

## **CULTURAL PERSPECTIVES OF DISABILITY IN PORTUGAL**

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### **ABSTRACT**

Approaches towards disability policies in Portugal have experienced profound changes over the course of the last thirty-five years. Current literature indicates that academia in Portugal has only fairly recently begun to explore the significance of studies in disability from cultural studies or disability studies perspectives, as opposed to other more well-established fields of study like history and sociology. While Cultural Studies lean towards a worldwide or national understanding of culture, disability studies questioned whether “a single identity of disability was sufficient to identify a culture, and, if so, what the parameters of that culture might be” (Davis and Drazen 2011: 1014). However, disability is very different to race, religion or gender as it can be easily changeable. The aim of this paper is to present and analyse the diverse perspectives of disability in Portugal with distinctly different socio-economic, political, cultural and historical experiences.

Keywords: disability; culture; disability studies; Portugal.

### **RESUMO**

As abordagens às políticas de deficiência em Portugal têm sofrido alterações profundas ao longo dos últimos trinta e cinco anos. A literatura atual indica que a academia em Portugal só recentemente começou a explorar o significado dos estudos sobre a deficiência na perspectiva dos estudos culturais ou dos estudos da deficiência, em oposição a outros campos de estudo mais bem estabelecidos como a história e a sociologia. Enquanto os Estudos Culturais se inclinavam para uma compreensão mundial ou nacional da cultura, os estudos sobre deficiência questionavam se “uma única identidade de deficiência era suficiente para identificar uma cultura e, em caso afirmativo, quais seriam os parâmetros dessa cultura” (Davis e Drazen 2011: 1014). No entanto, a deficiência é muito diferente de raça, religião ou sexo, pois pode ser facilmente alterável. O objetivo deste artigo é apresentar e analisar as diversas perspectivas da deficiência em Portugal com experiências socioeconómicas, políticas, culturais e históricas distintas.

Palavras-chave: deficiência; cultura; estudos de deficiência; Portugal.

## **1. Introduction**

Culture involves not only behaviours, habits, traditions, norms and rules, but it is also about shared history, and not least a common understanding of social history. Furthermore, culture is strengthened through common languages, symbolic values, clothing, music and other markers, all of which give a sense of identity and belonging. Surrounding patterns of behaviour and norms within societies and local communities will help to define and characterize the very perceptions someone has from earliest childhood years, and ultimately determine behaviour later in life. Social anthropologist Geert Hofstede defines this as “the collective programming of the mind which distinguishes the members of one human group from another” (Hofstede 1984: 21). Culture is held to be a hallmark of nations or peoples. However, there are also smaller groups in a society that differ from the rest through special features in norms, uses of symbols or ornamentation of the body, for instance. Such groups fall under subcultures like hipsters, swingers, drag, geeks, greasers, Hells Angels’ bikers and so many others. Cultural differences endure because culture is contingent on the knowledge and experiences of individual people, and oftentimes these differences make communication complex and challenging.

Certainly, over the course of past decades, the academic field of culture has turned into a distinctive inter, multi and transdisciplinary platform. It has allowed for reflection, enquiry, and study of what constitutes knowledge, representations and concepts of culture from perspectives of other areas such as the social sciences and humanities. In writing this paper, consideration has been given to preserve some semblance of continuity, relevance and cohesion in researching the nature of the relationship between cultural studies and disability studies, and consequently the main title of this study suggests a union formed between cultural studies and disability studies. Current scholastic literature identifies this as a relatively young relationship, albeit the union of which has already led to an offspring in academia, namely that of cultural disability studies. Therefore, in contemplating the essence of this relationship, it becomes appealing and seems worthwhile to look at different representations of culture and disability. To undertake such a task from a more global perspective would be dramatically overwhelming, complicated and unsuitable to the task at hand. Therefore, the aim of this paper is to present and analyse the diverse

perspectives of disability in Portugal with distinctly different socio-economic, political, cultural and historical experiences.

## 2. Disability: The designation of meaning

Approaches towards disability policies in Portugal have experienced profound changes over the course of the last thirty-five years. There has been a move away from a model based on welfare towards one that is rights-centred accentuating equal rights of those bearing impairments. Daniel, R. Kelemen and Lisa Vanhala argue in “The Shift to the Rights Models of Disability in the EU and Canada” (2010) that the reasons for this fairly swift change in conceptual models of disability are due to “cross-national paradigm shifts in the face of institutionalized mechanisms that one would expect to resist radical change,” adding that:

federal and supranational governments played a key role in encouraging the spread of the rights model of disability in their respective federal political systems and that this is crucial in explaining the timing of the shift. We find that reframing disability issues as a question of rights helped to expand the authority and the legitimacy of centralized governance (2010: 1).

Concepts of health and disability are elaborately interwoven with each other. In other words, for every function, there is a potential absence of function<sup>1</sup>. Thus, the meaning of disability has oftentimes been defined in different ways determined by the economic, social and medical tendencies at a given time. Whilst previously disability involved the study and diagnosis of a disease that afflicted a person, today it involves a more comprehensive array of considerations given not only to pathological, but also personal, social and environmental examinations.

Certainly, views of disability have unquestionably undergone changes over the course of many years and a number of conceptual models have surged that offer some sort of meaning as to the placement of disability, particularly in Western societies. However, the three models most frequently referred to are the *medical model*, the *social model* and *individual-environment model*. Primarily, the dominant medical model focusses on the deficiency an individual has because of an impairment or an illness. In essence, this model

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<sup>1</sup> To illustrate, one may have a well-functioning body but after a serious car accident can be left with legs that have lost the capacity to function fully and independently.

places the challenge of living with an impairment or illness solely on the bearer of said impairment or illness. To illustrate, if a wheelchair user cannot access public bathroom facilities, this model suggests that the problem lies with the wheelchair and not the facilities. In contrast, the social model sees the lack of access for the wheelchair as the disabling barrier, thus disability stems from a person with an impairment attempting to function in an inaccessible society. In other words, the social model contests that disability is a social construct, that society has failed to accommodate people with impairments.<sup>1</sup>

Also, the medical model attempts to remedy disability through a cure of sorts, or an attempt to make the impairment less prominent and thus make the person more “normal”, whereas the social model supports a shift in the way the individual and society interact. So, if public bathroom facilities become fully accessible, it will make no difference how one enters whether it is in a wheelchair, walking, pushing a stroller or running. The medical model supports the notion that an individual bearing an impairment has a deficiency or an abnormality, and that only trained professionals such as medical doctors or therapists, for example, can help this person to fit accordingly into society. In contrast, the social model maintains that an impairment is simply a difference much like a person’s age, race or gender and that it should not be seen as an abnormality or something negative.

