «works to improve access to culture for disabled people by providing opportunities for disabled artists, training cultural institutions to be more open to disabled people, and through running participatory arts and development programmes»[17]. Shape's role on *Re-framing disability* was to advise on all aspects of the project, to plan, host and facilitate the focus groups, recruiting participants and providing equality training for RCP staff. Without the support and advice from this highly effective partnership the project would not have been successfully realised.

CHALLENGES — THE MEDICALISATION OF DISABILITY

«You have to be slightly careful I think, in condemning doctors for their attitude to disability… doctors no more than anyone else, are a product of their culture»[18].

The RCP museum team had to address the fact that many of the people who would create the project, and the audiences who would experience the exhibition — may have negative associations with the RCP as a medical institution. The medicalization of disability is an «often contentious» area[19]. As Mik Scarlett says in the *Re-framing disability* film: «From really early on in our lives we have this love/hate relationship [with the medical profession]. I would be dead without them, but yet at the same time, I've had stuff done that went profoundly wrong»[20].

Tony Heaton, chief executive of Shape Arts writes in the exhibition catalogue: «For those whose lives are untouched by disability… there might be an assumption that our lives are inextricably linked to physicians, but for many people this is simply not true» Barriers to access are «potentially solvable by us all, particularly those of us who are providers of goods and services, or are in positions of power»[21].

«I've got a million identities, one of which is my disability»[22].

Many of the *Re-framing disability* focus group participants and exhibition attendees «described negative and damaging encounters with medical professionals throughout their lives»[23]. Penny Pepper, a focus group participant commented:

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[17] SHAPE ARTS, 2018.

[18] Tim Gebbels, *Re-framing disability* focus group participant (EVANS & ADAJI, 2011j).

[19] TELFER *et al.*, *eds.*, 2011: 10.

[20] EVANS & ADAJI, 2011g.

[21] TELFER *et al.*, *eds.*, 2011: 10.

[22] Jamie Beddard, *Re-framing disability* focus group participant (EVANS & ADAJI, 2011b).

[23] TELFER *et al.*, *eds.*, 2011: 8.

> *On a weekly basis, I come up against… an assumption* [from the medical profession] *of how I am as a disabled person,* [that] *has no bearing on how I actually live my life. When I meet a new doctor they assume that I do not work without even questioning me. I can't even rely on access to toilets in hospital, so how can I possibly expect your average doctor to look beyond the heavy labelling my wheelchair still carries*[24]*?* (See Fig. 3).

Fig. 3. Penny Pepper by Lynn Weddle, 2010
©Royal College of Physicians

Producing *Re-framing disability* gave the RCP a chance to address this issue reflectively and influence practitioners from within a medical institution. Most importantly the project was underpinned by the social model of disabililty in all aspects of production, language and interpretation. The social model «rejects a medicalised definition of disability and the need for 'cure' or treatment, and emphasises the need for society to remove barriers restricting disabled people». Disability is no longer defined as «a restriction or lack, resulting from impairment»[25]. Tony Heaton advocates «good access

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[24] EVANS & ADAJI, 2011i.

[25] TELFER *et al.*, *eds*, 2011: 6.

to buildings… public transport systems, accessible information, decent and appropriate services, education that meets our needs — removing the barriers to these 'taken for granted' things will often be cure enough»[26].

The experiences of two disabled doctors were also included in the exhibition, adding voices from the medical profession to the narrative, from both sides of the patient/physician relationship. It was also important in challenging stereotypes to represent disabled people as fulfilling professional roles. Neither doctor could attend the focus group dates, but their stories were captured through interviews and displayed within the exhibition.

The RCP's museum team defined themselves as non-disabled and it was vital that the project was led by disabled people as it could not be solely led and curated by a non-disabled team. The RCP partnered with disabled professionals and participants in every aspect of the project — from the voices and images within the exhibition, to the catalogue and publicity material. This was crucial for fostering a sense of ownership — this project was to be about disabled people's history.

CHALLENGES-FEAR OF DISABILITY HISTORY

«I think we still are on exhibition today»[27].

The RCP project team included highly experienced museum professionals, but the team lacked significant experience of interpreting sensitive material or working with disabled people or disability history.

So entering the (at times) highly political arena of disability history was terrifying. Project curator Telfer notes

> *We ourselves felt all the fear and reticence that has stopped museums from displaying this subject matter — we were unfamiliar with it, unsure of the right terminology and language. We felt the fear of creating offence and particularly a fear of sensationalising the prints. What if exhibiting them inadvertently encouraged audiences to stare in a way that was reminiscent of a freak show[28]? Could an exhibition be produced that did not view disabled people as objects of scrutiny, gazed at through the microscope, labelled… named… defined[29].*

As Dr. Julie Anderson describes in her catalogue essay, «criticism has been levelled at the depiction of disabled people in the modern media, with accusations that images have frequently been limited to the sentimental, pathological and sensational, or… simply not represented at all»[30].

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[26] TELFER *et al.*, *eds.*, 2011: 12.

[27] Patricia Place, *Re-framing disability* focus group participant (EVANS & ADAJI, 2011h).

[28] TELFER, 2011.

[29] TELFER *et al.*, *eds.*, 2011: 13.

[30] TELFER *et al.*, *eds.*, 2011: 15.

Many of the historical images selected for *Re-framing disability* are «undeniably exploitative or provocative to modern eyes»[31]. The research on the historical individuals represented in the prints was imperative to display them in an un-sensationalised way. It was the first element of the project completed with the award of £4000 from the Museums, Libraries and Archive Council (now Arts Council England funded London Museum Development) documentation improvement grant in 2009.

HISTORICAL RESEARCH

«If those gentlemen and ladies didn't exhibit themselves, then we wouldn't know about this»[32].

The research was completed by historians of medicine and disability, Dr. Julie Anderson, (University of Kent) and Dr. Carole Reeves, (University College London) who became project partners, writing for and editing the catalogue and exhibition text.

Reeves described the project commenting:

> *we looked behind the scenes at the societies and cultures in which these individuals lived and worked… and how their particular «disabilities» were understood and explained by their contemporaries.* […] *Working with the focus groups we came to the realization that whilst there may have been some exploitation going on, particularly with regard to the display of children with unusual bodies, most individuals had agency over their lives and were celebrated as «special» or «ondrous» in their own time… While the majority of people in Britain and Europe spent their entire lives in their home villages, the Colloredo Brothers, Chang and Eng. Bunker, and Wybrand Lolkes were crossing continents on a regular basis. These portraits remind us that whilst we should never be complacent about disability, we can gain a more nuanced glimpse into disabled people's lives and life experiences in different times and places*[33].

Anderson set out the landscape of the history of disability in her catalogue essay *Public bodies, disability on display*, introducing society's changing concepts of disability from the 17th to 19th century, from a belief in a correlation between sin and bodily deformity in the early modern period to the increasing interest of medical practitioners in categorising «disability, deformity and disfigurement» from the late 17th century onwards. In the 19th century, with «the growth of industrialisation, disabled people were excluded from new modes of production… and moved from mainstream society into institutions, often managed by doctors»[34]. Excluded from mainstream employment,

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[31] BASHAM, 2006.

[32] Mark Pampel, *Re-framing disability* focus group participant (EVANS & ADAJI, 2011d).

[33] REEVES, 2013.

[34] TELFER *et al.*, *eds.*, 2011: 20.

people with unusual bodies were likely to be compelled to exhibit themselves to earn a living and attracted large audiences in metropolitan centres.

Many of the individuals in our group of prints exhibited themselves for this reason including John Boby (promoted in his portrait of 1803 as «the wonderful spotted Indian») John Worrenburg (titled «the Swiss Dwarf» in c. 1688), Wybrand Lolkes («the celebrated man in miniature») in 1822, and Thomas Hills Everritt (shown with his mother as «the gigantic infant» in 1780). Their print portraits exist because they were created as publicity material or to buy as a memento of your visit.

CHALLENGING NEGATIVE STEREOTYPES

«[Buchinger] did a job which was within [the] performing arts, so of course people were looking at him, but I think a lot of his emphasis was on the actual talent of drawing and not on being a curiosity or a disabled person»[35].

All 28 portraits show people with a range of conditions, bodies and life stories. In his self-portrait of 1724 Matthew Buchinger sits on an embroidered and tasselled cushion (see Fig. 4). He wears a velvet jacket, waistcoat, an undershirt with ruffled cuffs and a lace-edged silk neckerchief and describes himself as «a wonderful little man of but 29 inches high, born without hands, feet or thighs». Buchinger was born in Germany, the youngest of 9 children. He was married four times and fathered 11 children. Buchinger came to England in the early 18th century and exhibited himself in London — like many disabled people represented in *Re-framing disability* Buchinger travelled far more widely than most people of his time. Admission to see him cost one shilling for a front seat or 6p for a backrow seat — which meant he had an affluent audience. Records show that Buchinger was multitalented performer — he played the bagpipes, the trumpet, performed conjuring tricks, danced a hornpipe in Highland dress, and was a celebrated artist — the curls of Buchinger's wig in his self-portrait are composed of the lettering of six Biblical psalms and the Lord's Prayer[36] (see Fig. 5).

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[35] Miro Griffiths, *Re-framing disability* focus group participant (EVANS & ADAJI, 2011c).

[36] TELFER *et al.*, *eds.*, 2011: 55.

Fig. 4. Portrait of Matthew Buchinger, etching with stipple after a self-portrait, 1724 ©Royal College of Physicians

Fig. 5. Detail of the Lord's prayer, portrait of Matthew Buchinger, etching with stipple after a self-portrait, 1724 ©Royal College of Physicians

One of the central aims of *Re-framing disability* was challenging negative stereo--types of disabled people. In order to achieve this, the research needed to uncover, as far as possible, the lives and cultures of the people portrayed to allow them to be seen as the people they were — as parents, husbands, wives, artists and professionals — and not be purely defined and viewed in terms of their impairment. Using the example of Buchinger — once the viewer of the print has been given biographical information (that he had four marriages, eleven children and his art work is in the British Museum) our question was: do they start to view the image differently and focus on the life of the man, and not primarily his body? Importantly the interpretation was not undertaking any form of retrospective diagnosis or focusing on the treatment or «cures» that the individuals might be been offered or given — unless it was central to the story of the print.

«We're permanently on display, whether we like… or not. So… if we're going to get looked at any way, we might as well get paid for it»[37].

What was revealing by the research and is discussed in detail in the catalogue is that many of the historical individuals had considerable autonomy and control over their lives, «marketing their differences and capitalising from it»[38]. Individuals like Count Joseph Boruwlaski from Poland and Patrick Cotter O'Brien from Ireland had «created a condition where they exploited their difference and controlled their own destiny»[39]. O'Brien was just over 8ft tall and Count Boruwlaski was 39 inches tall. Both started their careers exhibiting under management (when effectively they were the property of their agents) and eventually left — to manage themselves. Boruwlaski wrote an autobiography criticising those who identified him solely by his physicality. O'Brien exhibited for his own profit and could earn the equivalent of £600 a day (see Fig. 6).

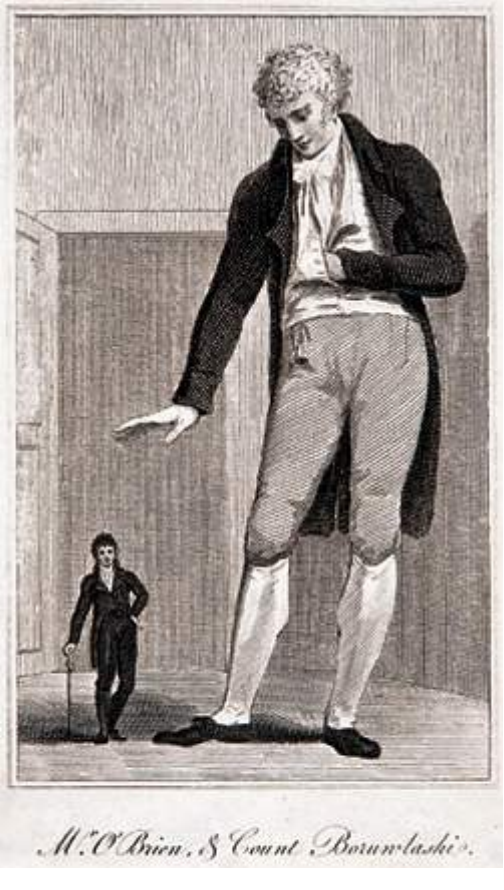

Fig. 6. *Mr. O'Brien & Count Boruwlaski* (Patrick O'Brien and Count Joseph Boruwlaski), etching by unknown artist, date unknown ©Royal College of Physicians

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[37] Sophie Partridge, *Re-framing disability* focus group participant (EVANS & ADAJI, 2011e).

[38] TELFER *et al.*, *eds.*, 2011: 15.

[39] TELFER *et al.*, *eds.*, 2011.

There are examples of appalling exploitation and cruelty within the stories. A boy from Lancashire born in 1857 was given by his parents to Dr. Joseph Kahn's Anatomical and Pathological Museum in London. We don't know his name — he was exhibited as the «Heteradelph» or «Duplex boy» in the print of 1865. He could viewed by the public 3 times a day — and there is currently no further information on how long he lived (see Fig. 7). But overall, in examining the group of portraits, a far more complex picture of disability emerges from the research than might have been assumed[40].

Fig. 7. *The Living Heteradelph, or Duplex Boy*, lithograph by unknown artist, date unknown ©Royal College of Physicians

FOCUS GROUPS

«My disability isn't my defining feature, and if it was, I'd be a very very boring man… but I'm not»[41].

The *Re-framing Disability* focus groups ran over three days in July 2010. 27 disabled participants gave their thoughts and opinions on the historical prints and any wider reflections they wanted to offer. Participants viewed large reproductions of the prints and the historians spoke about the stories and backgrounds of the individuals (see Fig. 8).

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[40] TELFER *et al.*, *eds.*, 2011: 67.

[41] Jamie Beddard, *Re-framing Disability* focus group participant (EVANS & ADAJI, 2011b).

Fig. 8. The *Re-framing disability* focus group, July 2010
©Royal College of Physicians

To recruit participants Telfer sent out invitations predominately using Shape's networks. No set criteria was asked of participants, apart from an interest in art and disability history. People applied by writing a short statement saying why they were interested. In accordance with the social model of disability applicants were not asked what their disability was, they were instead asked to state their access requirements on applying. We did not target people with specific types of disability similar to the individuals portrayed in the historic prints, but instead mentioned some of the conditions depicted to give applicants a sense of what they may see and discuss. The focus groups were recorded, filmed and photographed with BSL interpretation and a palantypist offered to participants[42].

The 27 selected participants came from across the UK and were of diverse ages, ethnicities and backgrounds including artists, actors, journalists and musicians (Appendix 3 lists all participants). The lively and stimulating sessions were inevitably provocative in terms of the themes of disability and disenfranchisement that were generated as the lives of the historical disabled individuals were discussed. The themes that arose were diverse — employment, autonomy, control and representation — in the media and in society in general. By filming and recording the conversations and interviewing and photographing the participants, new and important material was generated to create the exhibition and film.

Tony Heaton describes seeing the historical prints as «a revelation»[43]. Sophie Partridge wrote in her blog

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[42] TELFER, 2011.

[43] TELFER *et al.*, *eds.*, 2011: 14.

> *Somehow I had a sense of relief seeing these peeps [people] knowing generations had gone before, living in a world without any model of disability… As a young child, I knew I was never going to grow up a lot. But because I didn't know any small adults, I found it almost impossible to imagine myself in a future. Yet they were out there, I just had to keep living to find them*[44].

The participants' voices can be heard directly in the 15-minute exhibition film by Deaf filmmakers Ted Evans and Bim Ajadi, created to reflect and represent their views. Evans and Ajadi filmed interviews with the participants and showed the discussions on the prints. The film can be viewed at <https://www.youtube.com/watch?v=PALIKx1PFes>.

Photographic portraits of the participants directly parallel the portraits of the historical personalities with the aim of creating «a legacy of positive portrayals of disabled people, images over which the participants had control»[45]. Disabled photographer Lynn Weddle used a shutter release mechanism when taking portraits so that the sitter has control of the image and pressed the button to take their own photograph (see Figs. 9 and 10).

Fig. 9. *Re-framing disability* photographer Lynn Weddle, July 2010
©Royal College of Physicians

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[44] PARTRIDGE, 2010.
[45] TELFER *et al.*, *eds.*, 2011.

Fig. 10. Contemporary portraits from *Re-framing disability*, 2010
©Royal College of Physicians

OUTCOMES

«For myself I don't want to be known as Miro the person in a wheelchair, its Miro with all the beliefs and faiths and values he has, oh and by the way, he is also a wheelchair user»[46].

The formal evaluation of *Re-framing disability*'s visitor and participant responses was carried out by independant consultant Nicky Boyd. She concluded that *Re-framing disability* had met the original project aims and was positively and enthusiastically received by participants, audiences and academics in her quantitative and qualitative study of visitor comments and feedback[47].

The main aim of the evaluation was to find out if and how the exhibition encouraged audiences to rethink attitudes towards disability, question taken for granted stereo--types and actively engage with contemporary, disability-related issues.

A feedback form was developed specifically for the exhibition. Visitors were asked «Has this exhibition changed the way you think about disability? (Yes/No/Maybe/Don't Know)». They were then asked to explain their answer. The feedback form also asked visitors for basic demographic details as well as feedback about the different interpretive

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[46] Miro Griffiths *Re-framing disability* focus group participant (TELFER *et al.*, *eds.*, 2011).

[47] BOYD, 2011.

methods used and physical access within the building. Visitors were encouraged to add their comments to a board where they could be viewed by other visitors. Comments were also collected via general museum comments forms, a comments book available in one part of the exhibition and email feedback. Focus group participants were sent an email feedback form.

In her report summary Boyd concludes that

> *the exhibition prompted a wide range of rich and diverse responses from visitors about changing attitudes to disability (or not), support for the exhibition and venue, reflection on new learning, the social barriers experienced by disabled people in the past and today, the importance of using disabled people's own voices, the methods of interpretation, challenging stereotypes, the range of disability issues and experiences portrayed in the exhibition as well as their own identity as a disabled person or their professional experience of working with disabled people. There was a huge amount of support generally for the project (with 120 visitors leaving very positive comments), many citing that it was «thought-provoking», «absorbing», «powerful» and that it «challenges perceptions and images of disability». Many saw the value in and a real need for this kind of project*[48].

Other quotes highlighted in the evaluation included:

> *The exhibition offers many, often contradictory, views on disability which I think is a more realistic way of looking at any topic. It's great to see views expressed by people with disabilities in an arena (medical) which is usually avoided. This exhibition encourages people to question beliefs that we have, and the display has certainly done that for me.*
>
> *Prior to visiting the exhibition, I was unsure how the historical images could be seen outside the realm of the 'freak-show' but I think its great success was to provide information about the lives of these people where possible and highlight the often surprising sense of their individual's power and achievement that often came with being a «spectacle»*[49].

Bridget Telfer wrote a learning resource as a practical guide for museum and heritage organisations to use historical material to address contemporary social issues. Telfer's report comprehensively sets out the journey that she took to create the project and bring expert partners together. The resource lays out both the achievements, learning and

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[48] BOYD, 2011: 6.

[49] BOYD, 2011.

pitfalls of the project and outlines some best practice tips learnt from experts employed on the project team[50].

RE-FRAMING DISABILITY'S LEGACY

«I'm not so sure many people's attitudes have actually changed»[51].

After the closure of the exhibition at the RCP in July 2011, the museum team faced the challenge of creating the legacy for the project and disseminating learning to the museum profession. Telfer's post as audience development coordinator was a fixed term contract and ended in January 2012. The exhibition was always intended to tour and Telfer set up this element and toured it to three venues before her contract expired. Coordination of the touring run was taken on by RCP collections officer Peter Basham and his work developing and promoting the touring exhibition over the next three years to seven venues further developed and strengthened the museum's equalities practice. However the RCP museum's ability to take on independent work in this area was necessarily limited as a small museum with no dedicated staff or resources to take disability history projects forward.

Therefore the second significant legacy of *Re-framing Disability* for the RCP was an invitation to become one of four London medical museum partners in a collaborative disability history project led by the University of Leicester's Research Centre for Museums and Galleries. *Stories of a different kind* (2012-2014) developed Mat Fraser's award-winning public performance *Cabinet of Curiosities; how disability was kept in a box* first performed at the Royal College of Physicians in January 2014[52].

Professor Richard Sandell and Jocelyn Dodd directed and coordinated the Wellcome Trust funded project which «grew from more than a decade of work in RCMG, aimed at addressing the silence in museums on disability by stimulating and shaping new approaches to the representation of disabled people and disability history, arts and culture»[53]. The show won the Observer Ethical Award for art and culture in 2014 (see Fig. 11).

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[50] Boyd's evaluation report and Telfer's learning guide are currently unpublished and available on request from the Royal College of Physicians museum.

[51] Christiana Joseph, *Re-framing Disability* focus group participant (EVANS & ADAJI, 2011a).

[52] UNIVERSITY OF LEICESTER, 2014.

[53] UNIVERSITY OF LEICESTER, 2014.

Fig. 11. Mat Fraser, *Cabinet of Curiosities*, 2013
©Royal College of Physicians

In commissioning critically acclaimed actor and performance artist Mat Fraser to create a provocative and personal piece of theatre Sandell and Dodd engineered an innovative model of museum engagement practice that «transcends a mere history lesson»[54] and «crashes art-form boundaries»[55] to «share research and engage participants in debating its social and political implications»[56].

Fraser was invited to visit and discuss disability history-related collections with curators from the four medical museums. He incorporated the people, stories, images and objects held in the collections from the perspective of his own life and experiences of disability (Fraser was born with foreshortened arms after his mother was prescribed thalidomide during pregnancy). Fraser described this work as

> *a fascinating process poring over the archives of these museums, finding evidence of disabled people, some, if not most of which, is buried in the footnotes of displays about other things. But there are many objects that cry out to be presented with the fully rounded history that they deserve*[57].

In using the historical prints from *Re-framing Disability* in his performance, Fraser directly countered prevailing tendency of medical museums to focus on the clinicians' perspective and «incomplete or partial narratives» of medical history.

Fraser's charismatic and moving one-man performance was «an eclectic juxtaposition of academic lecture, autobiographical reflection, disability activism, punk, rap, social documentary, music hall pastiche and whimsy»[58]. Fraser commented

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[54] «*Cabinet of Curiosities: How Disability was kept in a Box*» […], (2014).

[55] GARDNER, 2014.

[56] UNIVERSITY OF LEICESTER, 2014.

[57] FRASER, 2014.

[58] BARTHOLOMEW, 2015.

> *For me looking at the weird collection of rejected limbs alongside images of boffins desperately trying to make these thalidomide kids look normal was melodramatically revolting. It was poignant because I know some of the people who had that enforced normality treatment imposed on them as kids*[59].

Following on from *Cabinet of curiosities*' success, Sandell and Dodd were awarded Wellcome Trust and Arts Council England funding for an expanded collaborative project *Exceptional and Extraordinary; Unruly Minds and Bodies in the Medical Museum*, 2014--2016[60]. The RCP became one of eight museum project partners providing inspiration for four artistic commissions by filmmaker David Hevey, play-wright Julie McNamara, dance company Deaf Man Dancing and comedian Francesca Martinez. Performances of all four shows were given at the RCP in July 2016 (see Fig. 12).

Fig. 12. *Exceptional and Extraordinary* artists: Julie McNamara, David Hevey, Mark Smith and Francesca Martinez, 2014 ©Julian Anderson

Martinez in particular responded to the RCP collections directly:

> *My visit… brought me face to face with how the medical fraternity has approached disability — a topic I've visited many times in the past!* […] *I thought of the slow progress in changing the view of disabled people as faulty products that need to be fixed… I came face to face with an imposing portrait of Sir William Osler, the*

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[59] FRASER, 2014.

[60] UNIVERSITY OF LEICESTER, 2014.

> *celebrated medic who coined the term «cerebral palsy», a term I've hated for as long as I can remember. Here was the moustachioed visage of my nemesis. That couldn't go unaddressed, so I brought him back to life to explain himself, in a scene in which I repeatedly interrupted him, challenging his assumptions, pointing out the consequences of his invention, and finally dismissing him from the stage, striking a blow for all the cerebrally palsied everywhere*[61]*!*

Martinez performed this confrontation at the RCP in July 2016 and later at the Museums Association's annual conference keynote in November 2017. Osler was «bought back to life» by actor Kevin Hely within the sketch describing cerebral palsy as an «elegant» medical term. Their exchange enables Martinez to comedically express her frustrations: «It's not very sexy is it?» «You are choosing to define me by what I can't do, but we all have things we can't do»[62]. Martinez ends with a call for less judgemental labels like her own choice: 'wobbly'. This direct, powerfully engaging and creative response to the RCP's portrait of Sir William Osler was a revelation to the RCP museum staff when first performed in 2016. The portrait had been pointed out to Martinez on her research visit as an aside. It has been on permanent public display in the RCP for over fifty years solely to celebrate and memorialise Osler's medical achievements. Martinez' interaction with the painting is a significant example of the recontextualization of a museum object through personal experience and highlights the impact bring artists and performers, «their political and creative passions and life stories [together] with the stories of the museum collections and objects»[63].