However, these two models are based either on a medical concept or a social concept and it became clear at some point that this presented limitations and from this grew a movement towards biopsychological models, from which the individual-environment model stems. After the 29<sup>th</sup> World Health Assembly in 1976, the World Health Organization (WHO)<sup>2</sup> ultimately issued the first internationally shared conceptual model of disability identified as the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). This model centres on classification within three areas: impairment, disability and handicap. It defines an impairment as anything considered to be an abnormality of body structure, appearance

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<sup>1</sup> For further information, see [https://www.ombudsman.org.uk/sites/default/files/FDN-218144\\_Introduction\\_to\\_the\\_Social\\_and\\_Medical\\_Models\\_of\\_Disability.pdf](https://www.ombudsman.org.uk/sites/default/files/FDN-218144_Introduction_to_the_Social_and_Medical_Models_of_Disability.pdf); “Models of disability”, available at <http://www.scielo.org.za/pdf/hts/v74n1/06.pdf>; “Models of Disability: keys to perspectives”, available at [https://www.theweb.ngo/history/ncarticles/models\\_of\\_disability.htm](https://www.theweb.ngo/history/ncarticles/models_of_disability.htm); “Conceptual Models of Disability» (2014) by Alycia Reppel and Segun Dawodu, available at <https://now.aapmr.org/conceptual-models-of-disability/>.

<sup>2</sup> Portugal was among the first eighteen active member states to join the WHO in 1948, and has actively supported its policies and activities.

and/or organ system and function. A disability is the consequence of an impairment in relation to functional performance and activity of an individual. A handicap is the disadvantage encountered by an individual because of an impairment or disability. In the International Classification of Functioning, Disability and Health (ICF),<sup>1</sup> disability and functioning are viewed as:

outcomes of interactions between health conditions and contextual factors. Contextual factors include external environmental factors and internal personal factors. There are three levels of human function [...] functioning at the level of the body or body part, the whole person, and the whole person in a social context. Qualifiers are then used to record the presence and severity of a problem at each of these levels, resulting in a classification system (WHO 2001).

These three models, as well as other models, offer different views of what disability means. And, not only will these models influence how governing entities define the rights and obligations of this minority group of citizens, but they will also have an impact on how disability is perceived culturally by fellow citizens. There is already a significant amount of research and literature within cultural studies and disability studies in nations such as the United States and the United Kingdom that has led to a wedlock, so to speak, between the two and the academic field of cultural disability studies has earned a place of its own in academia. Disability studies emerged between the late 1980s and early 1990s and gained its momentum from race, feminist and queer studies. It drew from the rapidly growing field of cultural studies to make sense of the cultural, social and political setting of disability as an identity.

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<sup>1</sup> The ICIDH has undergone several revisions over the course of the last decades since its first release in 1976, and today the model has been reclassified as the International Classification of Functioning, Disability and Health (ICF). The ICF is the WHO framework for measuring health and disability at both individual and population levels. ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 (resolution WHA 54.21) as the international standard to describe and measure health and disability. The ICF aims to categorize health and health related areas so as to describe alterations in bodily functions and structures, levels of individual capacity, and levels of individual performance. In the ICF model, the term functioning is a reference to all bodily functions, activities, and participation, whereas the definition of disability points to impairments, activity limitations and participation restrictions. Of equal importance is that the ICF places significant weight on health and functioning as opposed to disability, and is devised to supplement the International Statistical Classification of Diseases and Health Related Problems.

While Cultural Studies lean towards a worldwide or national understanding of culture, disability studies questioned whether “a single identity of disability was sufficient to identify a culture, and, if so, what the parameters of that culture might be” (Davis and Drazen 2011: 1014). However, disability is very different to race, religion or gender as it can be easily changeable. The line between being able-bodied and disabled can be crossed in mere moments upon being involved in an accident, for example. Similarly, the disabled body can return to an able-bodied state through treatment, remission and use of aids such as a hearing aid or a prosthetic limb. By all intents and purposes therefore, disability studies have had to take into consideration this irregular and volatile nature when examining culture and identity. It has also had to weigh in the well-established tradition of examining disability<sup>1</sup> as scientific discourse as opposed to a more humanities-based one that will consider the many (mis)representations of disability compared to other identities and mainstream ableist cultures. The question now begs asking of where Portugal stands in regards to studies within disability.

### **3. Cultural representations of disability: religious, economic and political**

Current literature indicates that academia in Portugal has only fairly recently begun to explore the significance of studies in disability from cultural studies or disability studies perspectives, as opposed to other more well-established fields of study like history and sociology. In an article entitled “The emancipation of disability studies in Portugal” published in 2014, Fernando Fontes, Bruno Sena Martins and Pedro Hespanha claim that:

Despite the interest of the social sciences in issues of exclusion and inequality, the question of disability, as a key issue of reflection, remains absent from many academic areas. The emergence of disability studies owes much to contexts in which the activism of disabled people has revealed the structural conditions that oppress and neglect experiences of disability (Fontes *et al.* 2014: 1).

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<sup>1</sup> Davis and Razen write that studies in disability look at “how it [disability] intersects with issues of social class, postmodern and postcolonial analyses of knowledge, and power... [it] is concerned with trying to understand and construct the way that dominant ableist definitions of “normality” can be imposed on people with physical and mental differences” (Davis and Razen 2011: 1015).

They go on to state that although disability as a research field is thriving in other parts of the world, in Portugal it “is still very embryonic both in terms of the political mobilisation of disabled people and in the academic world” (Fontes *et al.* 2014: 7).

Arguably, it may seem somewhat sweeping and presumptuous to say that traditionally, research into disability in Portugal has come mostly from researchers within the medical or social sciences. However, when searching for literature on the issue of disability from cultural studies or literary perspectives in our contemporary Western society, it does not take too long to realise that discussion around the placement of disability in Portuguese society reverts continuously to the medical and social sciences. Thus, it seems that amongst the narratives about discrimination, inequalities and bias that are articulated in the body, research on disability emerged from, and remains primarily in the fields of the medical and social sciences. Nonetheless, it is worthwhile to emphasize that this is not to say that other human sciences, such as research in cultural studies are completely disregarding the placement of disability from a cultural studies perspective.