CONCLUSION

UK museum practice in disability history and engagement still requires wholesale review and action. Individual projects such as *Re-framing Disability* are important and demonstrably impactful, but they remain small-scale without sector-wide re-evaluation of inequalities to provide not only physical access to museums but also address representations of disability, race, gender and sexuality.

Overall *Re-framing Disability* took the RCP museum team and programmes closer to a more integrated understanding of equality, accessibility and disability across many aspects of museum practice, but there is more work to do. Mat Fraser's call to the museum profession, delivered directly in his keynote performance of *Cabinets of Curiosity* at the Museums Association conference in 2014 remains urgent:

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[61] MARTINEZ, 2017.

[62] *Francesca Martinez and the Wobbly Manifesto*, (2016).

[63] Available at <https://www.unrulybodies.le.ac.uk/>.

> *If every museum in the UK did a re-think on even just one artefact this year, it would make a huge difference. If some of them had exhibitions that represented disability in some way, in the next two years, it would be a real mark of progress. Crucially, if disabled people could feel like history belongs to them as much as any other group — that their point of view is as valued as the dominant one — then perhaps museums could, finally, speak for everyone*[64].

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[64] MUSEUMS ASSOCIATION, 2014.

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APPENDIX 1

Aims and Objectives of the *Re-Framing Disability Project*

1) Set the historical prints within the context of the history of disability and medicine in order to:

- Understand why they were made (social and cultural attitudes of the time/ideas of «difference» changed over time/how disabled people came to be classified or labelled);
- Understand the human stories behind the images;
- Understand disabled peoples relationship with medicine and medical practitioners historically and today.

2) Examine representations and identities of disabled people, and how this has changed over time in order to:

- Examine what visual imagery can and cannot tell you about a person and challenge stereotypes surrounding images of disability;
- Understand that disabled peoples experiences, how they want to be represented and identities are all different.

3) Include disabled participants in the project and their voices and images within the exhibition, exhibition catalogue, and publicity material in order to:

- Reduce the cultural invisibility of disabled people in traditional museum displays;
- Create an opportunity for disabled people to comment and curate;
- Empower disabled people to take control of their own histories and identities, through discussion and debate;
- Encourage audiences in rethinking attitudes towards disability, question taken for granted stereotypes, and actively engage with contemporary, disability-related issues.

485 visitors came to the RCP specifically to see the exhibition between 14 February 2011 and 8 July 2011. There were 13,156 other visitors to the RCP between these dates, attending conferences, events and tours, who would have passed through the exhibition.

This 2011 exhibition resulted in the following outcomes:

- An exhibition at the RCP from 14 February 2011 – 8 July 2011;
- A permanent online exhibition;
- A film interviewing the 27 disabled participants of the project created by Deaf filmmakers Ted Evans and Bim Ajadi, hosted on the RCP website and YouTube;
- Contemporary portraits of each of the 27 disabled participants — images over which the sitters had direction and control — created by disabled photographer Lynn Weddle;
- New research on the historical prints of disabled people conducted by medical historians Julie Anderson, senior lecturer in the history of medicine at the University of Kent and co-founder of the Disability History Group, and Carole Reeves, outreach historian for the Wellcome Trust Centre for the History of Medicine at University College London. Research findings have been made available to audiences through the exhibition and on-line exhibition, the accompanying exhibition catalogue, the audio description of the exhibition (for blind and visually impaired people) and Adlib (the RCP's computerised documentation system);
- A touring exhibition;
- A publication (exhibition catalogue) containing the story behind the creation of the *Re-framing disability* project, the research findings exploring the historical portraits, and the autobiographical text of the disabled participants;
- A downloadable resource/tool kit from the RCP's website to support museums across the UK in tackling similar projects;
- Papers delivered at UK wide disability and museum conferences;
- Articles and reviews in disability, medical and museum journals and media.

APPENDIX 2

The Royal College of Physicians' Historical Portraits of Disabled People Researched and Exhibited for *Reframing Disability,* 2011

1. *Sara Baartman* (or *The Hottentot Venus*), etching by W. Wadd, date unknown;
2. *Mr. Lambert* (Daniel Lambert), etching with stipple by unknown artist, 1809;
3. *Mr. O'Brien & Count Boruwlaski* (Patrick O'Brien and Count Joseph Boruw-

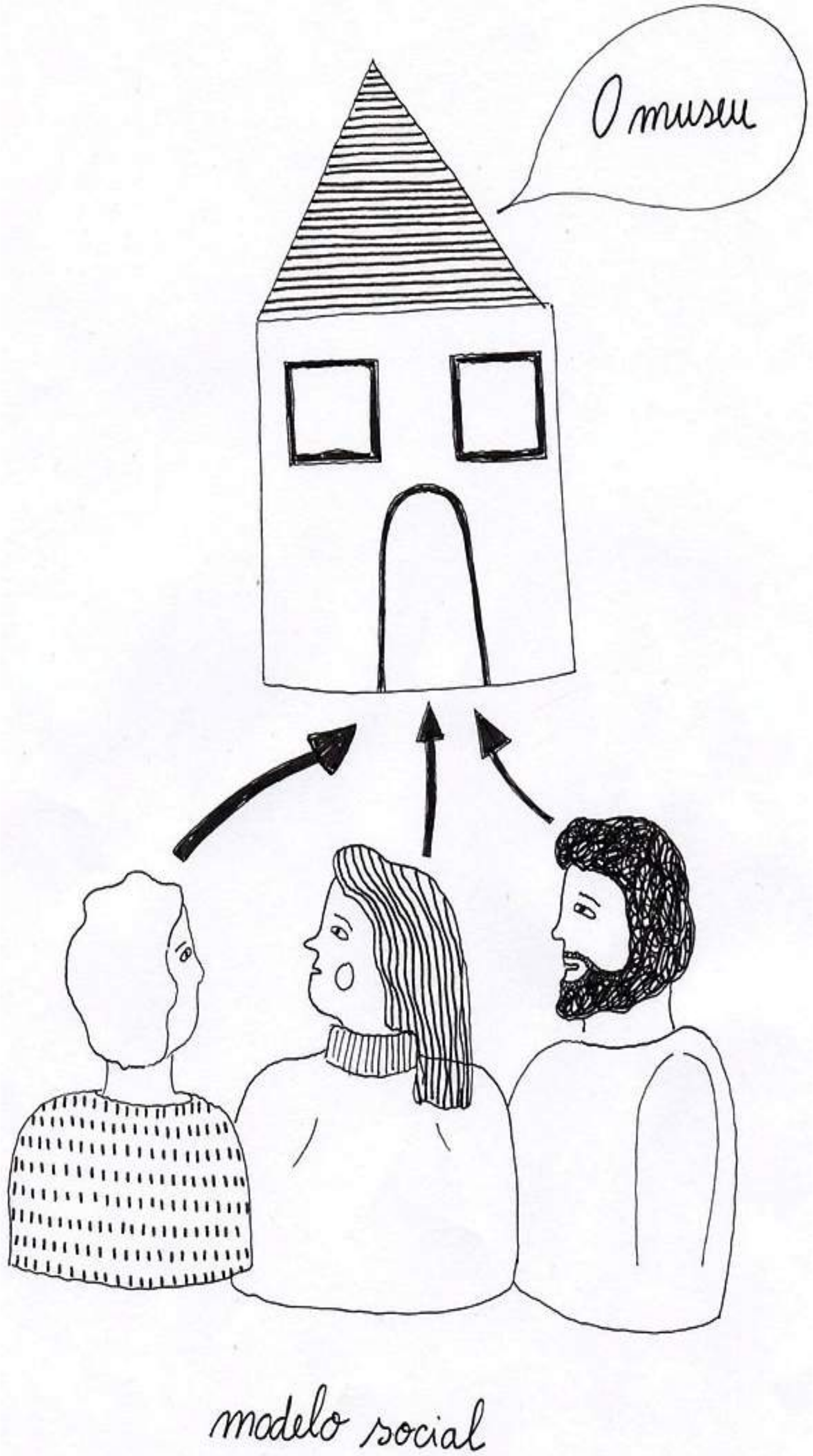
laski), etching by unknown artist, date unknown;

4. *Theorie des Ressemblances* (Chang and Eng), lithograph by C. Motte, 1839;
5. *Sarah Hawkes in her state of deformity*, stipple by unknown artist, 1836;
6. *Sarah Hawkes as she at present appears*, stipple by unknown artist, 1836;
7. *Master Joules and Miss Marianne Lewis*, stipple by Woolnoth, 1806;
8. *The Chinese Giant, Chang, with his wife and attendant dwarf* (Chang Yu Sing), wood engraving by unknown artist, date unknown;
9. *Thomas Inglefield*, etching by Samuel Ireland after Francis Grose, 1787;
10. *Thomas Inglefield*, etching with stipple, 1804;
11. *The Wonderful Spotted Indian*, John Boby, etching with engraving by unknown artist, 1803;
12. *Magdalena Rudolf's Thuinbuj von Stockholm aufs Gweden*, engraving with etching by Wolfgang Kilian, 1651;
13. *J. Worrenburg*, The Swiss dwarf (John Worrenburg), aquatint with etching by unknown artist, *c.* 1688;
14. *Matthew Buchinger*, etching by R. Grave, date unknown;
15. *Matthew Buchinger*, etching 1837, in facsimile of a printed notice by Matthew Buchinger, 1716;
16. *Matthew Buchinger*, etching with stipple after a self-portrait, 1724;
17. *Mynheer Wybrand Lolkes*, the celebrated Man in Miniature, etching by Wilkes, 1822;
18. *Israel, The Twin Brothers* (Lazarus and Joannes Baptista Colloredo), etching by unknown artist, 1634;
19. *Lazarus Coloredo* (Lazarus and Joannes Baptista Colloredo), etching by unknown artist, 1645;
20. *Mrs. Everitt and her son*, *The Gigantic Infant* (Thomas Hills Everitt), etching with stipple by unknown artist, 1780;
21. *Blind Granny*, stipple by unknown artist, date unknown;
22. *Joseph Clark*, etching by unknown artist, *c.* 1792;
23. *The Living Heteradelph*, or Duplex Boy, lithograph by unknown artist, date unknown;
24. *John Valerius*, etching by R Grave, 1698;
25. *Mr. Henry Blacker the British Giant*, engraving with etching by unknown artist, date unknown;
26. *James Poro*, stipple engraving by Maddocks, date unknown;
27. *J. Kleyser* (Johann Kleyser), aquatint by unknown artist, *c.* 1718;
28. *A Dwarf* (identified as Richard Gibson), oil painting by unknown artist (after Sir Peter Lely), 19th century;
29. *The Twin Brothers*, aquatint by unknown artist, *c.* 1716.

APPENDIX 3

The List of Participants for the *Re-Framing Disability* Focus Groups

1. Debbie Allaire;
2. Jamie Beddard;
3. Margot Bristow;
4. Hayley Davies;
5. Tim Gebbels;
6. Miro Griffiths;
7. Colin Hambrook;
8. Margaret Hughes;
9. Christiana Joseph;
10. Adam Lotun;
11. Julie McNamara;
12. Aidan Moesby;
13. Mark Pampel;
14. Sophie Partridge;
15. Penny Pepper;
16. Patricia Place;
17. Liz Porter;
18. Julia Poser;
19. Saleem A. Quadri;
20. Mik Scarlet;
21. Michael Shamash;
22. Jane Stemp;
23. Allan Sutherland;
24. Karen Sutherland;
25. Anya Ustaszewski;
26. Phil Willan;
27. Anna C. Young.



Label: [the museum] [social model]
©Dora Martins, 2017

THE IDENTITY AND REPRESENTATION OF THE PERSON WITH DISABILITIES

LIA FERREIRA*

> *Body sensitivity is the first factor in the accessibility world.*
> M. Merleau-Ponty

This sensitivity acquires body and expression in art and culture and generally museums are documented deposits, archives of the most diverse art forms.

Museums are also a social school in which prejudices show the path to more informed concepts.

The human figure is understood as the ultimate way to relaying states of soul and social/behavioural patterns. Thereby, museums throughout their existence, have been accumulating a vast collection of representations of the human being.

The disabled person emerges associated with intense emotional loads, assuming representative forms that go through the image of the beggar and the Divine. The striking symbolism they represent, prevents them from appearing as innocuous figures of meaning or significance.

The duality between the social perspective affected by the concepts and prejudices of the «normal» human and the reality felt by the human with disability is a theme which deserves an endogenous reflection led by experiences in the first person.

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In this meeting it was presented a set of reflections that look forward to analyse the identity of the person with disabilities, exploring the association between them, society and museums. The theme granted an appearance of several questions that invite us to the perception of a holistic vision.

The Exterior Perspective

What is the load associated with the disabled person? What role does society attribute to this person? What causes the figurative load carried by the disabled person?

Yet, in the external perspective it is important to understand how to organise an exhibition and what motives lead to certain decisions of exposition of the Museum estate.

The Identitary Perspective of the Disabled Person

How does this person see itself? What is the image it has about itself before the world and how does it put itself in this world? Does it see itself according to its physical limitation or does it have an idea of itself regardless of its limitation? Does it see itself as an integral part of the social world or does it feel excluded?

The Sequence of this Reflective Effect allows you to Deepen into the Subject

How does it feel about what it seems to be to other people's eyes?

What does it perspective on the world and its role in society?

What is it identity as a social and individual being?

How would it organise an exhibition about the human figure with disabilities? What would it decide to prioritize, how would it prefer to arrange the contents to be exposed?

What's its pattern and what is does it understand by normality?

To the ideological dialogue of Patrícia Roque Martins (CITCEM/FLUP) — «The representation of disability in the collections of the Museum of the DGPC: discourse, identities and sense of belonging. Introduction and presentation of the research project»; is added the optics of Emma Shepley (London Museums of Health and Medicine) — «Reframing disability: Exhibiting difference in the medical museum».

The discussion about what can be understood by normality is opened.

In the museological world where art is the social voice, disability marks with its presence. Not always in the foreground, that's true; however, due to the intense symbolic load, it almost assumes the protagonism in all representations.

Figures of beggars, prisoners, shapeless beings and circus freaks… These figures can represent the negative social contrast and also divine figures, although these have a less assiduous presence than those previously mentioned. All with some type of visible disability compose the scenario in which they are represented, therefore carrying the social message.

In the utopian world we would have a young, athletic and warlike population (ready for all challenges and without any kind of disability/inability). In the real world there is no more expressive pattern than that of biodiversity and the importance of interdependencies, which are our greatest richness.

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DOWN AND OUT AND DISABLED IN THE MIDDLE AGES? MEDIEVAL ATTITUDES, MODERN ASSUMPTIONS AND PUBLIC DIS/ABILITY HISTORY

CORDULA NOLTE*

Abstract: With a focus on visual representations this paper introduces current research of the interdisciplinary research group *homo debilis* at the University of Bremen. When it comes to exploring medieval dis/ability, specific challenges such as fragmentary sources, vague terminologies and varieties of discourses have to be dealt with. A selection of main results of our research concerning premodern conceptions of dis/ability will be presented. Some of these findings prove both scientific and popular assumptions of medieval attitudes to be in part anachronistic. By curating an exhibition in 2012 the *homo debilis*-group disseminated its approaches and conclusions to a broader public in order to challenge common clichés. This early experiment of public dis/ability history was based on the cooperation of contributors with and without disability. Following the principle of accessibility it addressed a heterogeneous audience. Drawing on this experience I would like to reflect, from a medievalist's perspective, on how to communicate a fresh and more complete history of medieval dis/ability.

Keywords: premodern dis/ability history, public dis/ability history, accessibility, museums.

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INTRODUCTION

According to popular notions, living in the Middle Ages meant hardship for people with disabilities[1]. Persons with impairments of the body, the mind or the senses, with deformities or chronic diseases are supposed to have been poor, living on the margins of society, dependent on charity, short-lived — if they survived at all and did not fall victim to infanticide. This bleak image is at least in part derived from premodern works of art as seen in museums, books and social media. Many paintings and sculptures do indeed show impaired figures as beggars and receivers of alms, as objects of pity, revulsion and spite[2].

Recently dis/ability historians have started to explore visual representations from a double perspective: They work on developing a specifically premodern dis/ability history on the one hand and on communicating this programme to the public on the other hand. Both premodern dis/ability history and public dis/ability history are rather new developments. In my paper I would like to introduce you to their objectives. After describing and defining some main characteristics of dis/ability history in general I will refer to the specific research project *homo debilis*. This interdisciplinary research group has been exploring premodern dis/ability for several years at the University of Bremen while being embedded in an international network of historians, art historians, historians of medicine and of literature, archaeologists and anthropologists. Team members focus on the centuries which according to traditional periodization are labelled «medieval» (500-1500) respectively «early modern» (1500-1800). This contribution informs about our collaborative work in progress which has been documented in several volumes but is far from being completed[3]. First I would like to point to specific challenges of premodern dis/ability history and to present some main results of our research. Next I will discuss how we tried to communicate our findings to an interested public by curating an exhibition. Finally I would like to share the experiences of this exhibition with you by commenting on difficulties and chances to transmit a fresh and more complete history of premodern dis/ability beyond popular prejudices.

DIS/ABILITY HISTORY AS A NEW PERSPECTIVE

Since the turn of the century, dis/ability history has been established in the humanities as an innovative, internationally recognized approach[4]. In the beginning research was conducted mainly on European and American societies in the nineteenth and twentieth centuries. Meanwhile its potential to investigate societies before 1800, to

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[1] The title of this paper refers to an excellent essay by FARMER, Sharon (1998) — *Down and Out and Female in Thirteenth-Century Paris*. «American Historical Review», 103.2, p. 345-372.

[2] METZLER, 2015b: 55-61; JARITZ, 2014: 105-106.

[3] NOLTE *et al.*, 2017.

[4] BAÁR, 2017.

«go global» and to compare different cultures across chronological and spatial borders has become apparent[5]. Also, there are growing efforts to «go public» and address broader audiences outside of academia[6]. This seems obvious considering the origins of dis/ability history: It originated from dis/ability studies which themselves sprang up in the course of emancipatory movements and rights activism[7]. Dis/ability historians share the notion of other historians that historical knowledge is relevant and meaningful in many political and societal contexts even if it does not offer immediate lessons how to act.

Writing the history/histories of people with impairments or disabilities is an important part of dis/ability history's agenda. These histories, however, are considered as essential, if still missing elements of general history. According to its self-understanding, dis/ability history takes into regard entire historical societies and cultures. The analytical category dis/ability is applied in conjunction with other categories such as gender, class or race in order to explore basic questions which concern societies as a whole[8]. In what way, for instance, did past societies differentiate between «normal» and «different»? To what extent did they have a concept of «dis/ability?» By writing the word dis/ability with a slash, historians indicate that they focus both on abilities and disabilities and their interrelations. Abilities and disabilities are regarded as shifting elements within a continuum of conditions without polarity.

Dis/ability serves as a lens in order to explore the whole spectrum of historical phenomena from a new perspective: societal, political, legal and economic structures, the realms of education, work and power, daily life experiences of women, men and children, representation and images of individuals and groups in literature and works of art, the formation of identity — just to mention a few topics. In various studies it has been convincingly proven that dis/ability is a socio-cultural construction, a variable, flexible and fluid phenomenon whose characteristics and expressions change in interdependence with its environment[9]. As differences can be embodied, performed and enacted in manifold ways, dis/ability must not be mistaken for an ahistorical and invariable condition[10].

Contemporary debates of societal challenges and practices of engagement and empowerment, especially concerning the accomplishments of inclusion, may be enriched by reflecting the historical and diverse nature of dis/ability. As historians in general, dis/ability historians wish to inform the public that/how our own experiences and practices came into existence through historical processes, and that they have been shaped by

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[5] BARSCH *et al.*, 2013; BLACKIE, 2013; TURNER, 2012; TURNER & VANDEVENTER PEARMAN, 2010.

[6] TELFER *et al.*, 2011; WHITE, 2013; BARSCH *et al.*, [s.d.]; WALDSCHMIDT, 2017. See also FRASER, 2012-2014.

[7] DISABILITY MOVEMENTS, 2015.

[8] «Like gender, like race, disability must become a standard analytical tool in the historian's tool chest» (LONGMORE & UMANSKY, 2001: 15).

[9] METZLER, 2017a; FROHNE, 2017; TURNER, 2017d; BARNARTT, 2010; HORN & FROHNE, 2013.

[10] FROHNE, 2015. On the concept of «embodied difference» see Frohne (FROHNE, 2017).

former cultures. Thus, scholars hope to support the search for identity, to inspire critical reviewing of contemporary attitudes, to contribute to current ideas of social and cultural participation, and to encourage practical efforts to create inclusive and accessible structures in all areas of life.

THE *HOMO DEBILIS* EXPERIENCE: PREMODERN DIS/ABILITY HISTORY GOING PUBLIC

Source Material and Methodology

As mentioned above, until recently dis/ability history meant conducting research mainly on the so-called modern age since *ca*. 1800. When applying this new approach to earlier centuries, scholars face considerable challenges. Material surviving from the Middle Ages is disparate and fragmentary. It comprises all kinds of written texts (example given are miracle accounts, autobiographical narratives, medical recipes, administrative records), of visual representations, of human remains, that is skeletons found in graves, and of artifacts from burials or rubbish pits (Figs. 1-4). Whereas each kind of source material offers valuable information, none suffices to draw general conclusions or to create a coherent picture[11]. In fact, evidence from texts, images, bones and objects must be put together like parts of a puzzle. Thus, it takes researchers from several disciplines who systematically analyze different material according to their specific methods. They may expect to obtain plausible results on a larger scale only by exchanging and sharing their necessarily limited interpretations.

Fig. 1. St. Gallus heals a blind man on crutches (ca.1460), Stiftsbibliothek St. Gallen, Cod. Sang. 602, p. 134

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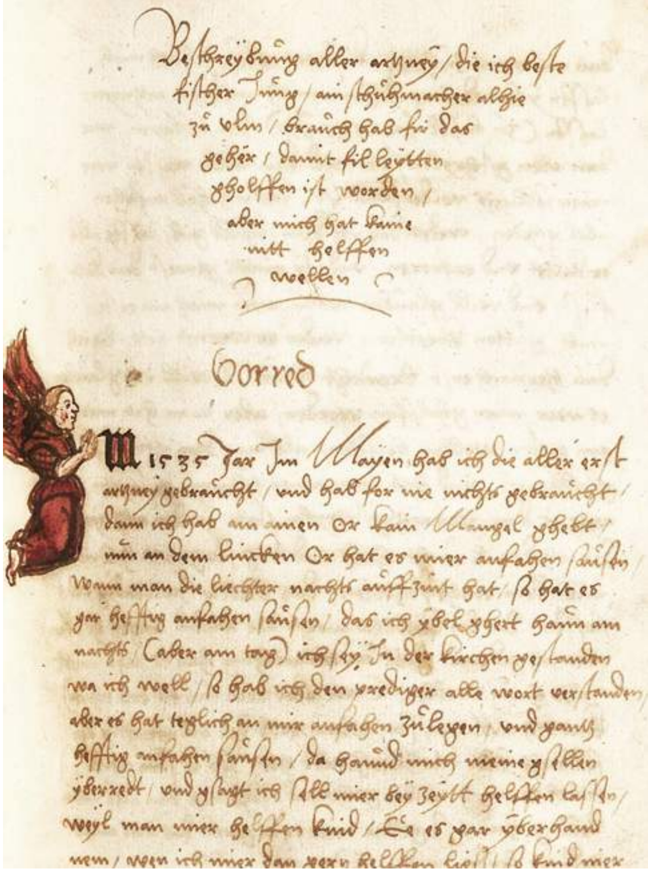
[11] LEE, 2015.



Beschreybung aller artzney / die ich beste
fischer Jung / ain schuhmacher alhie
zu Vlm / braucht hab fir das
geher / damit fil leytten
gholffen ist worden /
aber mich hat kaine
nitt helffen
wellen

Vorred

M 1535 Jar Im Mayen hab ich die aller erst
artzney gebraucht / und hab vor nie nichts gebraucht /
dann ich hab an einen Or kain Mangel ghebt /
nun an dem lincken Or hat es mier anfahen sausen
wenn man die liechter nachts auffzint hat / so hat es
gar heftig anfahen sausen / das ich ybel ghert hann am
nachts (aber am tag) ich sey In der kirchen gestanden
wa ich well / so hab ich den prediger alle wort verstanden
aber es hat teglich an mir anfahen zu legen / und gantz
heftig anfahen sausen / da haund mich meine gsellen
yberredt / und gsagt ich sell mier bey zeytt helffen lassen /
weyl man mier helffen kind / E es gar yberhand
nem / wen ich mier dan gern helffen liess / so kind mier

Fig. 2. First page of Sebastian Fischer's account of his hearing impediment and various (unsuccessful) attempts at a cure. Bayerische Staatsbibliothek München, Cgm 3091, fol. 62r Here Fischer informs the reader that he is going to describe all kinds of therapies he has tried in vain («Beschreybung aller artzney/die ich Beste Fischer Jung/ain schuhmacher allhie zu Vlm /brauch hab ir das geher/damit fil leytten gholffen ist worden/ aber mich hat kaine nitt helfen wellen»)

Fig. 3a. Ins, grave 8 (*in situ*)

Fig. 3b. The right tibia is visibly affected by osteomyelitis

The medieval burial site of Ins contained the grave of a ten or eleven years old child who had suffered from long-term osteomyelitis (right lower leg). This painful disease made intensive care necessary and could not be cured. Source: In Susi Ulrich-Bochsler. Kranke, Behinderte und Gebrechliche im Spiegel der Skelettreste aus mittelalterlichen Dörfern, Kirchen und Klöstern (Bern/Schweiz). Aussagemöglichkeiten zum individuellen Alltag. In Homo debilis. Behinderte – Kranke – Versehrte in der Gesellschaft des Mittelalters, ed. by Cordula Nolte. Korb: Didymos-Verlag, pp. 183-202, figs. 1 and 2.
Photos: a) Archäologischer Dienst des Kantons Bern, b) Historische Anthropologie Bern.

Fig. 4. Bronze sleeve Bronze of a peg leg from Griesheim, Germany, ca. 700
In Kay Peter Jankrift
Mit Gott und schwarzer Magie. Medizin im Mittelalter. Darmstadt: Wissenschaftliche Buchgesellschaft, p. 77
Photo: WBG

The language of premodern written documents is a specific methodic challenge for dis/ability historians and philologists. The vocabularies of Latin and vernacular texts prove to be difficult as none of these languages know a term equivalent to our modern umbrella term «disability». Accordingly, documents indicate that impaired individuals were not regarded as forming a specific group with common characteristics among the population. Terminological vagueness and ambiguity of meaning characterizes many written statements on bodily and mental conditions. Actually, a term such as *debilitas*, which sometimes may have indicated an impairment or a disability had a large range of meanings in different discourses of medicine, law, literature and religion. It could signify weakness on a physical, mental, economic or moral level. From a theological perspective it referred to human frailty in general when earthly living and spiritual wellbeing were discussed. Sometimes impediments of the body and the senses were described with specific terms such as lame, crooked, deaf, mute, blind. Whether these conditions were considered as disabling must be learned from the context, example given from the statement that somebody's usefulness (*utilitas*) in the field of work was limited due to a lack of certain functions. In view of these findings historical semantics are still emerging as a major field of research with regard to premodern dis/ability.

SOME MAJOR FINDINGS

The mosaic obtained by interdisciplinary collaboration does not yet show a complete picture of premodern attitudes towards dis/ability. Nevertheless, some important features are clearly recognizable. Some of our main observations concern societal structures, functionality in the working world, interrelations between social status and dis/ability, religious ideas and medicinal, therapeutic and caring practices.

Premodern societies consisted of heterogeneous and unequal social groups; accordingly, they did not have a single, uniform idea of dis/ability, but various group-specific concepts. Whether a person was regarded as dis/abled depended on her social group and her environment and on the specific function and role this individual was expected to fulfill[12]. Example given, an aristocratic girl with asymmetric shoulders may have had reduced chances to marry in accordance with her rank. This resulted from notions prevailing at noble courts that physical perfection and beauty promised fertility and qualified for political representation. Among peasants, however, such a condition would hardly have been of any consequence as long as it did not affect working capacities.

The ability to function was considered to be of highest importance. In this regard medieval societies were quite modern, actually. Maintaining or regaining one's ability to work, to sustain oneself and the family, to act in accordance with one's socio-economic position and to live up to the expectations of one's group played a major role in daily life. Discourses on health, illness, family relations, household obligations etc. often centered on questions of functionality and usefulness.

Just like today, social participation was mainly achieved by work[13]. Work meant earning one's living, shaping one's identity and ensuring embeddedness in social networks. Thus, each individual aimed at being part of the working world. In many areas of work and professional life persons with impairments actively participated and were integrated in pragmatic ways according to their abilities. If necessary they turned to different tasks or used personal assistance[14]. Persons who in spite of their efforts could not make a living due to chronic illness, impairment or old age received public financial support in addition to their small income. Those who were completely helpless and deserted petitioned to be admitted to hospitals. In late medieval cities, however, financial means and places of accommodation were scarce and thus reserved for needy as well as morally «worthy» individuals[15].

Disability did not necessarily go together with poverty[16]. Due to urban records and visual representations of impaired persons begging alms it has been assumed even by

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[12] TURNER, 2017a; HORN & KUULIALA, 2017.

[13] METZLER, 2013: 36-91; TURNER, 2017c.

[14] KUULIALA, 2017a.

[15] BONFIELD, 2013.

[16] HORN & FROHNE, 2013: 18-29; TURNER, 2017b; METZLER, 2017b.

academic mediaevalists that individuals with disabilities were usually part of the poor population at the margins of society. Disability was considered to cause social descend. Our findings clearly disprove a simple equation of disability and poverty. Impaired persons were to be found in all social strata, even in powerful and leading positions. They kept their position and rank as long as they functioned according to their specific roles and were members of families, neighbourhoods and other social networks. It took a coincidence of several factors to endanger this status. Impaired individuals were at risk of having to beg if they dropped out of networks, losing their parents by death or being deserted by friends who might care for them, if they lost their working ability completely and permanently, if they lacked any resources and were not admitted to hospitals. By the way, begging could also be practiced as a kind of regular work in addition to or alternating with other jobs to make a living.

Popular notions describe medieval attitudes as having been shaped by ecclesiastical norms of piety, by fear of sin and religious explanations for all kinds of phenomena, including bodily conditions. Some scholars also point to «associations of sin and disability»[17]. This notion of God punishing sinners was propagandized by some clerics in sermons and other normative and didactic texts. Yet, this interpretation did not dominate medieval attitudes, modern assumptions notwithstanding. Actually, the idea of dis/ability being a divine punishment for sin seems to have had little effect in daily life practices when it came to experiencing impairments of one's own or of others. Religious interpretations coexisted and intermingled with other discourses, some of which proved to be particularly important in terms of coping with incapacities. Pragmatic approaches prevailed in all social environments. If possible, medical treatment, care-giving, assistance, rehabilitative therapies and devices were provided in order to restore a person's mobility and working capability. As mentioned above, circumstances of living and working were arranged as well as possible in accordance with a person's (remaining) functions and abilities. In short: Pragmatism characterized premodern societies at least as much as religious orientation. It certainly should be considered as another «modern» feature of that epoch.

The emerging picture of energetic efforts and creative solutions to improve the well-being and participation of individuals may be surprising, especially in view of the poor image of medieval medicine and our little knowledge of caregiving practices[18]. In fact, there were a lot of conditions which could neither be healed nor improved by learned doctors or empirics. At the same time male and female experts and practitioners successfully dealt with a wide range of phenomena which threatened to permanently reduce a person's capabilities[19]. For instance, they performed cataract and hernia operations,

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[17] WHEATLEY, 2017; METZLER, 2015a.

[18] GREEN, 2009b; HORDEN, 2009; GREEN, 2009a.

[19] KUULIALA, 2017b.

removed bladder and kidney stones and trepanned skulls in order to avoid brain damage after injuries. According to recent studies, caregiving and support by paid or unpaid persons, in domestic and institutional settings, on short notice or long-term was organized and provided in multiple ways[20]. These ranged from injured servants being cured in their master's household to mentally disturbed and violent persons being taken into custody in separate rooms or buildings.

THE MAKING OF AN EXHIBITION: *LEIBEIGENSCHAFTEN*

In 2012 our research group and its partners curated a public exhibition in order to disseminate some of our results, especially those which questioned common clichés and which seemed apt to contribute to a new, more differentiated image of premodern societies[21]. Visitors were invited to reflect on and discuss today's attitudes by being confronted with complex and diverse historical practices.

This project of communicating dis/ability history to a broad public was guided by two main principles concerning the «making of» and the audience. First, team work was organized as a participative collaboration of different groups and individuals: persons with and without disabilities, students and lecturers from different disciplines, academic scholars, practitioners and representatives of several institutions and initiatives, professional curators and designers. Secondly, the exhibition aimed at a maximum of accessibility for a heterogeneous audience with various needs and preferences. We wished to address individuals of different cultural education and knowledge, persons with and without disabilities, with bodily or sensory impairments or with learning difficulties, visitors of all ages, from young pupils and school classes who need space to move and interact to elderly people who like to find occasions to rest. Thus, the exhibition was meant to employ the ideas of Universal Design (Design for All) in order to produce «science for all».

Due to an extremely low budget our team faced considerable challenges and had to find many inventive solutions in order to realize this ambitious concept. A collaborative volume which gives details on how we managed in spite of financial problems may serve as a guide for similar projects[22]. Fortunately, we did not intend to show original works of art and, apart from a few artifacts, did not have to pay for insurance. Thus, we could spend nearly all the money on the architecture, technical devices and installations which provided accessibility. All rooms and objects were made accessible for visitors with wheelchairs or walkers and allowed resting on seats in case of reduced mobility

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[20] FROHNE, 2014: 189-281.

[21] LeibEigenschaften. Der «beschädigte» Körper im Blick der Vormoderne. Bremen, Haus der Wissenschaft, 1.3.-30.4.2012. We invented the composite term «LeibEigenschaften» which alludes both to bodily features and to feudal dependence. The subtitle refers to the «defect» body in a premodern perspective (NOLTE & KINZLER, 2012a).

[22] NOLTE & KINZLER, 2012b.

or fatigue. An orientation system for blind people was fit into the floor (Fig. 5). At the entrance a touchable miniature model of the architecture allowed a quick tactile orientation before walking through the rooms.

Texts which introduced into the sections of the exhibition and explained individual objects were presented in several languages. Whereas the Braille alphabet (embossed printing) was used only occasionally because not all blind people can read it, we installed listening stations where visitors were audibly informed. We put up written texts both in Standard German language and in easy-to-understand German language. The advantages of the latter for all audiences soon became evident: actually, as other curators before, we came to learn that many visitors without learning difficulties, both adults and children, prefer to read easy-to-understand language in museums. Objects were also described and explained by sign language on screens next to them (Fig. 6). Audible information was sometimes supported by visual effects: Parts of paintings were highlighted while being described, thus guiding the listening visitors' eyes.

One of the main exhibits, the copy of a painting from the sixteenth century which shows a man with a deformed body, was turned into a three-dimensional sculpture (Fig. 7). This object and many other exhibits explicitly invited visitors to touch and sensorially explore them. Replica of reading stones, eyeglasses and mobility devices could be tested in order to gain hands-on experience on how medieval people used historical technology (Fig. 8).

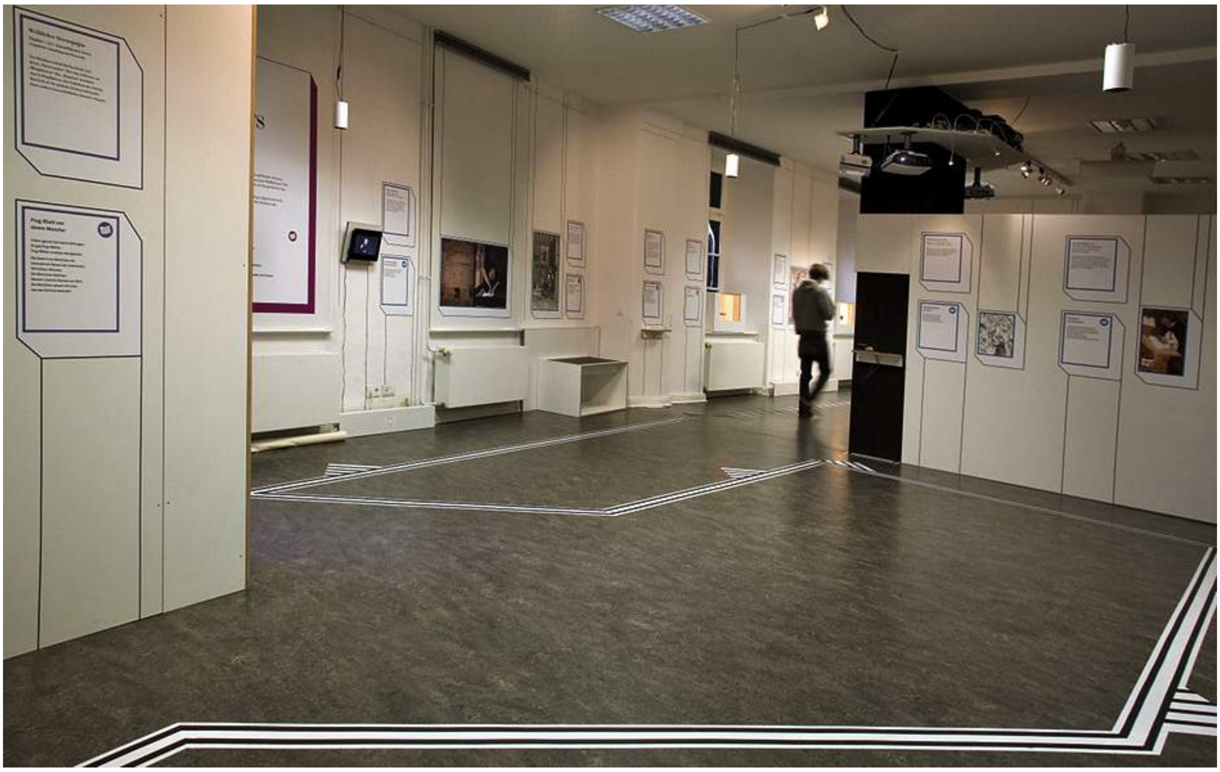

Fig. 5. Exhibition «LeibEigenschaften» with sufficient space for wheelchairs and walkers, an orientation system for blind visitors, seats to rest, height of exhibits adapted to the perspective from wheelchairs

Fig. 6. Exhibition «LeibEigenschaften» with audible information by headphones, screen with sign language performed by a deaf guide, written texts explaining objects in Standard German and in easy-to-understand German language (this latter version visibly marked by a symbol)

Fig. 7. Exhibition «LeibEigenschaften»: Bildnis eines behinderten Mannes (portrait of a disabled man), Kunstkammer Ambras (cabinet of curiosities), Kunsthistorisches Museum. Wien Ureol sculpture of the painted figure, inviting the visitors «please touch!» («Bitte berühren!»)

Fig. 8. Exhibition «LeibEigenschaften»: Hands-on replica of a reading stone and of eyeglasses, inviting the visitors «please touch!» («Bitte berühren!»)

All elements of the exhibition — the architecture, the written, spoken and signed texts and the ways they were presented and performed, the lighting, the sound-system — were developed and tested by members of the team with different abilities of seeing, hearing, moving and understanding. Finally, persons with specific abilities were trained as guides for various groups of visitors. Students for instance created didactic programs and guided tours for school classes, a colleague with learning difficulties guided mixed groups of visitors with and without disabilities and so on.

It was one of our main objectives to invite visitors to detect and discuss both parallels and differences between premodern and modern cultures. Thus, the exhibition focused on the one hand on topics we are all familiar with in our contemporary world: daily life experiences, access to public spaces, participation in the world of work, inclusive education, caregiving in domestic and institutional settings, personal assistance, availability of supportive devices etc. On the other hand the exhibition gave insight into ways of thinking and practices most of us do not share anymore. Especially religious phenomena such as pilgrimages, cults of saints and strategies to obtain miraculous healing have disappeared from the Western world whereas they are still traditional elements of cultures elsewhere.

In terms of communication we faced challenges many professionals in museums are familiar with. How can audiences without specifically historical education be encouraged to grasp and discuss historical subjects from a distant past? By which didactic strategies can a research-based vision of the past be plausibly transmitted, so that popular anachronisms and outdated, stereotyped opinions are put aside? Medieval art and artefacts, visual and textual representations are often difficult to understand. Also, they seem to suggest that religion dominated all aspects of life. It is crucial to select and present them in a way that takes into regard the ecclesiastical origin and religious purposes of many works as well as the audiences they addressed. Their symbolic content and their iconic tradition must be explained. At the same time, critical reading and contextualization should be offered. Interaction with the audience should be open for various interpretations yet aim at offering precise instruction. Furthermore, the current canon of works considered worthy to exhibit should be extended by hitherto unknown or disregarded material.

SELECTED IMAGES AND (CON)TEXTS

Some exhibits from «LeibEigenschaften» are chosen here as examples in order to discuss how images of different genres can be offered as sources of historical information on imageries, practices and material culture. If contextualized carefully, they can contribute to a new narrative of dis/ability.

The motif of Lucas Cranach's work showing Saint Elisabeth and Saint Magdalene (Fig. 9) is well known. Many saints were depicted performing works of charity on needy persons, thus calling for their veneration and the imitation of their exemplary behavior. This painting for instance shows Saint Magdalene and Saint Elisabeth of Thuringia offering ointment and food to a man crouching on the ground. His feet are missing, perhaps due to an amputation. His legs are strapped to wooden devices and his right hand grips another wooden tool (hand-trestles); these gadgets enable him to move along. We identify him at once as begging by the way his partly defect body, his mobility devices and his gesture of seizing the loaf of bread in Elisabeth's hand are put on scene. This representation obviously supports popular notions of impaired people having been poor, forced to beg, marginalized, reduced to being passive, dependent receivers of alms. Yet discussions with audiences may also point to other aspects in order to avoid the confirmation of stereotypes. The figure of the man must be regarded as a symbol which combined with other visual elements incorporates the idea of charity. In fact, he serves as a human attribute to the saints, next to their other attributes like the jar of ointment and the loaf of bread. At the same time he is depicted in a quite realistic fashion in terms of his physical appearance, his clothing and the tools he uses. As these tools appear in many other paintings we may conclude that they were regularly used as means to stay mobile. We thus come to know a detail of daily life practices. In terms of material culture we may assume that everybody could be equipped with tools which were cheap, simple and easily manufactured. Further information should be given that begging in the Middle Ages was generally accepted and regarded as a mutual giving, the beggar actively praying for the soul of the almsgiver. Even more, begging was considered to be work, sometimes even professional work. People often had several jobs at the same time, one of them begging, in order to survive.

Fig. 9. Lucas Cranach, Saint Elisabeth und Saint Magdalene (1519)
Kunstsammlungen der Veste Coburg,
Inv. M 037
<www.kunstsammlungen-coburg.de>

The idea of collecting alms being regular, active work can be corroborated by other images. An illumination in the Luttrell Psalter shows a male figure with deformed hands and a contorted leg on a pushcart, in front of him a bowl to put money in (Fig. 10). The cart is pushed by a man who has strung a rope around his neck and shoulders in order to put up with the weight. On the right hand a man opening his purse is about to donate money to the man on the pushcart. The sitting and the pushing men appear to be a team that as a matter of routine moves around for begging, sharing work and being technically well equipped with their innovative mobility-aid to do this job a long while and across spatial distances. We may assume that both of them earn their living this way and that their cooperation is of reciprocal advantage. The setting also suggests that the impaired person is not marginalized but, as part of the couple, socially embedded. Unlike other depictions of begging this one underlines the agency of the figures; their active partnership enables them to include themselves socially and economically. Of course, this scene does not aim at describing a concrete historical situation but at promoting charity. Yet, in a beautifully stylized fashion it refers to medieval attitudes towards dis/ability in a plausible way.

Fig. 10. Luttrell Psalter, first half of the fourteenth century. London, British Library Add MS 42130, fol. 186v.

In order to visualize that dis/ability was a phenomenon of all social strata I suggest to have a close look at images from secular contexts. Most of them are more or less unknown to public audiences and neglected by art historians due to their modest artistic quality. Nevertheless, they provide valuable insight into daily life experiences and pragmatic ways to cope with illness and impairment. An illustration from a manual of medicine by the surgeon Caspar Stromayr is supposed to demonstrate how a doctor should care for a patient after a hernia operation (Fig. 11). According to our research hernias frequently afflicted men (less often women) of all social groups. Many persons suffering from hernia used ligatures to keep the tissue from bulging, but this, of course, meant living with a disabling condition in terms of physical work, ability to perform and fitness in general. Such disabling effects could be prevented only by having surgery done. The illustration shows a well-fed, muscular man in bed, the doctor standing next to him. It can easily be discerned that this domestic scene reflects wealth and comfort. The wooden bed is broad and decorated with carvings. Pillows, sheet and bedspread look clean and cosy. The floor is covered with expensive tiles. The window is made from costly bull's eye glasses and lets in sufficient light. Precious silver or copper plates are exhibited on a shelf. A piece of bread and a spoon on the table indicate proper nourishment. The patient holds on to a sling made of cloth and fixed to the ceiling, and apparently tries to sit up. This scene is accompanied by an advice to the doctor: «Cover him carefully so that he does not suffer from the cold/fix a hook with a hanging towel above his bed/so that he can sit up and turn independently as he wishes». Modern spectators will be reminded of our contemporary ways to ensure that bedridden people get mobile again as soon as possible. In our exhibition this representation proved particularly apt to stimulate discussions on past and present attitudes concerning dis/ability, care and medicine. This illustration shows surprisingly modern aspects of premodern behaviour. At the same time it inspires us to think about historical differences, and, example given, to ask who could afford such doctors and therapies in societies without modern health systems.

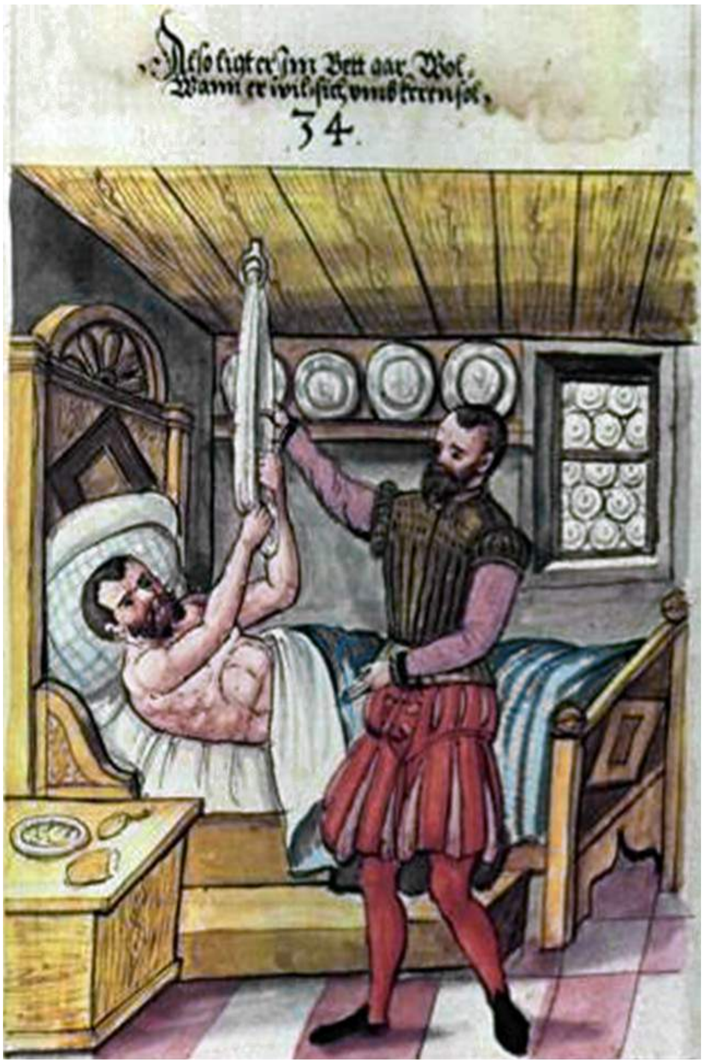

Fig. 11. Recovery after hernia surgery
The sling affixed to the ceiling is meant to help the patient sit up and turn around independently. Caspar Stromayr: Practica copiosa von dem Rechten Grundt Deß Bruch Schnidts, 1559,
Lindau, Ehemals Reichsstädtische Bibliothek, P I 46, fol. 106r.