As successors of gender and racial studies, theorists of disability models prompted a review and reclassification of what it means to be the bearer of a body with an impairment, which has for so long been regarded as falling outside of “normality”. Similarly, it is also evident that much discussion has been taking place in what concerns the linguistic dynamics of disability much like what has happened with other minority or discriminated groups of society, like women and LGBT groups. In what concerns disability in the international arena, new words and terminologies have been defined, popularized and coined, as was laid out in the publication of the ICF by the WHO. However, translations may hold different cultural nuances for the Portuguese versions, as argued by Diniz, Medeiros and Squinca (2007):

O termo escolhido para traduzir *disability* foi “incapacidade”. Talvez os tradutores tenham apostado na aceitabilidade do conceito de “incapacidade” no léxico ativo do idioma para representar o espírito guarda-chuva sugerido pela ICF para *disability*. Outra possível explicação é que a entrada em cena de um novo conceito facilitaria o trabalho de aceitação do vocabulário [...] No entanto, “incapacidade” ignora trinta anos de debate acadêmico e político internacional, em especial as contribuições do modelo social [...] A única tradução possível para *disability* – acurada e aceitável para o marco teórico que inspirou a revisão da ICF – é deficiência. *Disability* e deficiência são conceitos carregados de conteúdo normativo para o universo biomédico, e essa não é uma particularidade da Língua



Portuguesa. Mas a escolha de *disability* e não outra categoria foi exatamente para provocar a tradição biomédica de dois séculos que compreende deficiência como algo fora da norma. Havia um objetivo político e moral por trás da escolha de *disability*: desestabilizar a hegemonia biomédica no campo. Outro indício desse fenômeno foi a tradução de *impairments* por deficiências. Para o modelo social, *impairments* representam as lesões, isto é, as variações corporais, ao passo que *disability* é o que expressa a interação do corpo com a sociedade. [...] Há uma tentativa de redescrição acadêmica, política e moral da deficiência, um esforço conjunto de diferentes saberes por reconhecer a deficiência como uma expressão da desigualdade social. O neologismo *disablism*, cuja tradução seria a ideologia que oprime o corpo deficiente, isto é, a opressão pela deficiência, resume esse fenômeno: há uma ideologia que oprime e segrega o corpo com lesões (2007: 8).

There is general consensus among scholars that continuous repressions and stereotyping of the human body have led to the coining of various terms in English, such as the term *disablism*. Portuguese speaking scholars working within the field of disability, whether in Portugal, Brazil or other Portuguese speaking nations, have struggled to identify a satisfactory analytical classification in Portuguese that does not convey discrimination due to disability in much the same way there is discrimination due to colour of skin. Brazilian researchers Debora Diniz and Wederson Santos are of the opinion that there are analytical and discursive categories to describe such deviant forms of persecution by the body such as:

sexismo, no caso da discriminação por sexo; homofobia, no caso da discriminação pela orientação sexual; racismo, no caso da discriminação pela cor da pele ou etnia. No caso da deficiência, há uma ausência no léxico ativo da língua portuguesa. Nossa incapacidade discursiva é um indicador da invisibilidade social e política desse fenômeno (Diniz and Santos 2010: 10).

They go on to question firstly, how to define the contradictory impact of the principles of normality on bodies that bear impairments, and secondly, what name to give to those expressions of inequality endured by people with disabilities in their workplace, in their communities, and in relationships, among others.

Two terms originally used in academia have now been readily absorbed into mainstream disability lexicon; *disablism* and *ableism*. These are used to refer to disability discrimination, stigmatization, prejudice and preconceptions, much like the terms *racism* and *sexism* which are used to



refer to discrimination against different racial groups and women. Thus, disablism is used to describe discrimination or prejudice against people with disabilities, whilst ableism is used to describe discrimination in favour of people who do not have disabilities. Although both terms define discrimination against those with disabilities, the significance is not the same. In the case of disablism, the emphasis is placed on discrimination against people with disabilities, whereas in the instance of ableism the emphasis is placed on discrimination that favours able-bodied people.

And, herein lies one of the current ongoing discussions among Portuguese speaking scholars and disability activists, which is to find the most adequate Portuguese translation of the term disablism. Nonetheless, there appears to be general consensus about the meaning that “disablism is the result of the culture of normality, in which bodily impediments are the target of oppression and discrimination” (Diniz *et. al* 2018: 182). Normality is oftentimes taken as a reference to the biomedical understanding of how a body is created and is expected to function, and disability according to many scholars and activists “functions as a dustbin for disavowal for the category of normality” (Shakespeare 1994: 283). The attention being given to several terms such as disability, normality and abnormality along with their respective constructions, meanings and interpretations continues to provide much dialogue in several circles.

Setting aside this linguistic conundrum, it remains certain and undisputable that disability is an increasing reality in Portuguese society that cannot be disregarded. Due to considerable advances in science, technology, medicine and social structures, the quality and expectancy of life has both improved, and subsequently increased. People are now living longer, which means that the likelihood of gaining some degree of mental or physical impairment increases accordingly. The boundary between being able-bodied and disabled is unequivocally permeable, and this makes it evermore so important to contemplate disability issues critically so as to tackle the stigmatization, repression, segregation and marginalization people with impairments encounter daily. Failure to do so may come with dire consequences for the quality of our socio-cultural fabric as well as political and economic policies.

According to Fernando Fontes in *Social Citizenship and Collective Action: The case of the Portuguese Disabled People's Movement* (2011), “disability policies and politics in Portugal have been moulded by a combination of three main factors: the strong Catholic social background of Portuguese

society, the economic situation of the Portuguese state and the leading role of the family in social provision” (Fontes 2011: 101). He goes on to claim that the Portuguese state has harboured a more remote approach when it comes to dealing with disability issues opting to take on a subordinate position and acting only when society extends pressure (Fontes 2011: 101). Indeed, people with disabilities in Portugal have gone through very different experiences as opposed to those living in countries like the UK and USA where disability movements for equal rights began decades earlier, and activists were exposed to different realities. Some of these different realities have come about because of events in Portugal’s history, economy, politics, technological development and cultural modifications.

Advocates of the social model of disability defend that meanings of disability continue to be nurtured on a regular day-to-day basis by strong traditional convictions and religious beliefs, notwithstanding of course other factors such as economic structures. There are Portuguese and foreign academics alike, who believe that the implementation of oppressive and segregationist policies as well as stigmatizing social attitudes can be traced to Portugal’s inherently resilient Catholic past (Barnes 1997: 22). Certainly, religion was present long before the emergence of industrial capitalism and democracy in its modern-day framework. Fontes suggests that:

the Portuguese state’s attitude to disability issues has been characterised by detachment, i.e. the state has maintained a secondary role here, only acting when pressured by civil society [...] this reveals current and past laws and social policies regarding disabled people have been shaped by the combination of Judeo-Christian attitudes towards disability, the endemic economic crisis of the Portuguese state and the leading role played by the family in social provision (Fontes 2011: 79).