The last example from «LeibEigenschaften», a votive panel, belongs to the world of religious images again. It is from the chapel of Altötting in Bavaria dedicated to the Holy Virgin Mary, a cult center which attracted many pilgrims in the Middle Ages. In some publications the image is reproduced under the title «Raving mad female in chains»

(«Wahnsinnige Frau in Ketten», «Tobsüchtige in Ketten», Fig. 12)[23]. At first sight this representation seems to confirm common assumptions of mentally disturbed persons having being locked away. Actually, this young woman looks dangerous, her hair wild and somehow statically charged, her big hands like claws in a gesture that might evoke threat and fear, her large feet naked, one foot chained to the wall. At second sight, however, she does not appear to be caged like an animal, isolated and neglected and excluded. She is well-dressed, one of her shoes lying in front of her on the floor. The room is part of a rather fine building according to its architecture. There are decorated arches on the rear wall, tiles on the floor and two grated windows. Two pots or jugs on the floor indicate that the inhabitant is supplied with food and drink and that wastes are carried away. A person kneeling and praying on the right side embodies some kind of care for the young woman. The image forms the upper part of the votive panel. Beneath there is a text in German language which we have to read in order to understand the depicted scene. According to this narration a mentally disturbed girl was miraculously cured after her brother had prayed to the Holy Virgin. It may be translated that Margret, daughter of Hanns Eyselei of Mundraching, was rather deranged for four years. Her brother promised Our Lady to have a mass sung. Instantly Margret regained her good sense thanks to the intervention of the Mother of Grace. The votive panel thus illustrates different aspects of dealing with mentally disturbed family members. It shows how custody was organized as a measure of protecting themselves and others in case that they got out of their mind. And it gives evidence of material and spiritual care for them. This complex message of custody, protection and care in the frame of religious propaganda is not at all expressed in the modern title «Raving mad female in chains». Such a label evokes gruesome notions without considering the original intention and the complex composition of the work. It certainly corroborates anachronistic and simplistic ideas and is thus misleading.

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[23] SIGNORI, 2007: 68, fig. 4; NOLTE & KINZLER, 2012a: 41.

Fig. 12. Die Mirakelbilder der Hl. Kapelle in Altötting, ed. by Administration der Hl. Kapelle, Altötting 2007, p. 29 (Mirakeltafel II, n.º 12)

CONCLUSIONS

This cited example of problematic labelling leads back to the question how to communicate a more differentiated, less stereotyped history of dis/ability to the public. Summing up this paper I would like to stress the ideal or better: the necessity that first of all museums and cultural institutions transfer knowledge in participatory ways and in fully accessible surroundings.[24] Thanks to the United Nations Convention on the Rights of Persons with Disabilities the agenda of participation gets a lot of attention, but it takes time, money and innovative ideas to effect concrete changes. Fortunately, consciousness is rising that access for all means more than building ramps. With regard to the premodern era I tried to underline that visual representations and imageries must be accompanied by elaborate analyses based on current research. Sufficient explanation provided, audiences will be inspired to discuss differences, similarities and continuities of past and present attitudes. Further, unknown material from collections, archives and libraries which often uncovers unfamiliar aspects of historical dis/ability should be

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[24] MARTINS, 2016; TOUCHDOWN, 2016; TELFER *et al.*, 2011; FLIEGER & SCHÖNWIESE, 2007; DEUTSCHES HISTORISCHES MUSEUM, 2017-2018.

added to the canon of exhibits. Thanks to ongoing interdisciplinary research, hidden treasures are being found all the time. Finally, we should do without titles that favour ahistorical categorization. In my opinion, the misleading labeling of visual representations in museums and cultural institutions, in their catalogues and other publications perpetuates stereotypes concerning dis/ability. Many modern titles of premodern works of art refer in a one-sided and anachronistic way to bodily, sensorial, mental and psychic characteristics which from a modern medical perspective are called disabilities. If further information and contextualization is missing, this labeling prevents audiences from getting acquainted with more complex histories. Why, for instance, is Velázquez' portrait of an anonymous man called «Buffoon with Books» (Hofnarr mit Buch auf den Knien, Fig. 13) in the Prado and accordingly in an exhibition and catalogue of 2016? Whereas it can be assumed that this man was a member of the Spanish court, his name and his function have never been identified. Being of short stature, he may or may not have been a buffoon. In contrast to former notions many «dwarfs» at courts did not serve as «natural fools» or professional jesters[25]. So why not simply present this man as a court member? Fortunately, in this catalogue the portrait is accompanied by a detailed analysis. And, even better, without any categorization the man's face has been put on the cover of the catalogue (figure 14). Thus, finally he just appears as a dignified individual inviting us to exchange glances with him.

Fig. 13. Spaniens goldene
Zeit/El Siglo de Oro
Die Ära Velásquez in Malerei und Skulptur
Catalogue of an exhibition in 2016
(Gemäldegalerie. Staatliche Museum
zu Berlin
Kunsthalle München), Berlin 2016,
p. 189, figure 59. (I did not have
access to the English version of
the catalogue)

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[25] SEEMANN, 2018.

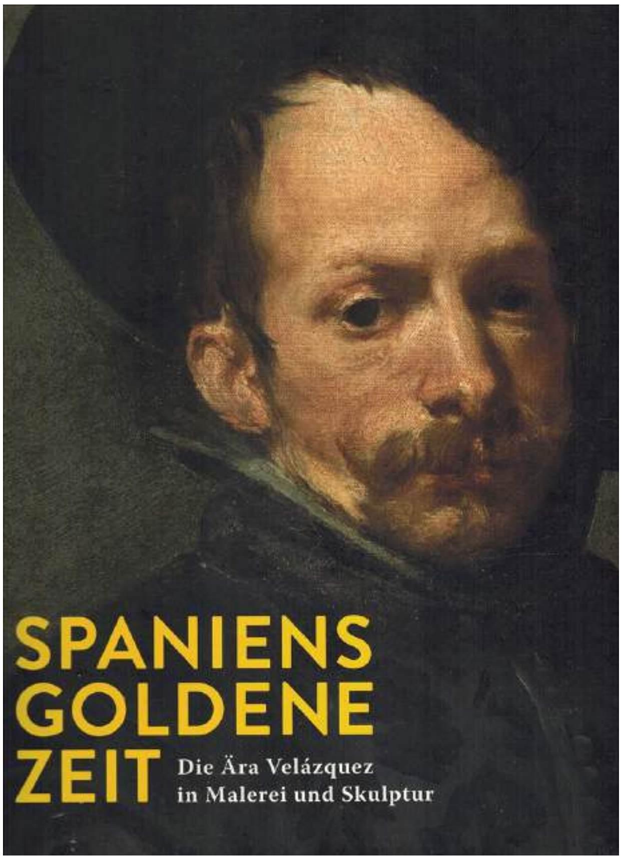

Fig. 14. Spaniens goldene Zeit/El Siglo de Oro
Die Ära Velásquez in Malerei und Skulptur
Catalogue of an exhibition in 2016
(Gemäldegalerie. Staatliche Museum zu Berlin
Kunsthalle München), Berlin 2016, cover

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[No title]
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MICROAGGRESSIONS REPRESENTED IN IDENTITY AND IMAGINARY OF DISABILITY IN MUSEUMS

HÉLIA FILIPE SARAIVA*

I explore the articulation between representations, identities and disability through the juxtaposition of present contributions in the research carried out, in the field of my doctoral project, besides alluding to the qualitative contributions led by the scholars who participated in the international meeting *Representing Disability in Museums. Imaginary and Identities*. How can we correlate premises of complex issues and after the discovery how can we equate them in a transversely perceptible way? The breadth of its dimensions is intrinsically linked to the transition from the biomedical model to social model as well as to lifting the obscuring veil of sociocultural oppression experienced by people with disabilities and emphasize their pertinent dignity and diversity. I articulate them with the concept of microaggression, in the sense that evidencing the targets of the microaggressors should allow us to uncover and experience their spatial identity, therefore we can become aware of the influential tension present in the salience of the reductive and limiting representational elements; on the grounds that they are based on attitudinal, behavioural and identity constructs, resulting from processes of adaptation to guidelines instilled in a society characterized by capacitating and normalizing stereotypes[1], which tend to compress and to stereotype the frailty of the human condition. This statement is particularly noticeable when we report it to the cognitive

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[1] DAVIS, 1995.

field of representative standardizations that tend to be portrayed as metonymic images. Its imagetic metonymical nature is not very flexible, and often shows aggressiveness, particularly when interpreters accommodated to the above-mentioned standardizations are faced with diverse, unusual and unique perceptions. This assertion is based on the fact that their combat provides because, according to Helgeson, when people disclose counterstereotypical conducts, they could be disciplined by antistereotyped behaviour and are dissuaded to «publicizing counterstereotypical behaviour, and by undermining performance in counterstereotypical domains»[2]. The perplexities raised by his statement lead me to some questions aroused by Hannah Arendt in the work entitled «The Human Condition», enunciated in the assertion «what we are doing, or think we are doing, in the world we have to live in»[3]. Its reflexive appeal is crucial, although the rejoinder is neither simplistic nor linear, I venture to say that some proposals were debated during the international meeting *Representing Disability in Museums, Imaginary and Identities* in relation to the link between representation, disability and the imaginaries. The assumption of the intense complexity, evident in the (a)representativeness process of interpretation of the incomplete interstices, that is to say, in the gaps of the blank spaces in the interpretative challenges. I point out my agreement with this logic by equating the representation of the work(s) exposed in institutions such as museums with the declaration that the text(s) is (are) lazy mechanism(s)[4], whose non-linear understanding obeys the appreciation made by the receiver, because the change of a model with a prescriptive prism add a change in the above mentioned models leading us to understand that «the text wants to leave the reader the interpretative initiative, although it is interpreted with a sufficient margin of univocity»[5] embedded in the fissures, intermittences and (in) visible scars present in the articulation between representativeness and imaginary. The intricate composition of the appealing interpretative performance, notorious both in the arendtian formulation and in the equian perspective, safeguarding the due differences between the two authors, seeks to emphasize the diversity of human life, manifested in the tacit acceptance of the translatable challenge in a demeaning work mentioned in the variously framed functionalities of the persecuted and «haunted» individual by the label of vulnerability and disability. For this reason, we should scan the vein attached to the challenge posed by the philosopher and the semiologist and, simultaneously, decipher the «blank spaces» in the paradoxical visibility overshadowed by the representations of people with disabilities. The above mentioned papers highlights the pregnant analysis, ironically expressed by Eco's «sloth», wich requires and stimulates competencies that ables us to face representations as pages, empty screens, whose cracks and crevices

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[2] HELGESON, 2015: 92.

[3] ARENDT, 1998: 322.

[4] ECO, 1998.

[5] ECO, 1998: 37. Our Translation.

disclose discriminations, microaggressions and persecutions both verbal and non-verbal that are still inflicted in the people in question. We admit that the delicacy of this subject induces some perplexity because the link between representation, identity and the discovery of seminal imaginaries in the so called «white spaces» can cause doubts. Nevertheless, its elucidation is intelligible, provided there is the notion that its analysis does not hinder access to interpretative decoding nor the rights that involve the enjoyment of functional diversity and trust, under penalty of being voted to live a damaging skepticism and even failure of self-esteem derived from monolithism, lack of personal autonomy and the need for knowledge, as Axel Honneth stated:

> *As in the case of love, the child, through the prolonged experience of maternal dedication, gains the confidence to make his needs known without hindrance, as the adult individual, by the experience of legal recognition, conquers the possibility of conceiving his act as an exteriorization, respected by all, of the own autonomy*[6].

The consequences of the circumstances arising from the aluded representative sectarianism are reflected in the perplexities felt by the excluded person, because they sustain interpellations from the fence by participating in the verbalization of their will, as well as in the consequent loss of social protection and dignity. The implications of this are important due to the existence of microaggressions felt indelibly in the individuals concerned and liable to stigmatize the imagery created around them, since they are susceptible of being entrenched, as we shall see, on the derogation effect. I now mention that microaggressions are defined as «brief and commonplace daily verbal, behavioural and environmental indignities»[7] which may occur intentionally. Although they are often carried out unintentionally, perpetrated in an automatic manner, leaving both aggressors and assaulted uncertain about the nature of the stereotypical or prejudiced nature of the acts performed. The ballast of the above-mentioned uncertainty influences decisively the derogations in the sense that they produce resonant psychological impacts, both in the people who utter them as in the receivers. Accordingly, the provisions tend to generate feelings of humiliation and denigration of a person or group; unleashing intense fragilizations and prostrations in the injured, causing long-term serious health implications for targets and creating stereotypes that are cramped and liable to trigger animosity because — according to the following perspective — the enunciation of insults tends to cause insurgents to overreach, to transpose a line which «opens up possibilities for addressing discrimination and prejudice»[8]. This disruptive communication leads to the above mentioned derogations becoming harmful when referring marginalized groups

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[6] HONNETH, 1997: 145. Our translation.

[7] SUE *et al*., 2007: 273.

[8] CHARMAZ *et al*., 2018: 242.

as well as minorities excluded by society due to what I call exonormality. In other words, some of the more distressing provisions with a transmissibility effect, according to the oil stain effect, involve ableist, gender, racial and sexual stereotypes. However, I emphasize that these degrading expressions do not appear to contain harmful implications, nor do they have an aggressive character similar to that of an aggression involving injuries resulting from bodily offenses. In this regard, I remember one of the images exhibited by Professor Cordula Nolte during the ministry of her communication entitled «Down and Out and Disabled in the Middle Ages? Medieval Attitudes, Modern Assumptions and Public Dis/ability History» when was shown a reproduction of a 16th century painting: «Bildnis eines behinderten Mannes». Respect and safeguard the right of the scholar to choose the said engraving, since it is illustrative of the perspective explained in her paper. Nevertheless, I would like to underline the microaggressive tendencies in the image mainly by the psychological affectation of the identity representation of people with disabilities, and to influence, in a non-flattery way, the look of the visitors on the cabinet de curiosités. The dyadic reading of this intention is very striking in the ambiguous nature of the microaggression, expository in the human being portrayed, due to the binomial assumption present in the mentioned portrait. By one hand, affection is transmitted in the way the man was dressed with a red cape and an apparently dignifying collar, but on the other hand, we cannot deny a less respectful nuance, given the exposure of his vulnerable and naked body, which can be understood as a way of disdaining and causing discomfort due to the eventual mockery and the alleged compliments that can be pronounced when the painting is observed. The effects associated with this type of images with an ambiguously derogatory feature leave a path of hurt and invisible wounds much deeper than a glance reveals, given the inexistence of the pictorial insertion of traumatisms resulting from physical blows or indelible injuries, such as prostheses and facilitators that inhibit bipedalism, by detracting the belief that oral or pictorial communication has no secondary effects, nor consequences embodied in the derogations. However, they produce several symptomatic impacts such as low self-esteem, ostracism, and resistance in contributing to cohesion and inclusion. The role that fits us as scholars, researchers and citizens interested in this field of study can be understood in the light of the Barthesian distinction between text of pleasure, «he who contends, fills, gives euphoria; he who comes from culture, who does not break with it, is bound up with a comfortable practice of reading»[9], and text of fruition «he who puts in a state of loss, until a certain annoyance), makes the historical, cultural, psychological bases of the reader, the consistency of their tastes, their values and their memories waver, makes their relationship with language in crisis»[10]. The admission of an uninterpreted discom-

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[9] BARTHES, 1987: 21. Our translation.

[10] BARTHES, 1987: 21-22. Our translation.

fort begins on the one hand, through the constant appeal to the process of representation when, *ad exemplum*, traditional norms and expectations are subverted, in the sense of the profound control exercised over the representation of disability identities. In this sense, the interpreter, as well as the visitor, of a museum is not warned for the conjunctural character, but is summoned to emerge in an imaginary based on the exposition of «factual sloths», that is to say, a deficient exposition of the individuals about whom we have pronounced. It should be remembered that these words, apart from being instituted as reflective exercises, are inextricably inscribed as marks of the work implicit in an unprecedented process of representation: perversion of the serious layer of normality, diagonally crossed by the exposition/denunciation of addictive and selective features, presents in the research carried out by this sphere's professionals. Indeed, the discourse designed to make this field knowable emerge inculcated by an anachronistic homogeneity, perhaps anodyne in other situations, but here it is revisited with an antithetical intention to the canon's consecration and the monocular version that a large number of representations impute to the surroundings of the people with disability.

The qualitative contribution of the presentations presented by the speakers were fundamentally aimed, in my view, to restore the injustice of the meager representation, both at the imaginary level and at the level of identity, which has been consecrated to their existence. We have, therefore, been in contact with the viewing, the tactility and the nominalization of high-quality lectures, as well as works related to the themes in question, which in some way give visibility and contribute to further research in this field, since filling spaces through theories concerning the biomedical model echo are being deprecated, as we move towards the social model, preventing the imaginary of the people mentioned from being viewed in a non-evolutionary way, but as part of a holistic and inclusive construct. Therefore, we can erect, as I hope, a critical process that is not anchored in anachronistic, frivolous, stigmatizing or excluded representations.

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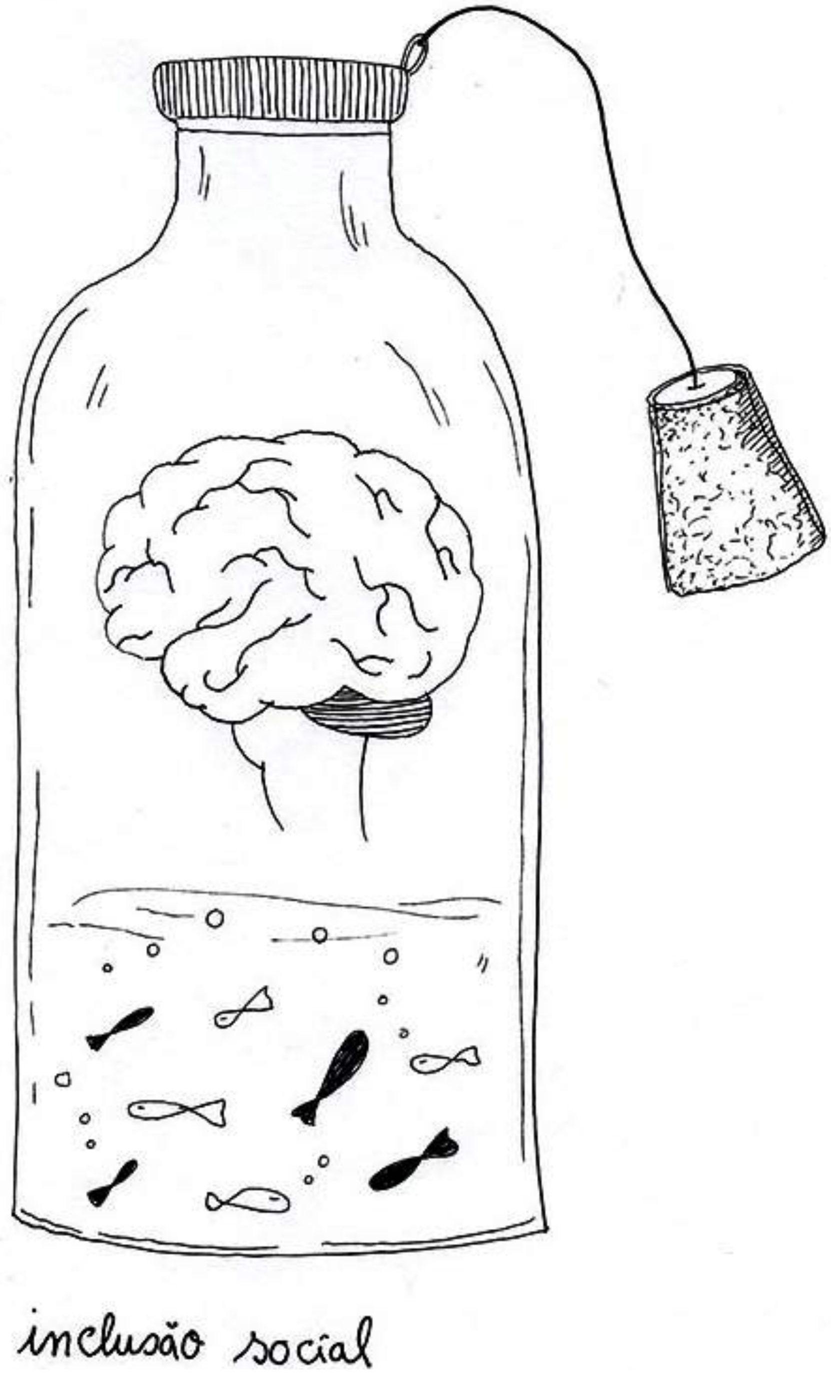
II

THE HISTORICAL AND SOCIAL CONTEXT OF DISABILITY



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FRAMING DISABILITY IN PORTUGAL: HISTORICAL PROCESSES AND HEGEMONIC NARRATIVES[*]

FERNANDO FONTES[**]

Abstract: The perspective used to understand disability impinges decisively on the rights and lives of disabled people.

The way disability is understood results from socially accepted and reproduced conceptions, which articulate with social and cultural dynamics that, in different historical and geographic contexts, mark the lives of those people categorized as disabled. Presenting a singular definition of disability is thus impossible. There are definitions that, by virtue of the hegemonic character have imposed themselves in different latitudes, resignifying or disputing the existing grammars. This multiplicity of grammars does not correspond to an equivalent range of life chances for disabled people. Throughout the centuries, disability has been reduced to the abnormalities and impairments of the body, and difference transformed into a factor of exclusion.

In each historical moment, it is, thus, crucial to identify the hegemonic narratives of disability and to reflect on their impact on disabled people's lives and life chances.

Keywords: Disability, Portugal, conceptions, impacts.

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INTRODUCTION

The perspective used to understand disability decisively influences the rights of disabled people and, consequently, disabled people's lives.

Based on a particular culture and ideology, the way disability is understood results from socially accepted and reproduced conceptions[1], which articulate the social and cultural dynamics that in the different historical and geographic contexts mark the lives of people cataloged as disabled. Presenting a singular definition of disability is, thus, impossible. There are, however, definitions that, by virtue of the hegemonic character of the modern western biomedical paradigm that sustains them or incites them, have imposed themselves in different latitudes, resignifying and disputing already existing grammars. This multiplicity of grammars does not have, however, an equivalent range of life chances for disabled people. Throughout the centuries, disability has been reduced to the abnormalities and incapacities of the body, and people defined as disabled have often been disregarded, marginalized, silenced, built as passive and dependent individuals, their difference transformed into a factor of exclusion and their lives have been disproportionately constrained by phenomena of poverty and social exclusion[2].

In this chapter I will analyze the processes that shaped disability narratives in Portugal and their impacts on the life chances and living circumstances of Portuguese disabled people. The first section will synthetize how the emergence of disability as a category has been theorized. In the second section, will draw a genealogy of disability hegemonic narratives in Portugal.

THEORIZING THE DISABILITY CATEGORY

The understanding of disability as a social construction is relatively new within social sciences. To interpret disability as a form of social oppression is even more recent. For centuries, disability was reduced to the abnormalities and inabilities of the body[3]. Disability remained individualised, medicalised and unpoliticised. This is not to say that there was no sociological interest in the study of disability, on the contrary, sociological studies in this area can be traced back to the early 1950s. In fact, in the field of sociology, the lives of disabled people have been scrutinised at least since the 1950s as a result of the works of Parsons[4] and Goffman[5]. The first, focusing on the social system, provided an analysis of illness as a social, as much as a biological category and suggested the idea of a «sick role» as a result of medical practice. The second, in contrast, focused on the

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[1] OLIVER, 1990.

[2] DAVIS, 1995; GARLAND-THOMSON, 1996; GARLAND-THOMSON, 1997; WINZER, 1997; BARNES, 1997; BARNES *et al.*, 2000.

[3] DAVIS, 1995; GARLAND-THOMSON, 1996; GARLAND-THOMSON, 1997; WINZER, 1997; BARNES, 1997; BARNES, 2000a; STIKER, 1999; BARNES *et al.*, 2000.

[4] PARSONS, 1951; PARSONS, 1958.

[5] GOFFMAN, 1963; GOFFMAN, 1987.

everyday life of the individual and introduced the notion of stigma and the management of a «spoiled identity». The problem with these studies was, however, that they were:

> *rooted in conventional wisdom; namely, that accredited impairment,* […] *is the primary cause of «disability» and therefore of the difficulties: economic, political and cultural, encountered by people labelled «disabled»*[6].

With the development of the Disabled People's Movement in the 1970s[7], a new era for disabled people began.