#### **4. Religious markers in defining disability**

In considering how disability is represented in today’s contemporary Portuguese socio-cultural structures, it is worthwhile to explore a bit further the meaning that disability has gained from religious markers. Certainly, and by no means exclusive to Portugal, religious references abound in everyday rhetoric like heavily stigmatizing and dismissive expressions to explain and almost exonerate a disability such as: “o coitadinho”, “pobre do aleijadinho” “um anjinho de Deus”, “Deus assim o quis”, “mas Deus

compensou com inteligência”<sup>1</sup> amongst others. The underlying intention of such sayings are oftentimes also attempts to minimize, justify or explain the notion of a divine punishment through some impairment as for example: “um presente de Deus” or “Deus não dá uma cruz maior que não se possa carregar”<sup>2</sup>. It could be argued that since its beginnings, Christianity has tried to find alternative approaches to dismantle beliefs of divine punishments by offering such alternatives. According to Thyeles Strelhow: “entender a deficiência assim torna-se um jeito tolerante de conviver com a pessoa com deficiência através de uma concepção de caridade, que em certo ponto remonta às primeiras comunidades cristãs e seu cuidado para com as pessoas marginalizadas (2018: 78).

It might be argued that the designation of meaning is originally linked to values, principles and historical events, which serve as the foundations for meaning to flourish, evolve and possibly eventually mutate. Similarly, one might say that the concept of disability has been subjected to considerable changes in meaning over the course of many years. One might even dare to say that disability remains in a state of morphosis. In Portugal, for a long time, the meaning and understanding of disability have been drawn from spiritual and religious interpretations which may in part explain the limitations in resources available that could contribute towards the advancement of those with impairments. Additionally, it is well known that such individuals were, and to some degree still are, oftentimes stigmatized, isolated, and hidden from society for fear of shame, seen as a punishment for sins committed and regarded as socio-economic burdens. One can effortlessly find an abundance of indications and examples of the low regard that several religions have held for those with disabilities. Much like religious misogyny, acts of intolerance and discrimination against those with disabilities have doctrinal support which not only serves to justify certain inequitable behaviours, but also provides apologetics used to address potential conflicts that arise. Many professed loving and compassionate religious denominations are able to identify scriptural rationalization for many behaviours that may explain, justify and even foster intolerance and exclusionary acts.

Indeed, scriptures of all faiths such as Judaism, Christianity, Hinduism and Islam, to refer to but a handful, have been subjected to various

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<sup>1</sup> These expressions also have their English counterparts: “poor thing”, “poor little cripple”, “a little angel from God”, “God wanted it this way”, and “but God compensated with intelligence”.

<sup>2</sup> Similar expressions are also present in English speaking cultures: “a gift from God”, “God wanted it this way” and “God does not give a cross greater than can be carried”.

interpretations to serve, explain and justify just about any behaviour. And, interpretations of the impaired body abound. To illustrate, in the Old Testament in the Bible, in Leviticus 21, it reads:

<sup>16</sup> And the LORD SPAKE UNTO MOSES, SAYING,

<sup>17</sup> Speak unto Aaron, saying, Whosoever he be of thy seed in their generations that hath any blemish, let him not approach to offer the bread of his God.

<sup>18</sup> For whatsoever man he be that hath a blemish, he shall not approach: a blind man, or a lame, or he that hath a flat nose, or any thing superfluous,

<sup>19</sup> Or a man that is brokenfooted, or brokenhanded,

<sup>20</sup> Or crookbackt, or a dwarf, or that hath a blemish in his eye, or be scurvy, or scabbed, or hath his stones broken;

<sup>21</sup> No man that hath a blemish of the seed of Aaron the priest shall come nigh to offer the offerings of the LORD MADE BY FIRE: HE HATH A BLEMISH; HE SHALL NOT COME NIGH TO OFFER THE BREAD OF HIS GOD.

<sup>22</sup> He shall eat the bread of his God, both of the most holy, and of the holy.

<sup>23</sup> Only he shall not go in unto the vail, nor come nigh unto the altar, because he hath a blemish; that he profane not my sanctuaries: for I the LORD DO SANCTIFY THEM (*King James Bible*, Leviticus 21:16-23).

Authors like James Andre Blunt (*The God Insanity: Biblical Christianity Disproved*, 2019) and Dan Barker (*Mere Morality*, 2018) have referred to such writings as being discriminatory and offensive to those with impairments, and an unacceptable way of thinking in our contemporary world. Barker argues that:

[such doctrine] is not morality. It is righteous discrimination. A person with a defect is insulted as a “desecration” to God’s perfection not because of any bad behaviour but simply for being physically imperfect. Whose fault is it if you were born a dwarf? The animals that God demanded to be sacrificed to him had to be the most perfect, clean and unblemished individuals (Barker 2018: 92).

Indeed, a brief overview of the pre-Christian Era in the Western world shows that those with impairments were on the whole stigmatized and thus

treated accordingly. They were neglected, treated very poorly, and faced hostility of varied physical punishments, inadequate conditions of hygiene, health and safety, unsafe working conditions, socio-cultural segregation and sexual exploitation. A child born with any visible impairment would be associated with superstitious beliefs, punishments and bad omens sent by the gods, demons or supernatural beings. These so-understood punishments were seen as supernatural interventions for bad behaviour, of the parents primarily, but also because of family members, and this remains deeply entrenched in Portuguese culture, particularly among the older generations that grew up at a time when religion was paramount to social acceptance.

When contemplating other religious doctrines regarding disability, it readily becomes apparent that it is not particularly challenging to find references to the impaired body. Buddhism can be put forward as another example of a faith offering interpretations of disability.<sup>1</sup> Buddhism embraces a diversity of beliefs, as well as traditional and spiritual practices which are based on the teachings of Buddha and subsequent interpretations and philosophies that have grown from these, one of which is karma. In Buddhist beliefs, karma refers to the cycle of rebirth, in which an action is moved by an intention, a deliberate action through the mind, speech or the body has consequences. Some well-known everyday expressions reflect this belief; “what goes around comes around” or “you reap what you sow”. Megan Smith, herself a wheelchair user, writes of her experience in Nepal:

having a disability, like being a woman, places you at a lower level of enlightenment, a result of karma from a past life. For persons with disabilities this translates to being objects of pity and charity, and for some Cambodians with disabilities it translates to an acceptance that we should suffer to build better karma for the next lifetime. This notion is highly egregious to my American disability rights sensibilities, where not only am I proud to have a disability, but I believe that the difficulties and the prejudices I face are not inherently due to my disability but rather a society that is not accessible. The notion that I should accept suffering in the hopes of not having a disability in my next lifetime is

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<sup>1</sup> Pew Research Center places Buddhism as the world’s fourth largest religion. Pew Research Center is a non-partisan fact tank based in Washington, DC that conducts public opinion polling, demographic research, media content analysis and other empirical social science research. In accordance with a demographic study carried out by Pew Research Center, and which was based on analysis of more than 2,500 censuses, surveys and population registers, it identified the global religious landscape as of 2010 as follows: 2.2 billion Christians (32% of the world’s population), 1.6 billion Muslims (23%), 1 billion Hindus (15%), and nearly 500 million Buddhists (7%) (<https://www.pewresearch.org/>).

fascinating within a space of cross-cultural exchange, however something I cannot personally relate to (Smith 2015: s/p).