In the North American context, drawing upon American functionalism and deviance theory, important works emerged linking the social construction of disability with the evolution of society. According to Barnes[8], the works of Stone[9], Wolfensberger[10] and Albrecht[11] epitomize this tradition.

Stone, in her book *The Disabled State*[12], outlines the idea of disability as an administrative category constructed by the state to accommodate the needs of those who cannot work. Since labour is the core system for the production and distribution of goods, a second system, based on the perception of needs, where access is conditioned by medical and political criteria, was conceived to accommodate those who cannot, or do not want to, work[13]. For Stone, the construction of disability is thus the result of the concentration of power on medical professionals and of the need to reduce access to public provision.

Wolfensberger[14], extending Stone's argument, states that this construction is a latent function of the acceleration, from 1945 onwards, of the human service industries. Accordingly, the existence of large numbers of dependent and non-valorised people is indispensable to the existence of these industries and to the security of its jobs[15]. Albrecht goes even further stating:

> *In our society, social problems have become the objects of massive human services that drive our economic system. These businesses identify social problems embedded in individuals and their social relationships, reify them, and make them and their solutions commodities to be bought and sold in the marketplace*[16].

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[6] BARNES, 2003: 4.

[7] CAMPBELL & OLIVER, 1996; BERESFORD & HOLDEN, 2000; THOMAS, 2004.

[8] BARNES, 2000b.

[9] STONE, 1984.

[10] WOLFENSBERGER, 1989.

[11] ALBRECHT, 1992.

[12] STONE, 1984.

[13] STONE, 1984.

[14] WOLFENSBERGER, 1989.

[15] BARNES, 1997.

[16] ALBRECHT, 1992: 27.

Hence, current societies first create specific types of illnesses, impairments and disabilities and then commodify them through their transformation into trade opportunities and the creation of a «disability business» and a «rehabilitation industry»[17].

In the European context, and deeply influenced by Marxist and materialist perspectives, the British tradition presents a more radical and emancipatory approach. Within this tradition I would stress the importance of four authors: Hunt, Finkelstein, Oliver and Barnes. Hunt[18] was one of the first to focus on social rather than biological factors surrounding disability. Through considering several personal accounts of disabled people he stresses that:

> *the problem of disability lies not only in the impairment of function and its effects on us individually, but also, more importantly, in the area of our relationship with «normal» people*[19].

The work of Finkelstein[20] represents the first historical materialist account of disability. Here, Finkelstein conceives disability as a social problem connected to the evolution of the dominant modes of production over time. He states that disability was produced by, and is a direct result of, the development of Western industrial societies. Based on this materialist perspective, Finkelstein pinpoints three stages in the history of disability. The first corresponds to a pre-industrial stage, characterised by the participation of disabled people in the economic life of their communities. The second phase, emerging with industrial capitalism, marked the beginning of the exclusion of disabled people from the labour market due to their alleged inability to adapt to the needs and pace of the new production machinery. This period witnessed the beginning of the segregation of disabled people into institutions outside of society. The third phase corresponds to a post-industrial society where technological development is expected to produce a social and economic revolution that will free disabled people and contribute to their inclusion in society.

In 1990, Oliver provided a more insightful understanding of the transition to a capitalist system and its implications for disabled people. Oliver extended Finkelstein's argument about the changes in the modes of production by taking into account the modes of thought and the relation between both. For Oliver, as with Finkelstein, the restriction of activity imposed on people with impairments, i.e. disability, emerged with industrial capitalism. As Oliver argued, within the capitalist system, disability took a new

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[17] ALBRECHT, 1992: 28.

[18] HUNT, 1966.

[19] HUNT, 1966: 146.

[20] FINKELSTEIN, 1980.

specific form, that of tragedy[21]. Disability is thus an ideological construction of capitalism. Ideology, understood as «a set of values or beliefs underpinning social practices»[22], is the key to understanding the social creation of disability and the economic and social disadvantages associated with impairment. Hence it was the combination of this central individualistic ideology, with the peripheral ideologies of rehabilitation, medicalisation, and personal tragedy, which led to the medical and individual perspectives on disability and thus helped to push disabled people towards segregation.

Finally, the work of Barnes[23] widened the perspectives conceived by the previous authors by tracing the oppression of disabled people back to the foundations of Western society. For Barnes, the nineteenth century, with the legacy from Enlightenment, utilitarian philosophy and belief in progress, simply provided new ground for the crystallization of old myths and practices. Nonetheless, it was after the nineteenth century that current hegemonic conceptions of disability were forged: namely, the individualization and medicalisation of bodies and minds, and the segregation of disabled people from their communities[24].

These approaches are representative of two different foci within the social model, or two social models: a materialist and an idealist social model[25]. The materialist position stresses the creation of disability by the capitalist mode of production[26] and the idealist position understands disability as being culturally constructed on a daily basis by religion and traditional beliefs[27]. Both perspectives impact directly on disability research:

> *Models which stress the social creation of disability in material terms will engender research which focuses on structural or institutional barriers; models which stress the social construction of disability in cultural terms will engender research which focuses on disabling attitudes and representations*[28].

During the 1990s, there emerged what I would call a second generation of disability writers[29]. These new perspectives (which include the previous criticism of the social model of disability), centred on the role played by culture in disability, on the need to include personal experience in the disability debate and the need to acknowledge not

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[21] OLIVER, 1990.

[22] OLIVER: 1990: 43.

[23] BARNES, 1991; BARNES, 1997.

[24] BARNES, 1997: 18.

[25] PRIESTLEY, 1998; FINKELSTEIN, 2001; SHELDON, 2005.

[26] FINKELSTEIN, 1980; OLIVER, 1990.

[27] BARNES, 1991; BARNES, 1997; BARNES & MERCER, 2003.

[28] PRIESTLEY, 1998: 76.

[29] MORRIS, 1991; MORRIS, 1996; STUART, 1994; CROW, 1996; SHAKESPEARE, 1997; CORKER & FRENCH, 1999.

only disability but also impairment in disability research. These questions, the authors claim, had been forgotten by the first generation of disability theorists.

The 1990s also witnessed the emergence of more eclectic perspectives[30] emphasising the need to combine both visions. The main idea here was the need to understand the individual experience within a structural analysis of the disadvantages and oppression faced by disabled people in a disabling society. These views are particularly important in my research since I believe that the social model is not obsolete and I doubt it ever will be, although I also recognise the need to consider the diversity that exists within commonality and the importance of culture in shaping disability.

In the 1990s there was also a set of new perspectives deriving from a post-modernist and post-structuralist background. These new perspectives questioned the earlier materialist grand theorising proposed by scholars such as Finkelstein[31], Oliver[32] and Barnes[33] and, drawing on the works of the French philosophers Jacques Derrida and Michel Foucault, suggested a new approach which rejected modern binary oppositions, focusing instead on culture, language and discourse[34]. This post-modern thinking can be found in the works of disability scholars such as Davis[35] and his exploration of cultural responses to impairment across time; Shakespeare[36] and his constructionist analysis of the body, impairment and disability; and Garland-Thomson[37], with her study of the cultural and historical construction of the «physically disabled body» in American society and literature.

Again, notwithstanding the significance of such analyses for deconstructing established conceptions of impairment and of the body, I am persuaded by Barnes and Mercer when they suggest that these proposals:

> *sidestep the material reality of impairment and provide little or no insight into how the problem of disability might be resolved in terms of policy or politics*[38].

Therefore, as they have been presented so far, post-modernist and post-structuralist theories have little pragmatic use in terms of disability activism which aims to foster the citizenship status of disabled people.

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[30] SHAKESPEARE & WATSON, 1998; PRIESTLEY, 1998; THOMAS, 1999.

[31] FINKELSTEIN, 1980.

[32] OLIVER, 1990.

[33] BARNES, 1991; BARNES,1997.

[34] BARNES & MERCER, 2010.

[35] DAVIS, 1995.

[36] SHAKESPEARE, 2006; SHAKESPEARE & WATSON, 2002.

[37] GARLAND-THOMSON, 1996; GARLAND-THOMSON, 1997.

[38] BARNES & MERCER, 2010: 95.

HEGEMONIC PROCESSES AND NARRATIVES FRAMING DISABILITY IN PORTUGAL

Disabled people have been one of the most discriminated, most excluded and most oppressed social groups. Several studies, at the international level, have demonstrated the link between poverty and disability resulting from this discrimination[39] or even the existence of a vicious circle between disability and poverty, in which poverty produces disability and disability is transformed into poverty[40]. Emphasizing this link between disability and economic deprivation and social exclusion does not mean, however, that the former is the cause and the latter is the result. The situations of deprivation and social exclusion experienced by disabled people are not the result of their impairments, but rather the result of the ways these impairments are socially and culturally constructed. Disability should, thus, be understood as a cultural construct or ideology. In western societies this construct, throughout time, has consubstantiated itself in a phenomenon of oppression and social exclusion of those people that are understood as disabled[41].

Unfortunately this is not, however, a past reality, nor does it originate in a recent past. Exclusion, oppression and, at certain historical periods, genocide constitute a fact in the history of disabled people. From classical antiquity, with the exposure of children born with any physical deformity, to the present day, with the gazing of disabled people by the Nazis and the recent massacres of disabled people in Japan and in the USA, perpetrated by criminals inside two institutional organizations for disabled people, many are the examples of this reality experienced by disabled people which reveal the prejudice disabled people face in their daily lives.

Historically, impairment has been used as a source of oppression for those identified as disabled[42]. Social model materialists[43] have suggested that the roots of that oppression reside in the establishment of the capitalist mode of production. Conversely, despite not denying this assumption, social model idealists[44] argue that disability is culturally constructed on a daily basis by religion and traditional beliefs, and contend that its origins may be traced back to Greek and Roman times.

These ambiguities have permeated, though, the politics of disability across time and they are still present in current cultures.

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[39] BERESFORD, 1996; COLERIDGE, 1993; TURMUSANI, 2002; ZAIDI & BURCHARDT, 2002.

[40] STONE, 2001.

[41] UPIAS, 1976.

[42] STIKER, 1999.

[43] FINKELSTEIN, 1980; OLIVER, 1990; GLEESON, 1997.

[44] MORRIS, 1991; SHAKESPEARE, 1997; GARLAND, 1995; GARLAND-THOMSON, 1996; GARLAND-THOMSON,1997.

The analysis of the Portuguese case defies, however, social materialist arguments such as the ones put through by Finkelstein[45] and Oliver[46]. In fact, Portugal did not experience industrialism on the same scale as the UK, where industrial production rapidly presented an alternative to agricultural employment. In Portugal that did not happen until the 1960s[47]. To illustrate this difference, in 1911, for example, 58% of the Portuguese economically active population worked in agriculture and only 25% worked in industry and 17% worked in services[48]. Nevertheless, in Portugal, as in the UK, disabled people's oppression goes back in time, I argue, therefore in line with social model idealists that it is not in industrialism or in capitalism that the roots of this oppression lie, but in older cultural conceptions, which have been sublimated, in the British case, by industrialism and capitalism and, in the Portuguese case, by the state's attitude.

Notwithstanding the chosen approach, the important point to raise here is that in both cases disabled people have been denied citizenship rights and their lives have carried the weight of stigma and oppression across time. It is my argument that in the case of Portugal, due to the strong Catholic social background, an extra factor played a key role in the development of attitudes towards disability and therefore curtailed the construction of a citizenship project for disabled people — Judeo-Christian morality. Plus, I also suggest that the Portuguese state's attitude to disability issues has been characterized by detachment, i.e. the state has maintained a secondary role here, only acting when pressured by civil society, reinforcing traditional attitudes towards disability and disabled people and pervasive disability narratives. Plus, the long duration of the Portuguese dictatorship (1933-1974) and the late development of the Portuguese welfare state and its consequent failures in welfare provision to its population, prevented the politicization of most Portuguese organisations of disabled people and the questioning of oppressive hegemonic disability narratives.

As happened in Greek and Roman cultures, Judeo-Christian morality has been permeated with conflicting images of disability and disabled people. Again, the attitude of the Catholic Church towards disabled people was ambivalent. On one hand, it fostered the charitable status of disabled people, developing the spirit of Christian charity:

> *Then Jesus said to his host,* […] *when you give a banquet, invite the poor, the crippled, the lame, the blind, and you will be blessed*[49].

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[45] FINKELSTEIN, 1980.

[46] OLIVER, 1990.

[47] BARRETO, 2003.

[48] PINTO, 2003: 2.

[49] LUKE 14:12-14.

On the other, it maintained a latent connection between disability, sin, evil, witchcraft, impurity and God's punishment[50]. In Judeo-Christian morality, disability emerges mainly as a question of spiritual and ethical conduct[51]. While it was the principle of Christian charity, developed in the New Testament, which mostly guided the approach of the Catholic Church, and molded society's attitudes towards disabled people in the following centuries, this ambivalence was maintained across time, surfacing at different moments to threaten, and even suspend, disabled people's citizenship rights. An example of this is the persecution of people with some type of illness and impairment by the Inquisition (established in 1183)[52]. The pervasiveness of this attitude towards disability is testified by its presence in the minds of more progressive thinkers of the time, such as Martin Luther (1483-1546), who professed that children with mental impairments were a mass of flesh without soul and were born of the devil, and who suggested that they should be drowned in the closest river[53].

Such ambivalence is also traceable in the Church's attitude towards different impairments. The majority of the scarce institutions created by the Catholic Church were devoted to blindness and to acquired conditions. In medieval times, Oswin[54] claims that:

> *Other groups of disabled children did not evoke the same interest and sympathy. They were called «cripples» and depicted as ugly and evil in art and literature*[55].

The impact of this disablist attitude also stemmed from the Catholic monopoly on service provision to disabled people over the centuries. In Portugal, assistance to disabled people was only partly secularised in 1835, with the establishment of the General Board for Beneficence[56]. Before that, disabled people could only rely on their families and Church support[57]. Under such conditions, the dominant disabling attitude could easily be found beyond the religious sphere[58].

In fact, since medieval times the history of assistance to disabled people has been closely connected with the political and religious history of Europe and of the Middle-East. Most charitable organisations addressing disability had a religious background and were designed to offer support to men impaired in the crusades, especially blind

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[50] LEVITICUS 21:16-23; DEUTERONOMY 28:28; WINZER, 1997; BARNES, 1997; BARNES, 2000a; BARNES *et al.*, 2000.

[51] STIKER, 1999.

[52] STIKER, 1999.

[53] WINZER, 1997; BARNES, 1992; BARNES, 1997; BARNES, 2000a.

[54] OSWIN, 1998.

[55] OSWIN, 1998: 30.

[56] MAIA, 1985; LOPES, 1994.

[57] MAIA, 1985; FERREIRA, 1990.

[58] WINZER, 1997.

men[59]. In Portugal, despite the absence of such asylums, there is evidence of charities connected to the Catholic Church offering assistance to disabled people, even before Portugal became an independent kingdom in 1143[60]. These ancient charities were connected to monasteries, especially to those close to pilgrimage routes, and assumed the forms of «brotherhoods», «confraternities», «shelters», «hospitals», «leprosy houses» and «shops»[61]. As happened in other countries[62], these institutions provided assistance to those in need under the same roof independent of their condition[63].

According to Maia[64], by the end of the fifteenth century most charitable institutions in Portugal were inefficient, their actions were hampered by clashes between religious orders and there was a surfeit of small charities fighting for scarce resources. The combination of factors, which included social and demographic changes resulting from maritime expansion and new economic strategies (resulting in greater numbers of orphans, widows, people with impairments and with ill health and street beggars) and the general tendency in Europe towards the centralisation of political power[65], led to a reform of public assistance in Portugal[66]. This reform, initiated by the state in the second half of the fifteenth century, disbanded old charities and incorporated others into a new type of charity — the *Misericórdias* or «Holy Saint Houses of Mercy». The first Misericórdia was created in 1498 in Lisbon[67] and they rapidly spread all over the country and its colonies[68]. From the fifteenth century onwards the *Misericórdias* were made responsible for assisting most of the population in need in Portugal. This included having a monopoly over the administration of numerous Portuguese hospitals, which only ceased in 1974 when the state took direct control.

What was new about these charities in relation to impairment was the introduction of specific services for disabled people within the community. These were home-based services, for those with incurable diseases (called the «visited» or the «listed cripple»)[69], what Barnes[70], in the British case, refers to as «domestic relief». These services provided by the *Misericórdias*, included free medicine, clothes, shelter, as well as offering some financial support too[71]. Disabled people continued, however, to be invisible within the

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[59] WINZER, 1997; BARASCH, 2001.

[60] FERREIRA, 1990.

[61] FERREIRA, 1990.

[62] SCULL, 1984.

[63] FERREIRA, 1990.

[64] MAIA, 1985.

[65] SCULL, 1984; MATTOSO, 1993; BARNES, 2000a.

[66] MAIA, 1985.

[67] FREIRE, 1995.

[68] ABREU, 2001.

[69] LOPES, 1994.

[70] BARNES, 1990.

[71] LOPES, 1994.

broad category of those in need of assistance. As with the British case, they formed an indistinguishable group of people in need[72].

In Portugal, this new type of charity was, however, run and organised by the Catholic Church. In fact, it seems that the Portuguese monarchs were reluctant to intervene directly in public assistance and opted for the maintenance of religious dominance, rather than assuming direct responsibility.

From the eighteenth century onwards, as a result of an increase in vagrancy after the Lisbon earthquake (1755) there was a change in the Portuguese state's political approach to the population in need, visible mainly in the introduction of policy measures to separate the «deserving» from the «undeserving» poor (i.e. the legitimate beggars from the «non-impaired» unwilling to work)[73]. A decree published in 1755 established that vagrants considered able to work were to be sentenced to forced labour and those considered «invalid» to work (namely the «blind»), the «real» poor, were licensed to go begging in an «orderly and virtuous way»[74]. In addition, in 1780 Casa Pia, a residential institution, was created in Lisbon, which aimed to collect and recuperate, vagrants and beggars through labour, as well as providing education to orphans[75]. The implementation of these measures targeting vagrants and beggars might be read in the light of the need to control the deviant behaviour of the time[76].

It is possible to read these initiatives as the first step towards public assistance run by the state[77], in a similar vein to the public policies that created the workhouses and implemented the Poor Laws in the UK and the large institutions in France for the confinement of people with impairments[78]. I argue, however, that the initiatives taken in Portugal diverge considerably, not only in scale, but also in philosophy, from those undertaken in the UK and in France. First, the tendency to segregate disabled people into residential institutions in Portugal only began in the mid-nineteenth century and never reached a dimension similar to those other countries. Second, in contrast to the UK and France, where such institutions were meant to segregate disabled people from the general population, in Portugal, again, up until the second half of the nineteenth century these initiatives were mainly meant to control vagrancy in general and did not target people with impairments specifically.

In the French case, the emergence of specialised hospitals, such as the Hôpital Général and the Hôtel des Invalides created in Paris, dating to 1656 and 1674 respectively,

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[72] STONE; 1984; BARNES, 1990; BARNES, 2000b.

[73] LOPES, 1994.

[74] LOPES, 1994.

[75] LOPES, 1994.

[76] MAIA, 1997; LOPES, 1994.

[77] LOPES, 1994.

[78] STIKER, 1999.

marked the beginning of the segregation and confinement of disabled people[79]. In the British case, the segregation seems to stem from the changes introduced by the industrial revolution[80]. Due to the inflexibility of the industrial mode of production towards individual specificities and difference, disabled people were rendered inadequate to the production process[81]. These changes, in combination with other social processes (urbanisation, mercantilism and the changes in the family structure, etc.), were responsible for the emergence of numerous institutions for disabled people and for their institutionalisation[82]. Barnes[83] goes even further, suggesting that the key to understanding the movement towards institutionalisation is individual wage labour. According to him, the spread of individual wage labour impacted upon the organisation of families in two different ways. Firstly, by making them «dependent on wage earnings [which meant that they] could not provide for its [their] members in times of economic depression»[84]. And, secondly, individual wage labour «made the distinction between the able-bodied and non-able-bodied poor crucially important»[85]. Following Ingelby[86], Barnes concludes that:

> *Segregating the poor into institutions had several advantages over domestic relief: it was efficient, it acted as a deterrent to the able-bodied malingerer, and it could actually create labour by instilling good work habits into the inmates*[87].

In a similar line of argument, Stiker states that, «the Great Confinement […] inaugurates a new phase of administrative repression in the treatment of the poor»[88]. The logic of this new phase was to establish public order through the physical concentration of, and circumscribing the presence of, disabled people.

The differences, in both the scale and philosophy of the initiatives taken in the area of disability, between Portugal and France and the UK were also the result of the limited impact of the Enlightenment and the consequent delay in scientific development in Portugal. Whereas in the UK the emergence of medicine as a scientific profession and its success in the medicalisation of impairment made it legitimate to introduce new radical changes in the treatment of impairment which, then, resulted in the expansion

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[79] STIKER, 1999.
[80] FINKELSTEIN, 1980; OLIVER, 1990.
[81] FINKELSTEIN, 1980.
[82] RYAN & THOMAS, 1987; BARNES *et al.*, 2000.
[83] BARNES, 1990.
[84] BARNES, 1990: 21.
[85] BARNES, 1990: 21.
[86] INGELBY, 1983.
[87] BARNES, 1990: 21.
[88] STIKER, 1999: 98.

of segregating institutions[89]. Furthermore, this new medical science introduced novel means of social vigilance and punishment of people with impairments. Medicine transformed disability into incapacity and limitation, leading social policies towards seclusion, imprisonment, social exclusion and encouraged the dependence of disabled people, and ultimately, led to the individualization of disability and the construction of disability as tragedy[90]. A huge array of new techniques, to identify, classify and regulate the lives of infirm and disabled people, were created, contributing to the construction of a «therapeutic state»[91] and to new conceptions of normal/abnormal, sane/insane and healthy/unhealthy. In Portugal this scientific development in general and in medicine in particular only became evident in the nineteenth century and only then did disability start to be defined as a problem of the body, with disabled people being transformed into a focus for medical attention and control, as had happened in the UK in the previous century[92].

Several reasons may account for this time lag. First, I would single out, the dominance of religion and the control exercised by the Inquisition, which prevented the development of Enlightenment thinking and of a new attitude towards disabled people based on rational scientific reasoning, that dominated till 1820, the year in which the Inquisition was extinguished, and when several religious orders were expelled from Portugal[93]. Second, the fact that all of the economic and social processes described for the British case — urbanisation, industrialisation, mercantilisation, individual wage labour settlement and the change in familial structures[94] — only occurred in Portugal in the second half of the nineteenth century[95]. Despite the similarities in terms of targeted groups («lunatics» and people with sensory impairments), my analysis reveals that in Portugal this movement was less comprehensive than in the UK. The reality was that Portugal's economic situation, the lack of political consensus within its liberal thinkers in relation to public assistance at the time and the late development of industrialism and capitalism deferred the transformation of disability, making it into a problem of management[96]. In fact, the emergence of residential institutions in Portugal was more a result of the need to control and repress vagrants, rather, than, as Stone[97] describes, an attempt to create an alternative distributive system based on need, which can be regarded as an embryonic form of citizenship rights.

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[89] BARNES *et al.*, 2000.
[90] OLIVER, 1990.
[91] FOUCAULT, 1989.
[92] HUGHES, 2002.
[93] NETO, 1993.
[94] FINKELSTEIN, 1980; RYAN & THOMAS, 1987; BARNES, 1990; BARNES *et al.*, 2000.
[95] MÓNICA, 1987; VAQUINHAS & CASCÃO, 1994; MARTINS, 1997.
[96] MENDES, 1993; LOPES, 1994.
[97] STONE, 1984.

Due to the fact that public assistance was a highly contentious issue amongst the liberal thinkers of the time, the successive reforms only added to its controlling character. The state only acted in cases of need, and public assistance was not an individual right; instead, it was an expression of the moral duty of the state[98]. Again, this conception of public assistance was one of the reasons for the lack of public institutions for disabled people in Portugal during the nineteenth century.

In Portugal the first specialised institute for disabled people — the Institute for Deaf-Blind Children — emerged in 1823[99]. This Institute was formed within the existing structure of Casa Pia of Lisbon, and combined the large institution's typical goal of confinement with a new medical spirit[100], which echoed what was happening abroad. Despite the fact that the first specialised institution created for disabled people was public, in the second half of the nineteenth century public initiatives focused mainly on the creation of hospitals for «lunatics», leaving it to the private sector to develop disability institutions.

In Portugal a categorical approach[101] only came into use in the second half of the nineteenth century, with examples of such institutions including: the Asylum for the Blind Nossa Senhora da Esperança created in Castelo de Vide in 1863 and the Asylum for People Impaired from Work, which was set up in Alcobaça in 1864[102].

However, the most obvious characteristic of disability policies developed in the second half of the nineteenth in Portugal was the emergence of a new concern with the education and professional training of sensory impaired people, specifically of deaf and blind people. This was the case with the Lisbon Municipal Institute for «Deaf-Mutes» created in 1887 and with the School for the Blind of Oporto set up in 1903. Most of these institutions resulted from the philanthropy of privileged families[103]. This new attitude towards disabled people, expressed through education, was, however, very biased and based on stereotypes and preconceived ideas about what a blind or a deaf person could do. The state only intervened where private initiative was absent, which is in accordance with the terms of public assistance at the time.

Despite the undeniable improvements in the education of disabled people in the second half of the nineteenth century and first quarter of the twentieth century, the implementation of the dictatorship would tear down previous gains and introduce further differences between disabled people in Portugal and those in other countries. In Portugal, the elimination of the idea of public assistance and the assumption of a secondary role by the state in the provision of social assistance, at a time when other

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[98] LOPES, 1994.

[99] COSTA, 1981.

[100] COSTA, 1981.

[101] HARRIS & ROULSTONE, 2011.

[102] GOODOLPHIM, 1900.

[103] PEREIRA, 1894; LOURENÇO, 1956; OLIVA, 2001; RIBEIRO, 2003.

states were developing comprehensive welfare-states, resituated disability as a charitable concern and maintained its connection to exclusion and poverty. In fact, the solutions developed by the Portuguese state were mainly directed towards the maintenance of disabled people within the family or towards the coordination and promotion of private initiatives. Contrary to what happened in most of Europe, Portugal did not develop a welfare-state until the collapse of the dictatorship in 1974[104]. Until 1974 a system of compulsory social insurance excluded a considerable number of citizens[105], including disabled people. In 1960, for example, only 13.3% of the resident population and 35.6% of workers were protected by this system of social insurance[106]. Under the dictatorship, social policies were structured around private initiatives, namely charitable organisations dependent on the Catholic Church[107]. However, during the first half of the twentieth century, this lack of a public system of social security was barely supplemented by a private charity system due to the state's control over all grass-roots organisations, including existing private charitable ones[108].

In Portugal these traditional conceptions and attitudes towards disability and disabled people started to be questioned in the second half of the twentieth century and more acutely after the re-establishment of Democracy, i.e. after 1974. Firstly with the emergence, from the 1950s onwards, of a new volunteer run, specific-impairment organisations sector, focusing on pedagogic and social issues, fostered by parents of disabled children and professionals[109]. Examples of these new institutions include the Portuguese League of Motor Impaired (1956), the Portuguese Association of Cerebral Palsy (1960) and the Association of Parents and Friends of Mongolic Children (1962)[110]. The development of this disability movement was extremely important in raising the state's awareness of disability issues, and its effects became evident towards the end of the 1960s with the publication of widespread legislation in the areas of education and social assistance.

The start of the colonial war in the 1960s and the subsequent return of thousands of injured military people, alongside their concentration in special military hospitals, led to the creation of a new consciousness of disabled people's situation within Portuguese society. This led to the creation of APD in 1972, the first non-single-impairment and non-single-issue Portuguese organisation of disabled people, which was followed by the Association of Impaired War Veterans in 1974, immediately after the re-establishment of Democracy.

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[104] SANTOS, 1999.

[105] PIMENTEL, 1999.

[106] CARREIRA, 1996: 38.

[107] PIMENTEL, 1999; PIMENTEL, 2001.

[108] HESPANHA *et al.*, 2000.

[109] COSTA, 1981.

[110] COSTA, 1981.

This led to the emergence of the Portuguese Disabled People's Movement. Despite the fact that the seeds of the Portuguese Disabled People's Movement were laid down in the first half of the twentieth century, these organisations lacked a political character, reason why they were tolerated by the dictatorial political regime of the time. The re-establishment of democracy in Portugal in 1974 finally allowed civil society's organisations to question disabled people's living conditions, the demand of political measures to prevent disabled people's exclusion and oppression, inaugurated therefore a new period of disability politics and policies and the beginning of a citizenship project for disabled people.

CONCLUSION

Disability and disabled people as a specific category in Portugal, is a modern creation, which is as recent as the nineteenth century. Several explanations for this were provided for the Portuguese case, including: the lack of specialised institutions for the assistance of disabled people in Portugal before the nineteenth century; the fact that disabled people were included amongst other groups of people as entitled to assistance by generic institutions; the prevailing connection between disability and poverty; and the fact that disabled people as a defined category for state support emerged only in the nineteenth century. I argue, therefore, that present disability hegemonic narratives in Portugal have been shaped by a combination of a pervasive Judeo-Christian ideology, with four major historical processes: the Portuguese state detachment towards welfare provision, the dominant role of the Catholic Church in welfare support and provision, the medicalisation of disability and, more recently, the emergence of disability political activism.

Despite the emergence of new winds clamming for change in the state and society's attitudes towards disabled people in Portugal, framed by a social understanding of disability and a human rights perspective on disabled people's rights, I argue that hegemonic oppressive narratives of disability and conceptions of disabled people are still prevalent. Portuguese society continues to reduce disability to the impairments of the bodies and the lives of disabled people to a fatalistic narrative of personal tragedy. According to this model of understanding, the restrictions and obstacles experienced by disabled people result directly from their supposed functional limitations. Such conceptions have validated the construction of the image of disabled people as passive and dependent subjects, the silencing of their voices and fed disability policies with oppressive and excluding impacts towards Portuguese disabled people. Recent reports, studies and statistics[111] reveal the persistence of a flagrant situation of social exclusion of disabled

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[111] FONTES, 2014; PINTO & TEIXEIRA, 2012; PORTUGAL *et al.*, 2014.

people in Portugal and of a legal and governmental inability to guarantee and fulfill disabled people's citizenship rights.

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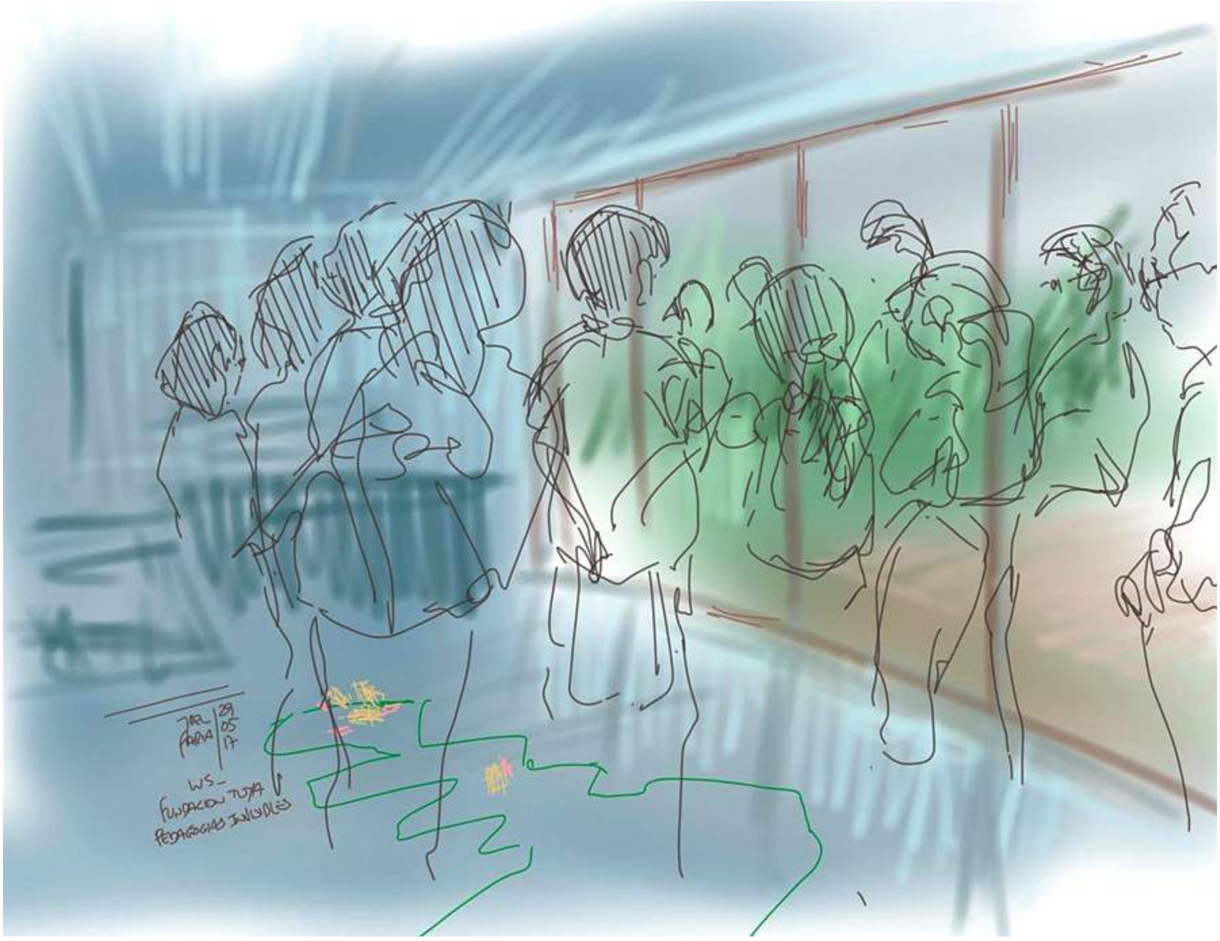
III

CULTURAL ACCESSIBILITY



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COLLABORATIVE ARTISTIC PRACTICES FOR CULTURAL ACCESSIBILITY: BUILDING BRIDGES BETWEEN DISABILITY AND COMMUNITY

AMANDA ROBLEDO SÁNCHEZ-GUERRERO*

Abstract: Services in the field of disability, immersed in the paradigm shift of diversity, are being transformed into *bridge organizations*. This new model is emerging to offer personalized support to citizens with different kind of disabilities who demand full participation in the community. The Tuya Foundation is a bridge organization that promotes Airea: international meetings where people with different capacity gather to build a more inclusive world.

The new concepts of cultural inclusion, social museology and accessible cultural heritage have promoted the emergence of art and education projects aimed at the context of disability. Museums and art centres are creating programmes and projects aimed at persons at risk of exclusion to enable their greater participation in the community. Pedagogías Invisibles is an independent cultural association that acts as a bridge between people with disabilities and the cultural environments of Madrid and Berlin.

Keywords: accessibility, disability, contemporary art, participation, mediation.

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CULTURAL ACCESSIBILITY AS A PATH TO FULL INCLUSION

Becoming Aware of Human Diversity

The paradigm of disability is experiencing an historic moment of change that is directly connected with the global transformation in the way of understanding human diversity.

Since the adoption of the *Convention on the Rights of Persons with Disabilities* in 2006[1], the inclusion of persons with disabilities in a democratic society has finally become a legal and ethical issue. The *Convention* has been the result of efforts made since the 1960s by social groups involved in fighting discrimination and seeking equality, in conjunction with the active participation and persistent action of people with disabilities.

Groups that have suffered discrimination because of their physical, sensory or cognitive disabilities demand new policies that consider all citizens under a new light: as a community of interlinked and diverse individuals.

The Independent Life Movement[2] philosophy is that everyone, regardless of their level of disability, has the right to enjoy a life as independent as possible in their community and to enjoy the best available social and personal support.

The main demand of people who have any kind of impediment (functional diversity) is deinstitutionalization. This is based on the idea that the processes of normalization operating in the society cause the part of the population labelled as «disabled» to be directed to specific services that, instead of promoting their inclusion, perpetuate their invisibility.

We would like to clarify that our study focuses mainly on the problem faced by citizens with intellectual or developmental disabilities as they constitute a group at greater risk of social exclusion. Here we should note that throughout this article we shall refer to the group of people who have specific limitations in their cognitive functioning as:

- People with intellectual or developmental disabilities;
- People with cognitive functional diversity.

People with *intellectual or developmental disabilities* is the expression proposed by the Spanish Confederation of Organizations in Favour of Persons with Intellectual Disabilities (*Plena Inclusión*[3]) to denominate that group of people. The Confederation has taken its definition of *intellectual disability* from the one adopted by the American Association on Intellectual and Developmental Disabilities: «It is a disability characterized

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[1] Convention on the Rights of Persons with Disabilities, April 21, 2006. Adopted by the General Assembly of the United Nations on 13 December 2006 and ratified by Spain: BOE of 21 of April, 2008. Available at <http://www.convenciondiscapacidad.es/index.htm>.

[2] GARCÍA ALONSO, 2003.

[3] Available at <http://plenainclusion.org>.

by significant limitations in both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills». That is to say, it is a limitation in the skills that the person has to learn in order to function in his daily life and that would allow him/her to respond in different situations and in different contexts.

People with *cognitive functional diversity* is the expression proposed by the group of people with disabilities who lead the Independent Living Forum (Foro de Vida Independiente[4]) in Spain. The Forum is a platform created to disseminate the philosophy of Independent Living, which defends a *new model of diversity*. This new model states that functional diversity is part of human diversity. Full dignity must be provided to all people, regardless of their diversity. Full dignity means giving the same value to all human beings and giving the same rights to all people[5]. The Independent Life Movement posits that main strategies for full inclusion are:

- Personal assistance (giving individualized quality support to create as independent a life as possible within the community);
- Elimination of the barriers of the environment.

We shalI use both concepts in this article to highlight the fact that today different models of disability coexist. The result of this coexistence is that we can find different and divergent ways of acting.

Fig. 1. People with cognitive functional diversity, 2016. ©Amanda Robledo

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[4] Available at <http://forovidaindependiente.org>.

[5] PALACIOS & ROMAÑACH, 2006.

Paradoxically, while the model of diversity (full inclusion) gains in acceptance, models that lead to social exclusion continue to be maintained: the exclusion model (which accepts eugenic practices such as population control), the medical-care model (which defines disability as the absence of health, designing segregated environments where patients can be treated by means of therapies and drugs) and integration dynamics (established by two groups of citizens: the minority group [integrated] and the hegemonic group [integrators]). This happens because we live in a society democratic only in theory, in which normalization processes operate that assign more value to some citizens than to others. Such discrepancy is reflected in society's use of these terms (some of them totally disrespectful) and in how society organizes its individuals.

Unfortunately, standardization does not only affect functional diversity; anyone outside the norm is more likely to suffer discrimination in their daily lives than those considered normal.

When disability is at large associated with dependency, and people with different functions are stereotyped as incapable of greater achievement than receiving help, that vision affects the way people with functional diversity perceive themselves. Frequently, the personal and social identity of people with functional diversity is reduced to their uniqueness, relegating to the background the rest of their values as individuals.

An in-depth awareness of human diversity leads us to question this social and legal classification of disability, which divides citizens into dependents and non-dependents. On the other hand, those who believe we are not dependent are denying reality, because in our life, sooner or later we are or we will be dependent on each other. Therefore, it can be stated that: *All of us are interdependent people with functional diversity*.

We want to underscore the idea that every human being, regardless of his or her characteristics, is diverse in his or her functioning, that is, in the way of being and of being in the world, and is connected to others, on which to a greater or lesser extent they depend to live. If we want to build a more inclusive world and a more just and egalitarian society for all, we should accept and love our own diversity and that of others. From this perspective, we understand that wealth and happiness lie in celebrating the similarities and differences that make us unique and diverse.

CULTURAL ACCESSIBILITY AS A RIGHT

The violation of the fundamental rights of people with disabilities, particularly their access to culture, is a problem not yet fully addressed. For one thing, cities still have urban barriers that impede full accessibility to many places. Furthermore, the majority of people with functional diversity do not enjoy an independent life and consequently their participation in the community has to follow the patterns of the specific services created to cover that necessity. As a consequence, the majority of persons with cognitive functional diversity do not fully enjoy the benefits they deserve as members of society, have very few opportunities of equal participation in community life and participate in the community only on a reduced scale.

Existing barriers in social spaces do not only affect the disabled community. Generally speaking, a fundamental aspect of the paradigm shift of diversity is to understand that the functionality of a person depends on their interaction with the environment: the fewer barriers there are, the greater the inclusion of the population. It is obvious that designing cities without barriers benefits mainly people with functional diversity, but it is also evident that it makes products and services more accessible and enjoyable for the rest of the population.

Within the community there are specific environments (what we might call «cultural heritage»: cultural centres, museums and art centres, meeting places, public places to gather diverse people with a common interest) that due to their characteristics favour greater social inclusion. When society shows sensitivity to excluded individuals and groups, it incites cultural institutions and agents to undertake actions to encourage public engagement with functional diversity. In other words, to look for and create innovative experiences that break stereotypes about disability and encourage accessibility to culture.

In addition to the elimination of physical, sensory and cognitive barriers, the key to full inclusion is to create spaces where people with and without disabilities can coexist, spaces that change our way of understanding human diversity, transform our style of relating to each other and strengthen our common bond.

Throughout the 1990s, growing interest in universal design drove the creation of «universal design principles»[6], which guide architects and designers today in creating accessible spaces and objects. Although institutions, architects and politicians focus on overcoming the physical and sensory barriers of cultural environments (the most visible), that does not ensure a design suitable for all. Access to cultural heritage is limited not only by these types of barriers, but also by cognitive barriers and especially attitudinal barriers. Up until recently, museums still had not perceived people with intellectual or developmental disabilities as potential visitors. Today we know that there are so many ways as people to approach, perceive and experience cultural heritage. Espinosa's concept of *accessible heritage*[7] surged forth to defend the right of any citizen to enjoy our common heritage; the meaning of accessible heritage («inheritance» and «communal good») guides us also in this regard. We already know that cognitive barriers are the most complex, and therefore difficult, to detect or act upon, since there are as many cognitive functions as people. In order to achieve a design for all, the intervention of people with cognitive functional diversity at all levels of cultural accessibility projects

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[6] Available at <http://universaldesign.ie/What-is-Universal-Design/The-7-Principles/>.

[7] ESPINOSA & BONMATI, 2013.

is essential. The best way to act on cognitive accessibility is through first-hand feedback about experiences in cultural institutions and ways of perceiving the world.

The Conect@Blog[8] project of the Museo Nacional Centro de Arte Reina Sofía (MNACRS) investigated new strategies of cognitive accessibility and social inclusion. Over the course of two years, a group of participants in the Museum project, with and without intellectual disabilities, analysed the museum's universal accessibility and related actions. If training professionals both in cultural and social spheres is key in terms of increasing accessibility, providing real inclusion in cultural environments that allow training in social skills and aesthetic sensibility of people with functional diversity is essential. Removing barriers and the inclusion of people with any diversity do not necessarily carry the obligation of programming specific activities.

Paying attention to the specific carries the risk that, trying to integrate, we could fall back into exclusion, even if it is a «positive» exclusion. Any special treatment is in itself discriminatory. It is much more appropriate to adapt existing resources to each type of audience than to design programmes, exhibitions or special events. In spite of that, museums still use specific programmes as the most habitual form of educative activity directed to this group of people. It is understandable, since people with functional — especially cognitive — diversity are supported by the specific organizations created to help them. Specific centres organize cultural activities for groups (group activities) when they program training seminars or working sessions. It is only during leisure time that people can decide their own private cultural agenda and manage personally what (natural or professional) can be helpful for their own enjoyment. Groups of people with intellectual and developmental disabilities participate in the greater culture through such group dynamics, users and professionals, that scarcely allow interaction with other groups. Connect@Blog precisely seeks to dilute the usual hierarchies and modes of interaction in the context of disability.

When we analyse the didactic programme of MNCARS[9], it is clear that its methodology has evolved over the last ten years to offer activities designed for all audiences today. The Education Department of the museum was the first to offer in Madrid programmes aimed at people with functional diversity. Drawing from accumulated experience and deep reflection, the Museum has since incorporated practices originally designed for audiences with functional diversity and applied them to general audiences.

The value of human diversity entails working with languages other than just the verbal. Since our daily activities are connected to a verbal and written environment, we assume that only literacy in those linguistic expressions is imperative. Coexisting with disability means living alongside people who do not always fully possess those skills,

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[8] Available at <https://conectamuseoreinasofia.wordpress.com.

[9] Available at <http://www.museoreinasofia.es/educacion>.

who have only partial abilities or who can carry out those abilities in a special way. What unites us beyond speech is an interest in the aesthetic and the expressive. In this way, to enrich all kinds of audiences, MNCARS uses in their visits new elements and more sensory processes, such as using the body as a fundamental tool or performances and music. Now the whole programme of the museum is universally accessible, which makes it easy for diverse audiences to participate successfully in any visit.

We can synthesize some key points to gaining cultural accessibility in our museums and art centres:

1. *To combine the specific with full inclusion*. The necessity of combining specific programmes aimed at the context of disability with truly inclusive initiatives where diverse audiences coexist;
2. *More personalized and long-term activities*. Promote programmes and projects developed over a long period, instead of programming specific visits. Working over a longer period allows group dynamics to result in activities designed with each participant in mind;
3. *Encourage a loyal audience*. Make partnerships with organizations focused on disability issues so that, through these programmes, a relationship that encourages a regular presence of people with functional diversity in museums can be established;
4. *Promote special projects based on collaboration*. Provide collaborative experiences that allow us to discover new ways of working based on dialogical practices, co-creation, transdisciplinarity and horizontality.

BRIDGE ORGANIZATIONS AND THE COLLABORATIVE TURNAROUND

The artistic manifestations in the context of disability remained unrelated to the world of Art until the appearance of the term «outsider art»[10] in 1972. Since then, the work of these unconventional artists has been gradually gaining higher visibility in art galleries, exhibitions and permanent collections of museums and art centres, both public and private. But what happens with the creators themselves? Are they, as individuals, also present in the ambit of artistic production? While it is true that the presence of some of their creations on the walls of galleries and museums challenges the traditional artists profile, training and professionalism of people with functional diversity on equal terms with others remains a challenge too. Since the 1970s, internationally, cultural projects have emerged from the context of disability. Those projects, even though heterogeneous, offer at least a creative space to people with cognitive functional diversity. Most of the creators with disabilities who develop their artistic work in bridge organizations

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[10] CARDINAL, 1972.

have been excluded from the training and promotional channels enjoyed by most other artists. We should recall that there are very few opportunities to access to an inclusive education, which is key to obtaining a quality training in Art. As a consequence, in the specific case of Spain, the majority of young people and adults with intellectual or developmental disabilities participate solely in artistic workshops programmed to people with disability. Unfortunately, the most prestigious and internationally reputed entities in that area (Creative Grow Art Center[11], Creahm[12], Danza Mobile[13] or Thikwa Theater[14], among others), both in terms of trajectory and professionalism, are accesible only to a few of those artists. Actually, most people with cognitive functional diversity are allowed a place in facilities that offer curricular activities and workshops oriented for the most part to handicrafts rather than visual arts, and whose education programmes are usually taught by professionals and/or social workers with little training in contemporary art.

Changing the paradigm of diversity is to demand something special. It asks us to leave segregated spaces behind and embrace everyone's right to fully enjoy community cultural services: museums, art centres, galleries, festivals, meetings, facilities, seminars, education courses, etc. Aware of what full inclusion means, those very valuable spaces for the education and artistic creation of people with disabilities are already looking for new *bridge* actions that allow them to move from specific, individual-oriented actions to broader, community-oriented actions. As we will see below, at the international level, projects based on contemporary artistic practices already emerging. They incorporate participation and collaboration in the cultural production process. Other experiences, focused in community development, are also arising at large.

Debajo del Sombrero Association: Inhabiting the Community

A good reference in matters of cultural accessibility is the association *Debajo del Sombrero*, a platform for the creation, research, production and dissemination of art whose main protagonists are people with intellectual and developmental disabilities. When in 2006 the team of founders devised *Debajo del Sombrero*, we made a key decision: to develop the project within cultural institutions of the community instead of creating an exclusive space. With this strategy, *Debajo del Sombrero* developed its programmes in Matadero Madrid, La Casa Encendida and the Department of Fine Arts of the Universidad Complutense de Madrid (UCM). The association's programmes allow participants to live with others, share activities with community cultural entities and disseminate the artistic value of the project. *Debajo del Sombrero* acts as a bridge between issues affecting disability and community. The platform connects adults with intellectual and develop-

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[11] Available at <http://www.creativegrowth.org>.
[12] Available at <http://www.creahm.be>.
[13] Available at <http://danzamobile.com>.
[14] Available at <http://www.thikwa.de>.

mental disabilities interested in the visual arts with formal environments for promotion and artistic training. One example is the collaborative project Artistic Workshop with the artist Jaime Vallaure[15], an experience developed within the European Expanding Realities Project, in the Intermediae facility at Matadero-Madrid. This drawing-and-action workshop, designed by the artist, generated a space of collaboration between three groups: students of the Ártica school, students of the Fine Arts Department of the UCM and artists of *Debajo del Sombrero*. The workshop's proposed subject addressed several important topics such as new ways of artistic mediation, how to manage the diversity of the participants and the connection between formal and informal educational contexts, among others.