However, to say that spiritual and religious interpretations of disability are purely denigrating, stigmatizing and hostile towards those bearing impairments, either physical or mental, would be misleading and incorrect. In *Valores, Preconceito e Práticas Educativas* (2005), Divino José da Silva and Renata Libório write that:

Houve uma mudança ética significativa na passagem dos ensinamentos do Antigo Testamento. Enquanto aquele trazia mensagens de castigos, punições, sacrifícios e vinganças, as palavras atribuídas ao Filho de Deus orientavam para uma novidade: o perdão. Junto à solidariedade, que alguns classificam como “compaixão”, o perdão era a ferramenta primordial para que se desenvolvessem o resgate e a inclusão social, retirando o indivíduo com deficiência de uma condição tabu (da Silva and Libório 2005: 85).

Most would be familiar with examples of such compassion in the *New Testament*, such as those of Jesus reinstating sight to a blind man, restoring a paralytic man's ability to walk again and healing a man with a withered hand, among other miracles. Yet, over the course of time different stigmatizing spiritual and religious interpretations of disability permeated deeply into the socio-cultural fabric of societies and remain ingrained to some degree. Although, in fairness, many present-day religious leaders as well as followers, from different faiths, feel ashamed and uncomfortable by the inhumanity of discriminatory doctrines and reject discriminatory interpretations.

Looking into religious perspectives, differentiations and reactions to representations of disability is important when considering cultural representations of disability. It is valuable to appraise the overlap in response towards disability between religious traditions and cultural communities. On the whole, it is acknowledged that religious doctrines and traditions take part in building up cultural markers for what is regarded as a normal healthy body and mind, and subsequently in determining a moral order for that normal healthy body and mind. In Portugal, religion has unarguably played a vital role in establishing not only how disability is interpreted but also how people bearing impairments are (mis)treated within certain historical-cultural settings. However, it has not only been religious and cultural issues that have determined different avenues in disability narratives and policies, and what pertains to rights of citizens in Portugal with disabilities. Fontes

further adds that: “historical, economic, political and cultural factors, such as the Inquisition, the low redistributive ethos of the Portuguese state, the dictatorship and Catholicism have shaped different trajectories in disability policies and politics and, above all, in citizenship rights” (2011: 101).

## 5. The road towards disability rights in Portugal

Scholars in Portugal might agree overall that it has only been with the advent of disability rights movements and activists relentlessly campaigning that finally advancements in advocating the social based model of disability have been made. It might be worthwhile at this point to consider contemporary approaches to the placement of disability in Portugal as there is still a significant amount of work to be done to bring down preconceptions of disabilities. Essentially, over the course of the last 30 years, according to Ema Loja, Emília Costa and Isabel Menezes, in the article “Views of Disability in Portugal: ‘*fado*’ or citizenship?” (2013):

there has been an evolution in the Portuguese society’s views of disabled people. Before this time, disability was seen as almost a fatality and there were only two types of response for disabled people: private assistance provided by family, or charity institutions [...] as a result disabled people were marginalised and segregated in their homes or in special institutions. In 1919 the first laws about social insurance and work accidents were passed but during World War II laws relating to the field of disability were not passed in Portugal as happened in other European countries [...] obviously the nature of the authoritarian regime of fascist inspiration that ruled the country from 1926 to 1974 explains this gap (Loja *et. al* 2013: 65).

In Portugal, the charity institutions providing assistance to those with impairments have traditionally been associated to the Catholic Church, even before Portugal became an independent kingdom in 1143 (Ferreira 1990). However, due to several events and circumstances, such as the ensuing demographic and socio-economic shifts brought about by the extensive Portuguese maritime explorations as well as European shifts towards a common centralisation of power, a reform in public assistance came into effect. Also, it is worthwhile to bear in mind that of the outcomes of Portugal’s imperial expansion was a plethora of illness, disability and eventual death. The many deaths from activities during the Portuguese maritime expansion, both in Portugal as well as in its colonies, brought about



an increase in widows and orphans, and that usually meant a decrease in living conditions and subsequently ill health. It also had an impact on societal needs, and which ultimately led to the creation of the first Misericórdia in Lisbon in 1498. The Misericórdias spread throughout both Portugal and its colonies, and were given the task of providing assistance such as medication, shelter, clothing, and health care to those members of the population that were needy, ill or bore bodily impairments. Some of this assistance involved providing care directly to people in their own homes, especially if they were bedridden due to an impairment or serious illness. However, this care was not necessarily readily available across the full spectrum of society or at all times. The Misericórdias pretty much held the monopoly in running most of the hospitals in Portugal and did so until 1974 when the state assumed control.

The dominance of religion continued to prevail in Portugal in most regards, as can be ascertained by the stringent control implemented by the Inquisition<sup>1</sup>. This thwarted any advancements of Enlightenment thinking and consequently prevented any new understanding about people with disabilities from a more rational and scientifically founded reasoning. For most of the nineteenth century, unlike other nations in Europe, like France and England, Portugal was lagging behind in terms of modernization of economic, political and social structures, and so public assistance for those with disabilities did not exist. And so, many people with disabilities who did not have family members to care for them, would find themselves either having to beg, or seeking out assistance from the Misericórdias. According to Robert Drake, a researcher in social policies, who published *Understanding Disability Policies* (1999): “A fundamental nineteenth century response to people with physical or cognitive impairments was either to ignore them or to incarcerate them in prisons, asylums and workhouses” (1999: 46).

It would be the introduction of the Portuguese Constitution in 1933, establishing the foundation of the authoritarian regime of the Estado Novo that Portugal saw the conservative dictatorship led by António Salazar deny citizenship rights to those with disabilities by removing access to public assistance. It fell therefore to the Catholic Church to undertake the task of providing assistance to those with disabilities (Pimentel 1999). Notwithstanding, just a few years prior to the implementation of this dictatorship, Portugal had witnessed perhaps the most significant feature of disability policies that had hitherto been developed, and that was the surfacing of a new interest in providing specialised training and education for people

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<sup>1</sup> The Inquisition in Portugal lasted from 1536 to 1821.

with sensory impairments; namely the blind and the deaf. In mid-1927, a group of Portuguese citizens, some of whom were themselves blind or had a member of the family who was blind, noted the need to organize themselves and join forces to secure better life conditions. In part, they were following on the wake of events post-World War I in other countries in Europe which were experiencing a more compassionate posture towards those with injuries and disabilities. And so, the first organized association by and for people with visual impairments or blindness in Portugal was founded on 25 July 1927 - Associação de Cegos Louis Braille (ACLB). Its motto was to provide: “auxílio aos trabalhadores cegos [...] apoiar a habilitação profissional dos cegos” (ACAPO)<sup>1</sup>. This Association was also equally pioneering in initiating contact with other international counterparts and thereby preparing the way for collaboration and cooperation. In contemporary Portuguese society, when considering the language of disability, some people feel there are terms that are more suitable and avoid discriminatory labelling or bias. So for instance, for the blind, some prefer to use terms such as “visually impaired” or “sight challenged” although most disability activists favour the word “blind” as being perfectly acceptable.