Fig. 2. «Debajo del Sombrero Association: inhabiting the community», Madrid 2008
Carlos Mariscal's Project

From Participation to Collaboration

As we analyze in Jaime Vallaure's artist workshop, the interest in public participation moves many current contemporary art creators to approach their work transversally, that is, as the intersection of their own interests with the needs of community

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[15] For more information on the project, see <http://www.debajodelsombrero.org/proyecto.php?id=894>.

contexts. Museums, artists and mediators are joining the fight against exclusion through projects involving those less present in the cultural landscape. In the field of art there has also emerged a commitment and interest towards minorities in a situation of inequality. Social commitment and activism are the essential features of the new collaborative art movements. This commitment is used by museum education teams and art centres to design new programmes and projects based on participation. One example is the projects of visual artists and professors Isabel Banal and Jordi Canudas, invited by the La Panera Art Center, Lleida, as part of its series of participative projects aimed at audiences at risk of social exclusion. Through two proposals, Taller Casa Dalmases (2008) and Mercat de Santa Teresa (2009)[16], the artists used participatory artistic practices to offer people from special centres for adults in Cervera and Lleida an inclusive experience in contemporary art. The education service team at La Panera explains the conclusions of these workshops:

> *We considered these two workshops as a good example of an inclusive artistic practice, since these workshops could have had as participants other groups such as students, children, the elderly, among others*[17].

Raising awareness of the fact that a special education programme is of interest to any member of the public is the path we should follow in order to transform something specific into something that is universal. Based on this approach we can devise inclusive strategies that encompass diverse sections of society within a shared cultural project. Teachers at La Panera have also highlighted the importance of generating activities in which the participants play an active role. Working with contemporary art helps to train participants regarding aspects such as self-determination, thanks to the freedom of choice, decision-making and autonomy characteristic of any creative act. The involvement of contemporary artists within the realm of disability can lead to some exciting and creative projects that also constitute marvellous learning experiences, both for people with functional diversity and for the professionals working at the centres and the artists themselves. However, we know that in order to bring about a profound shift in the paradigm of disability we must dilute the habitual roles granted to participants with and without disabilities and make progress in a horizontal sense.

An analysis of the programmes and project outlined above encourages us to take a further leap, from mere participation to full collaboration. What does this mean? It means that we must rely on people with functional diversity themselves when it comes to designing the cultural projects they take part in, and not only in terms of implementing

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[16] Available at <http://www.lapanera.cat/home.php?op=62&module=editor>.

[17] PICAZO, 2011.

these projects. Let us not forget the slogan of the Independent Living Movement: «nothing about us, without us». This subtle but essential shift corresponds to the full-inclusion needs of the disability realm. Disabled people are attempting to overcome existing hierarchies between professionals and users in order to make progress in terms of self-determination. In this sense, collaborative artistic projects constitute an extremely rich experience for this group. It is important to point out here that co-creation entails establishing a point of departure and building a project according to the interests and decisions of the participants. The shift in paradigm of disability requires self-determining participants, people who are able to lead transformation within their particular realm. Whilst participative projects are proposals that originate from outside disability contexts and depend on the presence of external agents from beginning to end, collaborative projects grant greater independence to the participants and give them a bigger say. The idea of working from the perspective of collaboration is to co-create initiatives for change that belong to the participants within the realm of disability themselves.

Pedagogías Invisibles: Accessible Cultural Mediation

Pedagogías Invisibles[18] is the name of a group whose goal is to make learning that we acquire unconsciously, invisible learning, visible, with a view to transforming that knowledge which we do not like. Contemporary art is our great ally throughout this entire process and our work in art + education ranges from mediation to training, not to mention the management of cultural events and research.

Being well aware of the problems of people with functional diversity when it comes to gaining access to culture, we promote specific projects aimed at persons with cognitive functional diversity at occupational centres, special education schools and associations. These projects are based on cross-learning experiences through art, in which all participants, including teachers and support and accompanying staff, can open up other ways of understanding and building new and useful tools that can be brought into play during the day-to-day work of these institutions. In this respect, we carry out various sessions, the first at habitual work, study and meeting centres, and the rest at the hall, museum, etc. Throughout these sessions we address different questions, such as the process itself, autonomy, identity and the different languages with which it is possible to take action, being well aware of the fact that the result of this experience is an additional contribution within the realm of cultural production.

One example of accessible cultural mediation at museums consists of our programme known as *Arte Accesible: Más Que Una Visita* («Accessible Art: More Than Just a Visit»), which we have implemented at the art centre Sala de Arte Santander (Ciudad

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[18] Available at <http://www.pedagogiasinvisibles.es>.

Grupo Santander, Boadilla del Monte, Madrid) since 2013[19]. This project fulfils a two-fold objective: on the one hand, it brings the realms of art and culture closer to the context of disability and, on the other, it conceives of the art centre as a learning space in which it is possible to acquire teaching tools that can be taken back to the participants' own environments, thus contributing to the goal of full inclusion. Our working methodology can be consulted on the Foundation's web page, where we have published the teaching summaries for the exhibition entitled «Looking at the World Around You» Qatar Museums Collection (2016)[20]. These summaries are especially aimed at teachers working within the field of functional diversity and the objective is to provide them with a proposal that helps them to see how many different ways there are to approach contemporary art and the learning opportunities that can arise based on the different perspectives we are able to generate. At the same time, the fact that such projects have been conceived from the perspective of accessibility does not mean that they are limited solely to this context. Quite the contrary, in fact. They can be developed within any learning context and, in this respect, are aimed at all and any teachers interested in working the idea of diversity.

Fig. 3. «Pedagogías Invisibles: Accessible Cultural Mediation» Madrid, 2013
Arte Accesible Programme, Pedagogías Invisibles

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[19] Available at <https://www.fundacionbancosantander.com/es/accesibilidad>.

[20] Available at <https://www.fundacionbancosantander.com/media/files/Arte/Fichas_experiencia_arte_accesibilidad.pdf>.

Another example under the heading of accessibility is provided by our «Mural E» Project[21], which we carried out in Instituto Cervantes of Berlin, in 2016. In this case, *Pedagogías Invisibles* joined forces with the Thikwa Art Centre in order to design a collaborative art + education project. *Thikwa/Werkstatt für Theater und Kunst*[22] is a centre for the training and promotion of artists with functional diversity. In recent years, the creative team at Thikwa has been searching for new ways of boosting the Centre's participation within the community. As a cultural mediation intern at Thikwa, the author promoted this inclusive experience, building bridges between the educational realm, the world of art and the context of disability. The project's objectives were as follows:

- to create more accessible institutions and foster social inclusion;
- to offer a collaborative art experience by applying democratic working methodologies through contemporary art;
- to break away from the stereotypes that exist regarding intellectual and development disabilities.

Convinced of the importance of enabling new generations to enjoy inclusive experiences in which people with disabilities play an active role in terms of contributing something to their community, *Pedagogías Invisibles* and *Thikwa/Werkstatt für Theater und Kunst* created a team to jointly design a creative work proposal aimed at a class at the Joan Miró school. The goal was to create a collective mural on the large windows of the Cervantes Institute building in Berlin in order to celebrate the institution's *Sommerfest*. During the working sessions, the team of artists and mediators guided the students and teachers in the creation of the mural, to which everyone contributed. Artists, students and teachers thus made up a learning community that resulted in an original and unique project. The collective mural was presented on Saturday 18th through an Open Workshop, in which members of the public were invited to collaborate by adding their own designs to the mural.

Through collaborative ideas of this kind we are able to promote the empowerment of all participants, effectively promoting shared leadership and horizontal approaches.

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[21] Available at <http://berlin.cervantes.es/FichasCultura/Ficha108701_57_1.htm>.

[22] Available at <http://www.thikwa.de/werkstatt/index.html>.

Fig. 4. «Pedagogías Invisibles: Accessible Cultural Mediation», Berlin, 2016. Mural e Proyect in Instituto Cervantes Berlin, Pedagogías Invisibles, Thikwa Theater, and Joan Miró School

Airea: An Invitation to Reflect and Act Together

One initiative that offers full-inclusion experiences is known as AIREA, run by Fundación Tuya[23]. This social body, created in 2009, is a guardianship foundation for persons with intellectual and development disabilities and it works with people both within and outside the realm of disability at an international level. The Foundation's initiatives are enriching for people whom Tuya refers to as «pathfinders»: other citizens who are also searching for new ways of living and working within the community. Based on this vision, Fundación Tuya has created what is known as «Airea» («Aerate»), a space for exploring and achieving a more in-depth understanding of the values of inclusion. Airea invites people with functional diversity, professionals and families within the realm of disability to work alongside other citizens interested in the idea of social inclusion.

«Aireas are inclusive learning spaces. This means that we learn alongside people with different experiences and different needs. «Airear» or «to aerate» is to prepare the soil for subsequent cultivation. Together we seek to create communities that work well for all kinds of people. John O'Brien asked us in the «New Paths to Inclusion Network» (2011): *What else is possible? How can we support people individually so that they can live*

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[23] Available at <https://fundaciontuya.net/airea/>.

a full life within the community?[24]. We believe that the answer to this question depends, in large part, on the quality of the community. We created AIREA in order to consciously enhance communities, in order to create a better space for reflection for all people». Ester Ortega Airea involves three key elements:

- diverse teams of people with and without intellectual disabilities, which is to say, citizens of any profile who are interested in enjoying a unique inclusion experience;
- progressing through questions that inspire reflection, departing from the personal realm in order to reach a collective level;
- learning by doing, through a methodology based on praxis, this being the ideal means of guaranteeing universal accessibility.

AIREAs are implemented in residential environments that are located close to nature over periods of two or three consecutive days, so that participants have sufficient time to both reflect deeply and develop their interpersonal relationships. These days are designed in a simple and attractive way, a way that makes sense for each and every one of the participants. The experience is structured by means of a series of actions in which visual and body language facilitate a horizontal dialogue amongst the participants.

Fig. 5. «Airea: An Invitation to Reflect and Act Together»
Fundación Tuya and Pedagogías Invisibles, Porto, 2017

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[24] Available at <http://www.personcentredplanning.eu>.

> *[At the workshop PINCELADA AIREA PORTO, which took place in the afternoon session at the Museu Nacional Soares dos Reis, as part of the international meeting Representing Disability in Museums, Imaginary and Identities, we presented Fundación Tuya's AIREA Project by means of a series of actions that invited the participants to learn about and discover this experience. Given that Airea is something more than just a training proposal, this workshop was just a «pincelada» or «brushstroke» of what Airea could mean to your community. You can find further information on the web page of Fundación Tuya].*

CONCLUSION

Collaborative artistic practices constitute a type of action that fosters *empowerment* within the context of disability. Working in a cooperative manner allows both professionals and individuals with *cognitive functional diversity* themselves to take on active and horizontal roles. In turn, these actions drive greater awareness regarding the shift in the paradigm of disability, which cannot occur through traditional services, structures and roles. The social capital that exists within the realm of disability has an immense potential, one that only becomes visible when taking part in the cultural life of the community. Based on the idea «Nothing about us without us», collaborative projects allow people with functional diversity themselves to lead transformation within their immediate environment, thus breaking down the stereotypes that exist regarding disability. In this respect, it is essential for new cultural programmes and projects aimed at the realm of disability to facilitate cooperation amongst diverse people, thus demonstrating new ways of maintaining interpersonal relationships amongst participants.

Thanks to collaborative projects, a new organisational model based on a *bridge* concept is emerging. *Bridge agents* (professionals, artists, independent organisations, etc.) play an essential mediating role between social bodies and cultural entities, breaking down the structural rigidity of these institutions and creating new links between them. Through these full-inclusion experiences in cultural contexts, we are able to build community services that are accessible to all.

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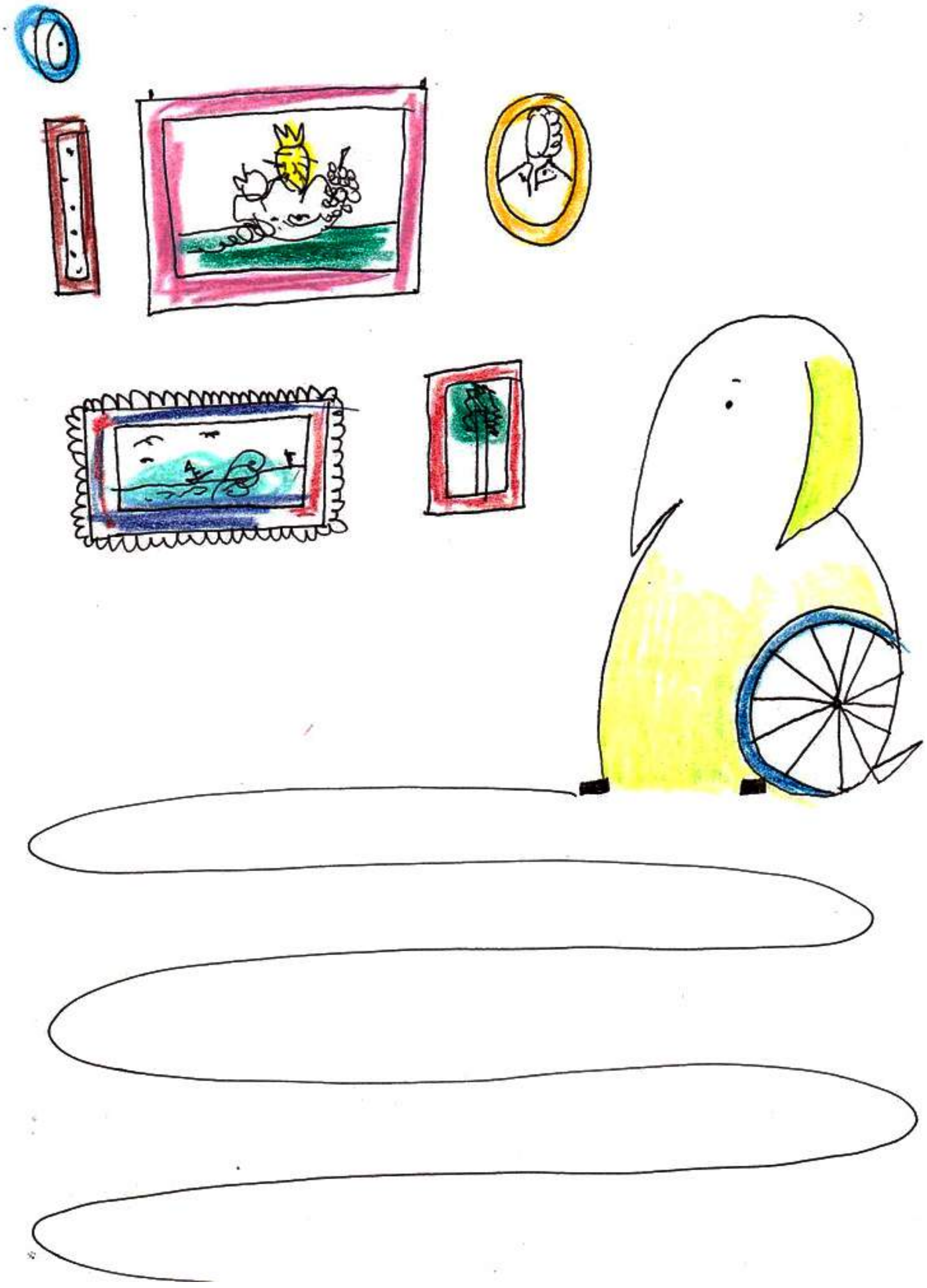

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THE POLITICS OF «CREATIVE ACCESS»: GUIDELINES FOR A CRITICAL DIS/ABILITY CURATORIAL PRACTICE*

AMANDA CACHIA**

Abstract: In this chapter, I offer guidelines or instructions accompanied by examples for a critical dis/ability curatorial practice, which involves an application of «creative access». «Creative access» extends from the generally understood meaning of «access», which is the ability to approach and use something. Access typically encompasses qualities of ease, according to Elizabeth Ellcessor, which might involve, for example, «user-friendliness of a system, or financial affordability»[1]. In the context of a critical curatorial practice, where curators are understood to provide «access» to an audience in terms of an exhibition's content through objects, ideas and text, adding the word «creative» to curatorial «access» has a political agenda. First, the idea of «creative access» is manifold: on the one hand, the goal of «creative access» is to advance a more complex curatorial model for contemporary art exhibitions that can be made accessible to an array of complex embodiments, where, for example, American Sign Language, captioning, and written and audio translations of sound and image are embedded into the material, structural and conceptual aspects of an exhibition. On the other hand, «creative access» also means an active curatorial engagement with artists who use «access» as a conceptual framework in

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[1] ELLCESSOR, 2016: 6.

their practice, so that a curator's notion of access and an artists' interpretation of access are conflated and juxtaposed in an exhibition, providing a dynamic dialogic exchange between the physical and the conceptual, or the praxis and the theory.

Keywords: disability art, creative access, disability curatorial practice, guidelines for accessible art exhibitions.

INTRODUCTION: CURATORS' ACCESSING ACCESS CREATIVELY

My stake in the work of «creative access» is from the perspective of a curator who identifies as physically disabled and who has been deploying «creative access» in all my exhibitions since 2011. Not only has my curatorial work engaged in «creative access», but my exhibitions have also engaged in social justice themes focused on disability and the disabled body. I have curated these exhibitions with the ambition of transforming reductive associations of the disabled body at large, in tandem with introducing audiences to Tobin Siebers' idea of «disability aesthetics», illustrating his concepts through the art objects on display and providing alternative definitions of aesthetics[2]. My projects have also explored activist positions within specific disabled community groups, including people with dwarfism, people who are deaf and/or hearing impaired, and people who are blind and/or visually impaired. My commitment to these themes called for an equal but also robust commitment to access, given that projects focused on disability must also surely consider the audience member who identifies as disabled. Therefore, I found myself not only paying attention to the artist and their work as part of conventional curatorial labor, but I also had to focus new energy into considering access in creative and conceptual ways that could be enlivened both practically and conceptually.

Some of the earlier examples of my projects engaging with «creative access» is when I started with *Medusa's Mirror* at ProArts Gallery in Oakland (2011), where I decided to record audio descriptions of the artwork on an old iPod. I left my iPod at the Front Desk so that the audience could listen to these at their leisure, and to open the idea that the curator can provide information about an artwork that is less interpretative and more descriptive, on both subjective and objective terms. For *What Can A Body Do?* at Haverford College in Pennsylvania (2012), I continued to extend the idea that audio descriptions could be more creative by allowing students from the college to participate in the recordings. I had at least three descriptions per object, so that audio descriptions were offering numerous channels of information from multiple and, ostensibly amateur, perspectives, debunking the idea that audio description must be left solely to the professionals.

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[2] SIEBERS, 2010.

I argue that «creative access» is an important tool to deploy within a critical dis/ability curatorial practice because it elevates and complicates our rudimentary, although no less important, understanding of access in the museum. This is because «creative access» embodies both conceptual and physical possibilities, where the very idea of «access» can be discovered in an artists' work, and can be fruitfully curated into exhibitions, while at the same time, it can be incorporated into projects under the leadership and imagination of the curator. «Creative access» then calls for curators to weave in a new aspect to their practice that demands a consideration for a greater diversity of bodies, represented both in the complex embodiment and consequently the objects by artists with whom they work, and also the audience themselves that visit the museum and consume their ideas. What I am suggesting is that «creative access» perhaps offers a more compelling intellectual engagement with typical notions of access: through its regular and consistent deployment, the curator, artist, and audience member will enhance their knowledge of standard conventions such as captioning, whilst also enjoying how artists engage with such conventions creatively. Perhaps this will motivate curators to take on the work of access in more meaningful, concentrated ways. This is not to water down the significance of providing conventional physical access, and those professionals who execute such work, such as captionists and sign language interpreters. Rather, «creative access» can be both practical and creative at once.

Offering «creative access» in the form of guidelines is important, because it acknowledges a significant absence in curatorial practice that has long ignored the work of access. The work of access is most often conducted by education staff in museums, as it is seen as a physical consideration and indeed, a legal stipulation, that must be executed in a usually non-creative, logical manner. «Creative access» instead suggests that there is much conceptual material to be found in the ideology of access, through a collaborative curatorial and artistic engagement. I offer my guidelines, beginning with the strategic and concluding with the tactical, with the same spirit of revolutionary intent that an artist has historically developed through the manifesto. The manifesto has an important place in art history, with significant contributions by artists within various art movements that proved pivotal to transforming art movements that came before their time, while shaping the movement they envisioned for their contemporary moment that would speak to their current political beliefs and ideologies. Landmark manifestos include F. T. Marinetti's *Manifesto on Futurism* (1909), *The First Manifesto of Surrealism* (1924) by André Breton, Allan Kaprow's manifesto on the «blurring of art and life» (1966) and the Guerilla Girls feminist slogan artworks (1985-90). I am inspired by the legacy of the manifesto as a tool that represents disruption, a call for change, and a signpost, notice, and semiotic for «alert-ness». I am also inspired by the work of non-visual learner Carmen Papalia, who developed a similar list of playful, if ambiguous, suggestions for museum access from his perspective as a person who is blind for an issue of *Disability*

Studies Quarterly (Papalia, 2013). While Papalia's work is important, it doesn't necessarily account for the diversity of all bodies. For example, he calls for a viewership of an object that demands an audience member to crawl along the ground. While I appreciate Papalia's antagonistic take towards a «reversal» of access that involves making physical space more uncomfortable for the able-bodied viewer, he doesn't necessarily consider what this means for other disabled users. For instance, crawling might prove difficult for someone who is a wheelchair user or was born without a certain number of limbs. So within the chapter, I offer my guidelines as a list of to-do items, or a template for how one might enact this critical curatorial dis/ability curatorial practice for the benefit of a wide range of users. It is a work in progress, mostly because it is unfinished, but also because I have not yet exhausted of all the list's possibilities, and because each item assumes an atmosphere of experimentation. One thing that is certain is that access must constantly be open to revision, as access is individual and cannot ever speak to a so-called «universal» subject in a museum, according to Danielle Linzer and Cindy Vanden Bosch, which is quite the antithesis to the societal constructs that we currently operate under[3].

GUIDELINES FOR ACCESSIBLE ART EXHIBITIONS

1. Curator, artist(s) and venue should work collaboratively on all access components;
2. Carefully consider the needs of the audience, as this differs from venue to venue, but remember that access is also a symbolic political gesture that should be provided as a means to transform museum practice in general. In other words, access should be implemented, regardless on if a guaranteed «disabled» audience will be present (see Sandals 2016);
3. The curator should consider incorporating work by disabled artists in the exhibition as a means to offer a «disability» perspective in the work itself, especially in ways that artworks engages conceptually with access. Beyond this, curators can also encourage new modalities for the production of works of art by artists who do not identify as disabled;
4. Use of the wheelchair symbol: the usage of this symbol in labels and other informational formats should be considered in order to make connections with disability community and so that audiences understand that an institution and curators/artists are sympathetic and mindful of their disabled audiences;
5. An accessible website as an accompaniment to an exhibition is ideal, where it can be designed so that it is screen-reader friendly. (See WebAim's «Designing for Screen Reader Compatibility»). It is also ideal to design the website for

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[3] LINZER & BOSCH, 2013.