For the Deaf community, opinions over terminology differ. Historically, the term “deaf-mute”(surdo-mudo in Portuguese) was used to identify a person who was either deaf and resorted to using a sign language to communicate, or was both deaf and was unable to speak. Today, the term is still used to refer to people who are deaf (surdo) and unable to use an oral language, or people who have some degree of speaking ability but who opt not to speak because of the dissenting or undesired attention atypical voices might receive. However, most agree that terms like “deaf-mute” and “deaf and dumb” are offensive if used outside their historical contexts, because the inability to hear and speak does not indicate intellectual disability. Today in Portugal, many deaf individuals see themselves as members of a singular cultural and linguistic minority who use sign language as their main language. In Portugal, members of this deaf community ascribe to *Cultura Surda* (internationally recognized as Deaf Culture), which champions several shared social beliefs, demeanours, principles and history.

These communities also share the common experience of deafness and use sign language as their main means of communication. Thus, in

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<sup>1</sup> In November 1988, three of the main and oldest Institutions for Portuguese with visual impairments (ACLB, LCJD and ACNP) merged and gave origin to ACAPO. Further information can be read here: <https://www.lerparaver.com/lpv/historia-acapo>

Deaf Culture, *Deaf* with a capital letter is used to indicate that a person is different, and not disabled, that he or she is part of a community with his or her own language and culture, in other words, that person belongs to a linguistic minority. The word *deaf* with a lowercase letter usually presents the pathological condition, the absence of something, the loss of hearing, as well as the term disability. The current terminology to characterize the person with hearing loss or deafness is “hearing impaired” or “deaf”, however, in academic literature it is common to find both cases. However, deaf people prefer to be called “deaf”, because “hearing impaired” carries a pejorative stigma. Joana Pereira writes that:

Desconstruir a representação da pessoa Surda como indivíduo inacabado, inferior e incapacitado pela falta da audição permite apresentar ao público ouvinte uma realidade totalmente inversa, rica e surpreendente. Afinal, a pessoa Surda com “S” maiúsculo é alguém com um sentido de pertença a uma comunidade minoritária, orgulhoso falante de uma língua que se move no espaço e desenha ideias, opiniões e sentires que nos chegam pelos olhos. Afinal, os espaços onde estes indivíduos se movem detêm valores e padrões comportamentais próprios - a cultura Surda, a bandeira que a comunidade Surda empunha na constante luta pelo acesso à igualdade de direitos (Pereira 2012: 65).

In most European countries, the end of the first World War had seen a fleeting supportive phase for those who had been left injured, or disabled, as laws about social insurance and work accidents were enacted (Campbell and Oliver 1996). Unfortunately, the subsequent aftermath of both world wars so close after each other meant economic strife, and consequently there was a hesitance and withdrawal of support and benefits for people with disabilities. This was the case for European countries, like the UK, that had previously begun to review disability policies. It would be once again in the early fifties that attention would be focussed on creating impairment organisations that looked to developing more pedagogical approaches to training and education for those with disabilities, especially for children.

Yet, this was to be more challenging for Portugal due to the dictatorial state that governed the nation at the time, and the ideal of a state providing any sort of social assistance was evidently not going to manifest (Loja *et al.* 2013: 65). Any attempt at safeguarding civil rights and state assistance to those with disabilities was minimal, inconsistent, disorganised, and thus any assistance was left primarily in the hands of the Catholic Church or the families. Portuguese sociologist Fernando Fontes argues that:

The only reason these organisations were tolerated by the political regime was because these collectives remained as peer meetings and/or sports groups, reinforcing the social isolation of disabled people [...] none of them developed any political understanding of disability or undertook any type of public-political intervention, and their approach reinforced the charitable perspective of disability (Fontes 2011: 97).

It was nonetheless, under these circumstances that the Liga Portuguesa dos Deficientes Motores (LPDM)<sup>1</sup> was established in the early 1950s, which means that it has been in existence for well over sixty years now. Initially, it was run as a charitable organization offering assistance not only to people with disabilities but also disadvantaged people, and today it remains a private institution which prides itself in continuously looking to keep up with social changes and advancements in the field of rehabilitation. The LPDM was at first based on the medical model of disability mostly due to a poliomyelitis<sup>2</sup> outbreak. Of relevance, from the start of the twentieth century, throughout the Western world, including Portugal, there had been a growing interest in the establishment of psychiatric sanatoriums. This was in part a desire for greater social control over those labelled as “mentally defective”, “feeble minded”, “lunatics” or “spastics” and the intention was simply to segregate them from the rest of society thereby ridding society of those labelled as “degenerates”, “vagrants” and “delinquents”, and the root of many social problems (Ryan and Thomas 1987). Of those institutionalized were for example people with Down’s Syndrome, epilepsy, depression and even included people with physical impairments. And, although it

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<sup>1</sup> In English: The Portuguese Foundation of the Physically Impaired.

<sup>2</sup> Poliomyelitis is a contagious viral illness that can cause paralysis or death. If the spine is attacked, it can cause physical deformities, and treatment involves long term rehabilitation, physio-therapy, corrective footwear, braces or surgery. The discovery of a vaccine in the 1950s is still considered to be one of the greatest advances in modern medicine and certainly contributed to greatly reducing the onslaught of physical impairment. It also serves to illustrate the active role of the Catholic Church in this process. In an article in the Portuguese newspaper *Diário de Notícias*: “Entre 1954 e 1965 foram registados 2945 casos com paralisia e 345 mortes. E muitas aconteciam na infância [...] em 1965 lançámos uma grande campanha de vacinação que permitiu em dois anos vacinar mais de três milhões de crianças até aos 9 anos. A doença praticamente desapareceu num ano. Foi uma campanha incrível. Em todo o país instalaram-se dezenas de postos de vacinação, os padres tocavam o sino, a população juntava-se e chegavam os médicos e os enfermeiros”. Full article here: <https://www.dn.pt/sociedade/a-polio-era-a-doenca-que-mais-medo-metia-os-filhos-facilmente-a-podiam-ter-5148802.html>.

is not fully certain that all institutions advocated eugenics and associated sterilization programs, collectively they did segregate those institutionalized from mainstream society. An underlying principle of this ideology to isolate those with what were considered mental impairments was the belief that poverty was brought about by mental disorders, and which in part explains the attention of the Portuguese regime to establish psychiatric hospitals for most of its rule (Bastos 1997)<sup>1</sup>.

## 6. The dawn of the disability rights movement in Portugal

The 1960s saw the Portuguese Armed Forces heavily involved in colonial wars in Africa against the organized forces of liberation movements of the then Portuguese colonies of Angola, Mozambique and Guinea-Bissau. The outcome was devastating in every sense, and left thousands with physical impairments and mental traumas. In answer to this, the regime created some services such as rehabilitation and physical therapy centres aimed at responding to the needs of these people returning with impairments from the colonial wars. However, the sense of dissatisfaction at both the limited and poor quality as well as the restricted offer of these services among Portuguese war veterans helped to generate different interpretations of what disability was, and as a direct outcome a new group of advocates for disability rights surfaced. This kind of discontent with assistance provided among those returning home with disabilities after fighting in wars has been a landmark in encouraging disability movements. In *Exploring Disability Identity and Disability Rights through Narratives: Finding a Voice of Their Own* (2014), Ravi Malhotra and Morgan Rowe write that:

Spurred by returning and often politicized veterans at the end of the two World Wars and the Vietnam War in the United States, a disability rights movement has coalesced and has fought for the development of vocational rehabilitation programs, labour market integration and dignity for disabled workers to perform fairly remunerated work with accommodations. This has taken the form of political lobbying, education and, at times, demonstrations and civil disobedience (Malhotra and Rowe 2014: 101).

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<sup>1</sup> To illustrate, Hospital Sobral Cid was established in Coimbra in 1945, and the Hospital Magalhães Lemos was founded in 1960 in Oporto. Both continue to this day to provide specialized mental health care although naturally within the scope of contemporary medical practices.

The culmination came in 1972 with the founding of the Associação Portuguesa de Deficientes (APD)<sup>1</sup> that came into being “como consequência do debate surgido em torno da primeira iniciativa legislativa sobre reabilitação em 1971 [...] é declarada instituição de utilidade pública em 1978 e é das associações mais antigas em Portugal na área da deficiência” (APD)<sup>2</sup>. The overriding aim was to create a distinct understanding of what it meant to be a person with an impairment separate from the till then charitable, separatist and stigmatizing views.

It would only be after a military coup overthrew the authoritarian regime of the Estado Novo and democracy was restored to Portugal that the APD and other groups representing people with disabilities were able to become involved in political activities, which meant greater presence and contribution towards policy making that involved those with disabilities. However, in present-day Portugal, there are those Portuguese researchers and activists alike, who feel that people with disabilities still have not been fully integrated into the political decision-making processes (either at national or local levels) that have a direct impact upon their lives. Fontes *et al.* attribute this to:

the inadequate democratisation of relations between the state and the organisations that represent them – as a result of the socio-political inertia shaped by authoritarianism – and economic vulnerability, which does little to free organisations and disabled people for any more coherent form of political action and in which the legacy of the dictatorship is also evident. The suppression of the idea of the welfare state – with the state assuming a secondary role in providing social protection – and the affirmations of a benefits mentality in which disability mainly emerges as a charity issue has established a paternalistic logic that even today takes precedence over recognition of political and economic autonomy as a right that enriches the democratic arena” (Fontes *et al* 2014: 7).

This is compounded by the fact that unlike many other Western countries, Portugal has never become a true welfare state, and what exists in Portugal according to Santos is a “semi-welfare state” or “*quasi-welfare state*” (Santos 1993: 20). Furthermore, the Portuguese State is seen to preserve and even encourage some of the practices prior to democracy in what concerns stigmatizing the identities of those with disabilities as being incapable of determining their own lives, and frequently refer people with disabilities

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<sup>1</sup> The Portuguese Association of Disabled People

<sup>2</sup> <https://www.apd.org.pt/>

to family for care. Therefore, activists and organisations for disability rights have tended to focus more on bettering living conditions like advocating for legislation that eliminates transportation, employment and educational barriers as well as supporting rights to benefit payments.

## 7. “Unidos jamais seremos vencidos”<sup>1</sup>

“Unidos jamais seremos vencidos” is a teaching that has been passed down by popular culture over centuries, through fables and parables, and its effectiveness is even more relevant today in which we are witnessing such powerful popular socio-cultural movements advocating for an end to discrimination, oppression and the implementation of equal opportunities and rights such as the Black Lives Matter, as well as the #MeToo movements. However, while these movements have undisputedly gained substantial amounts of media attention, public support and generated considerable discussion, this has not been the case for disability rights movement. For some disability rights activists and researchers, despite many openly praiseworthy actions in seeking out what many would call access to basic rights for those with disabilities, they see it as deviating from the true calling of such organisations and activism. Essentially, they argue that these organisations have become extensions of a welfare state and reflect “the low commitment of the state and the inability of civil society to change the social inequalities that disabled people face, and this dual fragility translates, from the outset, into a systematic lack of coherent legislative change” (Fontes *et al* 2014: 8).

Nonetheless, there those who view that there have been advancements made in the manner in which society perceives and reacts to people with disabilities, and certainly one can only agree that there has been positive change. To illustrate, as opposed to some 30 years ago, today due to advanced technological advancements, a person in an electric wheelchair has a given amount of autonomy, for instance in a shopping centre where planning for these needs has been taken into account when allocating parking spaces, considering width of and facility of doorways, access to public bathrooms, and so forth. Yet, by no means can it be said that there are still not many physical barriers, as well as cultural barriers, to be overcome as can be ascertained in the many blogs, social media posts, newspaper and magazine

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<sup>1</sup> In English: *United we will never be defeated*. Interestingly, this originates from one of Aesop’s tales “The Lion and the Three Bulls” in which the moral of the story is that there is strength in unity. The set of Aesop’s three short fables addressing unity in strength can be read here: <http://phonicstest.com/books/aesopset06.htm>



articles, among others covering the issue of the struggles of people living with disabilities in Portugal in this new millennium.

Disability activists in Portugal continue to campaign for removal of physical barriers that are still very much visible in everyday life; such as stairs that do not have ramps (and some ramps which do not have the norms of inclination), lifts that do not have enough space for a wheelchair, bank terminals not within reach for wheelchair users, sidewalks without ramps, and other public facilities without adequate access. People with disabilities are the focus of substantial discrimination, particularly when it comes to employability. There are many companies that do not clearly consider people with disabilities in company diversity policies (Ball, Monaco and Schmelting 2005) and show unwillingness to hire. This adverse behaviour could be explained by damaging and stereotypical attitudes held towards people with disabilities, who are frequently viewed as helpless, reliant on others, unskilled, frail and fragile.