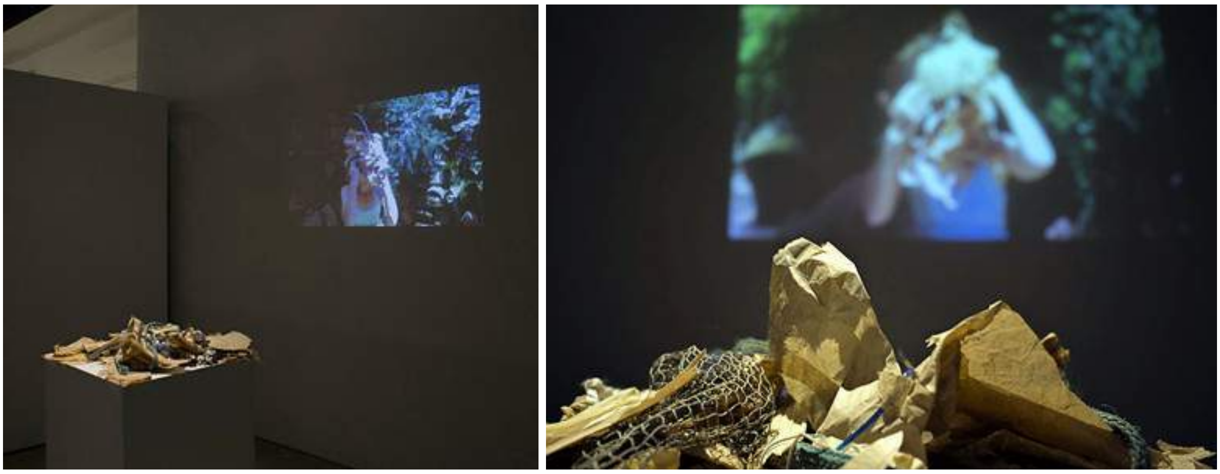
low-vision and colorblind accessibility, where the font, size, and other settings on the screen can easily be adjusted;

6. Timing: Implement all accessible components well in advance of an exhibition opening — 3 months is ideal;
7. Budget: Incorporate sufficient funds in the budget for all appropriate access components as a critical part of the overall enterprise;
8. An honorarium should be incorporated into the artist and curator fees if there is specific labor attached to creating accessible components, such as asking either party to develop the audio descriptions, and/or an accessible website;
9. Arrange for Braille label copy through organizations like Lighthouse for the Blind;
10. Text-based label copy to be in 18 point, san-serif font. This is because a larger font size is easier to read for people with vision impairments. San-serif fonts are also known to be more accessible for people with vision impairments as the extending features of the «serifs» at the end of a stroke in a word can be confusing and distracting for the task of identifying the letter;
11. Audio descriptions to be made available for each work. These audio files can be uploaded on the venue's website (or the artist and/or curator's websites) in order for people to download and listen to the files using their phones or another device. Ideally, there is a device that is already provided by the gallery that is made secure to prevent theft. Information on how to create audio descriptions can be found at the Art Beyond Sight website, and an online site where descriptions can be recorded is called Vocaroo. For examples on how I have implemented «creative» audio descriptions into my own work, see «What Can a Body Do?» at Haverford College in Pennsylvania in 2012, where there are multiple audio descriptions for each object, or in the case of «Marking Blind», there are also written transcripts of the audio files (with an Irish accent!), which offers more access to access;
12. Artwork hung at a level between 4-5 feet; in the event that the work cannot be hung lower, display a sign that offers the viewer with the opportunity to see the work in an alternative format. This format may take the form of a book with images, or an online resource of images. I implemented this strategy when I curated *Composing Dwarfism: Reframing Short Stature in Contemporary Photography* at Space4Art in San Diego as I wanted to be sure that people of short stature could effectively access the work in the gallery space.

Fig. 1. Installation of *Composing Dwarfism: Reframing Short Stature in Contemporary Photography*, Space4Art, San Diego, 2014. Photo courtesy of Michael Hansel

13. Encourage artists to make art that can be touched where possible, and ideally, touched at all times as part of a strategy towards haptic activism. However, if touching in the gallery cannot be supervised sufficiently, then it is important to develop regular touch tours etc. For example, I curated an exhibition at the San Diego Art Institute in 2016 entitled *Sweet Gongs Vibrating*, which was a multimedia, multisensory exhibition that broke with the ocularcentric by embracing myriad modes of perception. This project aspired to activate the sensorial qualities of objects to illustrate alternative narratives regarding access, place and space for the benefit of a more diverse audience, especially for people with visual impairments and/or blindness. I was especially interested in challenging the occularcentric modality of curating exhibitions, and the tendency to rely on the convention that objects must be experienced through vision alone. It was my attempt at curatorial haptic activism as an off-shoot to «creative access», as I aimed to have the visitor directly touch all works in the exhibition as much as possible. (To learn more about the history of touch in the museum, see Candlin, 2010). This proved difficult owing to insufficient resources of the gallery, however, I did engage with many of the artists in the project to request haptic-based pieces for the exhibition. One example was a video installation by Canadian artist Raphaëlle de Groot entitled *Study 5: A New Place* (2015). In order to achieve the activation of the modality of touch for the audience member that I was seeking in de Groot's work, I asked her if I could include the original found materials that she used to create her make-shift head-mask seen in the video. The artist then allowed me to place the work as a disorderly bundle on top of a pedestal in front of a projection of the accompanying video. The projected video literally broke through the flat two-dimensional visual representation on the wall so that we

could not only see the physical detritus of what the artist was experimenting with on her face and head, but the viewer could, importantly, touch it. As a gallery visitor engaged with touching the bundle of scraps, I wanted them to explore the varied surfaces of de Groot's papers, ropes, roughly-formed pieces of charcoal, plastic and other materials. If one was hearing and seeing, then one could visually observe how their touching actions mirrored the touching of the same materials taking place by de Groot in the video as she covered her head, and/or one could hear how the crinkle, crinkle, crunch, crunch noise to emerge as a result of hands making impact with crumpled paper were echoed in the sounds emanated from de Groot's same haptics. Extending de Groot's work in this way was a bid to achieve a heightened level of tactile engagement, and I argue that it is these types of «creative access» interventions that need to be encouraged as we consider the expansion of the sensorian and haptic activism within our museums and galleries.



Figs. 2-3. Raphaëlle de Groot, installation shots of *Study 5, A New Place* (2015) in *Sweet Gongs Vibrating*, San Diego Art Institute, 2016, curated by Amanda Cachia. Photos by Emily Corkery

I also negotiated for the same method of «creative access» with another artist in the exhibition. San Francisco-based artist Darrin Martin included a video entitled *Objects Unknown: Sounds Familiar* (2016), where fragmented, layered abstract forms were projected onto a wall, moving up and down in a long, thin, vertical strip similar in shape and function to a film strip. I had asked the artist to produce a three-dimensional version of these abstract shapes, so that they could be accessible to the touch. The artist decided to use 3D printing technology to create scans of the objects from collaged foam packing material. It is thus these same objects that have been animated digitally and then merged via analog video tools that further abstract the image and produce sound through the manipulation of electronic frequencies. Mounted on pedestals that also serve as speakers, the printed objects vibrated with the same sounds emanating from their projected counterparts.

Fig. 4-5. Darrin Martin, installation shots of *Objects Unknown: Sounds Familiar* (2016) in *Sweet Gongs Vibrating*, San Diego Art Institute, 2016, curated by Amanda Cachia. Photos by Emily Corkery

14. An American Sign Language (ASL) interpreter should be arranged to accompany all speaking engagements. It is also ideal to ensure that a permanent curator's talk/tour in ASL can be made available through various technology devices and also permanently online. For a template, see the Whitney Museum of American Art's vlog. When I curated *LOUD silence* at the Grand Central Art Center at California State University and then later on, at gallery@Calit2 at the University of California San Diego, I used this Whitney template to create both DIY and professional videos that were made available on iPads and online during the run of the exhibition. One was filmed on an iPhone and editing using software on a laptop at home, while the other was created in a professional television studio on a university campus. While the quality is indicative of the resources available for each project, the objective is the same: to provide access to a deaf and/or hearing-impaired audience, especially given that the exhibition itself focused on the experiences of sound and silence from a deaf and hearing-impaired perspective.

Fig. 6-7. Screen shots of Amanda Cachia providing a curator's tour of *LOUD silence* accompanied by American Sign Language interpreters (on left at Grand Central Art Center, and right at the University of California San Diego)

15. All videos with sound should be captioned. If a video cannot be captioned (or any other object that makes sound), then a listing of the sounds can be included on the label.

16. Similarly, if there are scent-based works in an exhibition, a description of the odors can also be provided. This is what I did for my *Sweet Gongs Vibrating* project at the San Diego Art Institute (along with Braille labels and instructions for how to «participate» in the work.

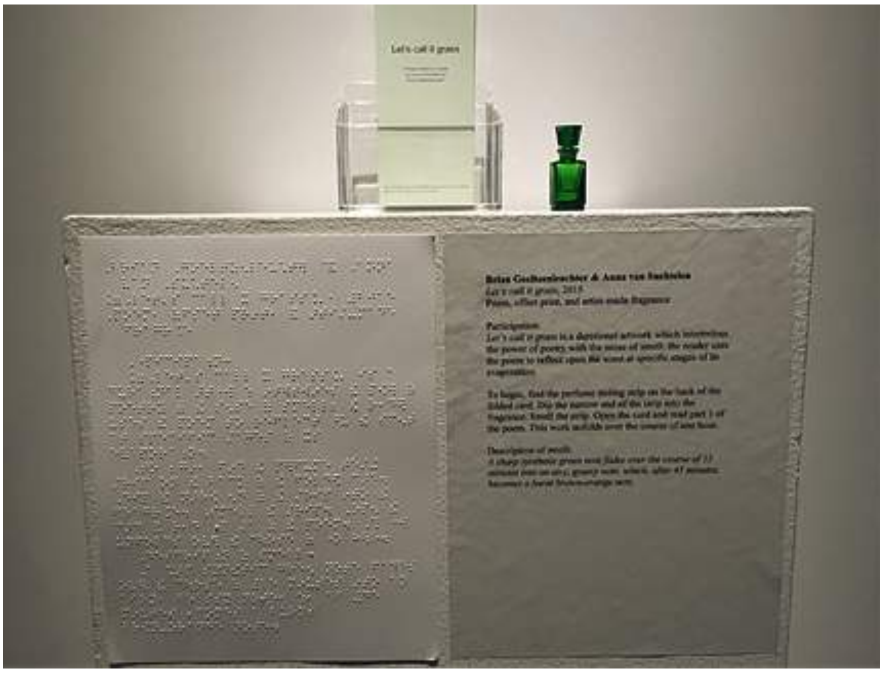


Fig. 8. Brian Goeltzenleuchter & Anna van Suchtelen, *Lets call it grass*, 2015, poetry olfaction in 3 parts as part of *Sweet Gongs Vibrating* at the San Diego Art Institute. Photo by Emily Corkery

CONCLUSION: MATERIAL AND IDEOLOGICAL ACCESS IN THE MUSEUM

In this chapter, I have attempted to build a constellation of approaches to the methodology of «creative access» within my guidelines and some curatorial examples in order to illustrate its conceptual and physical possibilities for the artist, curator, and ultimately, the audience member who engages with the object and/or work. «Creative access» has both material and ideological components that are meant to stimulate physical, cognitive and sensorial functions of the human body. Access is not as one-dimensional as people might think because it can incorporate other sensorial experiences into the work that include tactile elements, sound, captions, audio description, and more. In the execution of this work, I have found both artists to be responsive and receptive to my ideas, as much as I have been inspired by theirs. Therefore, the spirit of «creative access» suggests that it is a fluid process that takes place between the curator and artist(s) so that each party reaches consensus on what «creative access» should mean in a particular time and place for a particular exhibition and audience. In part, this also means that «creative access» is advocating for a politics within the ordinary curator-artist dialogical exchange, where each party might consider it a necessity to discuss how «creative access» will be seen, felt, and heard for the benefit of a complex embodied audience. Each instance in this essay where «creative access» has been deployed has also attempted to indicate how the artist/curator exchange on its critical import has evolved. In other words, «creative access» is not monolithic, nor uniform, much like the general definition of access itself, which is always going to be variable and dependent on a number of conditions. If the artist and curator are prepared to imaginatively engage with the work of «creative access», then conditions of narrow standardization will eventually not only be disrupted as they transform curatorial practice and the museum and gallery experience for the visitor, but vital new approaches to art-making and thinking will thrive.

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IV

NOTES FOR THE FUTURE

Fundacíon Tuya/Pedagogías Invisibles
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UNCOVERING HIDDEN STORIES IN MUSEUMS: A PATH TOWARD VISIBILITY, DIVERSITY AND INCLUSION

ANA CARVALHO*

This chapter results from the participation in the discussions that emerged from the international meeting *Representing Disability in Museums, Imaginary and Identities*, held at the *Museu Nacional Soares dos Reis* (Porto) the 29th of May 2017[1]. The *raison d'être* of this meeting was shaped by the ongoing research project *The Representation of the Disability in DGPC Museums Collections: Discourse, Identities and Sense of Belonging* lead by the researcher Patrícia Roque Martins, which was granted in 2015 with a fellowship from the Portuguese Foundation for Science and Technology. The project is being hosted by University of Porto in collaboration with the Directorate-General for Cultural Heritage (DGPC). It addresses the issue of disability in Portuguese national museums from the perspective of representation, aiming to rethink the theme by looking at collections and analyzing material evidence about disability through time, a theme that remain so far unexplored in the Portuguese museums panorama.

Can museum objects really address disability, and moreover, can they help to develop narratives that engage audiences in rethinking attitudes towards disability in contemporary issues and debates? The answer is affirmative as the project rationale

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demonstrates, but one would not be surprised if, among museum professionals, the idea can still cause some reservation, suspicion or oddity.

While the topic is receiving more attention internationally, including within the museum studies and in museums practice[2], and some positive developments can be identified from a main framework at European level and national polices[3] — addressing the issue as a human rights concern — disability-related narratives in museum exhibitions still lack representation and visibility. This was also a point remarked during the international meeting *Representing Disability in Museums, Imaginary and Identities*, while discussing several case studies of exhibitions dealing with the representation of disabled people. That was the case of *Reframing Disability* (2012-2015), an (awarded) exhibition organized by the Royal College of Physicians Museum (London) that explored a group of rare portraits from the 17th to the 19th centuries depicting disabled people, combining it with a contemporary view by inviting 27 disabled participants to bring their testimonies. In this exhibition, in one of the wall panels a central sentence strikes out — *An exhibition exploring four centuries of hidden history* — underlining the importance of exploring this topic but recognizing its marked absence as well. Another case presented was the exhibition curated by the research group *Home Debilis* from the University of Bremen in 2012. By using medieval texts and visual representations, the exhibition aimed to question common clichés regarding dis/ability in the premodern era from different perspectives (history, history of art and of language, archeology and anthropology) — which is at the core of the research carried out by this group of academics.

By gathering projects in exhibiting disability taking place in different contexts, the international meeting clearly reinforced a common ground for discussion that crosses different disciplinary and institutional experiences, and the need to share common principles and practices. At the same time, it also contributes to put in the agenda a theme that, while having some recognition, is still in the margins of contemporary museology debates. Furthermore, it remains central that a research project such as *The Representation of the Disability in DGPC Museums Collections: Discourse, Identities and Sense of Belonging* can catalyze debate and action in the museum field — where the universities role is key —, especially in present times where it seems to be less space to experimentation, in part due to budget restraints in the museums panorama — in consequence of the financial crisis that lead to main changes in public polices in last years, putting museums at minimum levels of action and to basic functioning parameters[4]. Another point that the project The *Representation of the Disability in DGPC Museums Collections* emphasizes is the mutual benefits of a more active partnership between academia and museums,

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[2] SANDELL *et al.*, 2010.

[3] MARTINS, 2017: 21-55.

[4] See, for instance, ICOM PORTUGAL, 2017 for a global assessment report about some of consequences that Portuguese museums have been facing in the last years.

which means to find more effective paths to interlink theory and practice in museums, a connection that still lacks in the Portuguese case in a more systematic and enduring way.

CONTRIBUTING FOR SOCIAL TRANSFORMATION

Taking in consideration a larger framework, bringing disability issues to present-day debates also challenges museums to reframe their social role in contemporary society. In the last decades extensive literature has been produced about museums role, discussing the need to adapt to a changing and continuously challenging society, reviewing museum frontiers and methods. The demand for a more acting role is also linked to the need to achieve relevance, as museums are rooted in society, and where there is a role to fulfill reflecting on historical issues, but also linking them to the social and cultural issues of present-day. For instance, the report and campaign *Museums Change Lives* (2013) from the Museums Association makes that point clear, advocating for the importance of maximizing the museums social role and impact in contemporary life. More recently, the UNESCO *Recommendation Concerning the Protection and Promotion of Museums and Collections, their Diversity and their Role in Society* (2015) also establishes general guidelines about the museums social role, underlining their contributions to social integration and cohesion, and diminishing inequalities[5].

In such umbrella for museums social role can also be included the banner of cultural diversity and inclusion, reinforcing museums as spaces of representation of different identities and multiple views about the world. In 2017 the theme chosen to reflect and celebrate the International Museums Day was *Museums and Contested Histories: Saying the Unspeakable in Museums*. An array of possibilities emerged: from controversial and contested stories to traumatic historical events (holocaust, genocides), taboo issues (in some countries: slavery, colonialism, etc.), reconciliation stories (ex. Apartheid), objects repatriation, illicit traffic, sub representation of groups or communities, and other issues related to genre, migration, etc. Clearly, there are many hidden stories in museums to uncover as acknowledged by the ICOM's choice of theme. One could argue that disability representation is among the hidden stories to uncover in the museum's scenery. Furthermore, as observed among the projects discussed in the international meeting *Representing Disability in Museums, Imaginary and Identities*, one of the driving leitmotifs is the possibility of using museum objects no only as relevant material evidence to sustain re-interpretation or new narratives, but also the opportunity for museums to engage with contemporary topics. This envisages the idea that museums can contribute to shape conversations about disability in our society, tackling misunderstandings and stereotypes to promote comprehension and dialogue. As spaces of negotiating difference, museums select what is represented, what is included and excluded. Consequently, there is the

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[5] Cf. CAMACHO *et al.*, 2016.

potentiality of affirming themselves as spaces for the promotion of intercultural dialogue by debating society issues and a plurality of views, bringing to the arena silenced or neglected voices by creating constructive environments that facilitate collective reflection. In this way museums can contribute for dialogue, and to a better understanding of the obstacles of living in society[6]. In theory, this is consistent with abandoning the idea of a museum discourse based in neutrality, and framed exclusively in one voice. This acknowledgment means also rethinking museum practices: who and what is represented, how is represented, and who speaks for who?

In fact, there are many opportunities for museums to be working more closely with their constituencies and to become and stay relevant in society. Yet, in spite of embracing a more conscious role in society, many museums fail to be «for» people and «with» people. As museum director, David Fleming, points out, museum strategies committed to social relevancy are still considered radical thinking, and remain at the margins of mainstream museums[7].

APPROACHING DISABILITY IN PORTUGUESE MUSEUMS: IN A TURNING POINT?

The most recent history of museums has been marked by a change of paradigm that points out a need for museum transformation and redefinition, traditionally viewed as elitist and exclusive, to become socially responsible organizations. This requires for museums to be more accessible, participatory and inclusive, taking in consideration the needs and interests of different audiences[8]. In this path to ensure public policies towards diversity, museums have been developing strategies to eliminate barriers at multiple levels, from ethnicity, to genre, religion, sexuality (ex. GLBT), intergenerational, but also to physical, social and intellectual aspects of access. These strategies not only suggest the need to adapt museum spaces, but also the need to provide useful information and improve communication and review the way people are welcome in museums. Another aspect is to design public programs that are relevant to specific groups. Furthermore, to use museums as spaces for representation of different identities involving groups under-represented. But above all, it means developing a diversity strategy at different levels of the museum practice and crossing all sectors. It also reinforces the need of a strategy focused at diversifying audiences by envisioning diversity as a central concern of the museum practice rather than taking the form of episodic or peripheral measures.

Disability is not a strange word in the context of Portuguese museums. In fact, some developments can be observed, especially with the turn to XXI century. In what concerns disabled people, it has prevailed a strong focus in improving physical access.

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[6] KREPS, 2013.

[7] FLEMING, 2012.

[8] See also CARVALHO, 2016.

Furthermore, some specific public programs have been developed; globally, can also be observed a growing understanding of museum accessibility beyond the physical barriers. However, in spite of some improvements in eliminating architectonic barriers and some advances in communication and welcoming staff and facilities, many barriers still persist, including physical, but not exclusively, that still apart disabled people from museums[9]. The recent digital publication *Guia de Boas Práticas de Acessibilidade: Comunicação Inclusiva em Monumentos, Palácios e Museus*[10] still emphasizes the need to improve access conditions and communication in cultural spaces. In that sense, it makes clear that it is a working process, and additional efforts should be taken into practice in the Portuguese museum sector in order to move the issue to another level. Main challenges are also identified by Martins[11] that point out organization (and strategic) changes, professional capacitation crossing all museum departments, namely museum leaderships strongly committed, investment in involving groups of interest by promoting active partnerships, a continuous offer of museum public programs for disabled people, and the need to evaluate programs and initiatives impact and effectiveness. In resume, museums in order to be capacitating need to be firstly capacitated. Another step to be taken is within the context of representation, where the project *The Representation of the Disability in DGPC Museums Collections: Discourse, Identities and Sense of Belonging* bring novelty, may open new and future insights.

ADDRESSING THE RISKS AND MOVING FORWARD

Dealing with the subject difference in museums, whether in the realm of disability or other kinds of differences, brings along risks that should be taken in consideration and reflected by museum professionals prior to any action. Building on the discussions, formal or informal, that emerged within the international meeting, some of those risks were tackle. Among them, the risk of reinforcing differences (from a negative point of view), and misunderstandings; the risk of increasing a divisive line between us and them; the risk of offering sensationalism instead of comprehension; the risk of using inappropriate language and terminologies (not an obvious topic and in some ways not consensual); finally, the risk of perceiving disability as a homogeneous group. As a social minority, these groups have shared in common social exclusion in society, but disability presents itself in a multitude and diversity of situations and different levels that, consequently, require specific needs.

By briefly mentioning these risks, one does not argue a passive role from museum professionals, by the contrary, the need to approach disability in museums practice in a better-informed process. As demonstrated in this international meeting by Fernando

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[9] MARTINS, 2017.

[10] MINEIRO, 2017.

[11] MARTINS, 2017.

Fontes (*Framing Disability in Portugal: Historical Processes and Hegemonic Narratives*) an historical perspective that highlighted how disability has been understood through time and by several institutions (state, church, associations, etc.) clarifies that there is no single definition for disability and remarks the contribution of other areas to better understand this reality.

PERSPECTIVES

One of the points mentioned in this international meeting was that there are no definitive solutions dealing with disability in museums. However, a more acting role of museums and professionals is needed to push forward creative thinking in designing practices to approach disability, contributing to reduce its invisibility. Furthermore, it requires considerable changes. In this respect, several aspects remain crucial. Amongst them, the need of sensitization about these issues within the organisations governance, and the commitment of leaderships at different levels.

Another point is the awareness that there are different models of understanding integration and inclusion. If in the past some strategies that envisage integration were conceived in a way that reinforced a sort of exclusive bubbles by developing programs strictly orientated to and within groups of disabled people, revised strategies may be necessary to support deeper inclusion. This reinforces the combination of diverse and complementary strategies in order to place inclusion as a mainstream goal. Evaluation of such processes remains essential to assess programs impact and move forward in a reflexive and constructive way. Active listening, as a soft skill, and the empathy of placing ourselves in the place of the other may be an exercise that offers some guidance in the self-assessment of the programs carried out.

Developing sustainable partnerships with groups and communities associated with disability remains a central issue. The notion of participation is not new in the field of museums — and cultural organizations at large[12] —, and is seen as a challenging growing field of experimentation[13]. However, working collaboratively and capacity building of such partnerships in the context of disability groups in a more committed way is still a struggling issue in the Portuguese museums panorama[14]. On the other hand, the episodic nature and lack of continuity of projects and activities dealing with disability, their remit to special programs carried out isolated or in specific museum departments instead of approaches that involve the museum as a whole, are indeed critical challenges.

The diverse perspectives feature in this Meeting offered not only a common ground of principles in this area but contributed also to a stimulating ongoing debate to explore new ways of envisioning the role of the museum in the XXI century — a museum more

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[12] CARVALHO, 2016.

[13] ANTOS *et al.*, 2017.

[14] See MARTINS, 2017.

connected to society, that celebrates cultural diversity, promote accessibility, representation and the participation of diverse audiences. Clearly, projects such as *The Representation of the Disability in DGPC Museums Collections: Discourse, Identities and Sense of Belonging* may contribute to unlock new fields of experimentation and critical thinking.

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Label: [museum]
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Amanda Cachia has curated over forty exhibitions, many of which highlight disability politics in contemporary art. She is an Assistant Professor of Art History at Moreno Valley College in Riverside, California, and Director of the new Moreno Valley College Art Gallery, scheduled to open in 2020. She completed her PhD in Art History, Theory, and Criticism at the University of California, San Diego, in spring 2017.

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Emma Shepley is a senior freelance curator, writer and museum consultant. Her clients include Historic Royal Palaces, Science Museum, London and the Museums Journal. She was Senior Curator of the Royal College of Physicians Museum, London (2005-2016), establishing and directing the museum, staff and curatorial projects and programming. Emma is a former Chair of the London Museums of Health and Medicine special subject network www.medicalmuseums.org and Curator of Paintings, Prints and Drawings at the Museum of London (2000-2005). She started her career as Assistant Curator at Haslemere Educational Museum, Surrey.

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REPRESENTING DISABILITY IN MUSEUMS

IMAGINARY AND IDENTITIES

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