In reading the abundance of literature online, it quickly becomes apparent that the efforts, stigmatizations and barriers seem eerily similar to those back in the twentieth century. An online newspaper article published in *Sapo 24 Notícias* in December 2016 exposes the struggles of a young adult with a disability who yearns for independence:

Em vésperas do Dia Internacional das Pessoas com Deficiência, a realidade destas pessoas em Portugal está ainda longe do ratificado na Convenção Internacional, que determina que os países devem assegurar que as pessoas com deficiência escolhem como, onde e com quem vivem, bem como os serviços e os apoios de que precisam. Da conversa com vários interessados no tema, a conclusão é a de que as pessoas com deficiência em Portugal não têm como ser autónomas e estão obrigadas ou a viver no seio da família, caso esta tenha as condições económicas necessárias, ou a recorrer à institucionalização, muitas vezes em lares de idosos [...] é tetraplégico desde os 28 anos, devido a uma lesão na medula, tendo 90% de incapacidade, o que faz com que precise de “apoio para quase tudo”, como seja vestir-se e despir-se, posicionar-se na cama, fazer a higiene diária ou transferir-se da cama para a cadeira de rodas. Sendo um dos rostos mais visíveis da luta por uma filosofia de Vida Independente, e “contra a institucionalização compulsiva levada a cabo” em Portugal, viu-se obrigado a ir viver num lar de idosos por não ter condições financeiras para pagar a cuidadores.

In another newspaper, the socio-cultural stigmas and taboos traditionally tied to disability are still starkly and unhappily evident in modern-day

Portuguese families and societies with many issues still to resolve such as family pressures, poverty, lack of inclusion, as well as social and physical barriers. The title “Os pais de crianças com deficiência têm pânico de morrer”, though arguably typically worthy of newspaper sensationalism, does have the desired impact of creating fear for the well-being of one’s children. The journalist of this article in *Observador*, Catarina Marques Rodrigues, interviews a Portuguese researcher in disability politics from the University of Coimbra who states that:

somos mais condescendentes com quem “fica deficiente” do que com quem “nasce deficiente” [...] vemos a deficiência como uma sentença de morte e [...] só quando temos de andar com um carrinho de bebé num pavimento desnivelado é que percebemos as dificuldades de uma pessoa em cadeira de rodas. A opressão e a falta de inclusão têm a ver com a forma como as pessoas com deficiência são vistas na sociedade portuguesa. São vistas como sendo inativas e como não tendo capacidade de trabalho. O seu corpo é perspectivado como um objeto estranho. Têm custos acrescidos porque vivem em sociedades que não estão abertas à diferença, com constantes barreiras à participação e à mobilidade (*Observador*, 18.09.2016).

Some common, and still very much present in contemporary Portuguese society, condescending responses to parents who learn their child has an impairment are: “Mais valia que Deus o levasse”, “Vocês agora vão ter uma cruz a carregar” or “Esta criança vai ser um fardo nas vossas vidas”. And, to a great extent, this is because disability is still viewed as a tragedy built on cultural inheritance which has never shown great acceptance towards bodily imperfections, opting to see them rather as manifested forms of impurity, sin and punishment.

In Portugal, the family unit remains at the core of issues related to disability because most of the consequences of living with a disability, whether physical or mental, rest on the family. To illustrate, a home with a child with a disability that requires regular visits to therapy or doctor’s appointments in which an entire morning is taken up, or sometimes a whole day if the consultation is in another town or city, one of the parents is unable to maintain fixed employment. Naturally, this has a direct impact on the parent’s professional life as most often than not employers are not sympathetic to these needs and so contracts may not be renewed, and subsequently the household income is reduced. Parents of children with disabilities also greatly fear something happening to them, and what the

consequences of their demise would be on their children, which explains the “panic” in the title of the newspaper article. This choice of word to describe fear of death implies a fear so overwhelming and dominant that all sense of reason and logic is washed away. The mere suggestion that a parent must live with these persistent feelings of angst, agitation and uncertainty over an uncertain future of a child, who cannot fend for themselves even as adults, inevitably leads to other situations of poor health, social victimization and possibly family breakups. Disability can have many other far-reaching effects on the family unit which are not always related to finance. When for example one of the spouses suddenly find him or herself incapacitated due to an illness or disability, the relationship can experience a loss of libido as one of the partners becomes the other’s caregiver.

Additionally, cultural stereotypes systematically reveal a stigmatizing set of ideas used to characterise social groups of people with disabilities as being inept, dependent, of lower intellectual capability and asexual. In contrast, it has also been shown that stereotypical beliefs about persons with disability are not necessarily negative despite still being considered as negative and condescending by some. Persons with disability are sometimes viewed “positively” as courageous, heroic, hardworking, persistent, conscientious, honest, moral, and friendly<sup>1</sup>. The physical, emotional and financial strain on the couple and the family can become overwhelming.

The psychological barriers have to do with social prejudices, which are preconceived ideas about people with physical impairments. It is quite common for people with disabilities (both children and adults alike) to experience patronizing behaviour such as being patted on the head, being spoken to in an infant-like voice, being spoken to in a raised voice despite having no hearing impairments, or having questions directed at someone else next to them who does not have an impairment<sup>2</sup>. On the other hand, there are other stereotypical views of people with disabilities that are not necessarily negative, in which people with disabilities are portrayed as

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<sup>1</sup> These stereotypes can be seen as running parallel to many about people who are overweight. For example, fat people are also supposedly jolly, friendly and honest.

<sup>2</sup> A possible explanation why people raise their voices when speaking to a person in a wheelchair or opt to address a question to someone else next to them, rather than the person with disabilities themselves, may lie with pre-conceptions that disability and intellectual inferiority are synonymous. There are certainly instances in which someone with a physical disability may also have an intellectual disability but that is not always the case, and it is certainly patronizing and dehumanizing to tie intellectual capacity to physical ability.

being heroic, persistent, attentive, friendly, and brave. Odile Rohmer and Eva Louvet refer to these in “Implicit Stereotyping against People with Disability” (2016):

ambivalent judgements towards people with disability [as being] in line with the theoretical framework of the stereotype content model [...] according to this model, most social groups are not uniformly evaluated along a single “good/bad” dimension, but along two fundamental dimensions labelled as warmth and competence. Warmth refers to the appraisal of others’ motives and includes social and moral qualities [...] competence refers to the appraisal of others’ ability to effectively enact their motives and includes intellectual and motivational qualities (Rohmer and Louvet 2016: 128).

It could be argued that these so-called-positive views about people with disabilities could stem from “an overcompensation strategy” (Rohmer and Louvet (2016: 129) founded on the incentive to come across as unbiased and open-minded.

In 1986, Portugal became a member of the European Economic Community (EEC) and this has unequivocally had a tremendous impact on Portuguese policies and legislation<sup>1</sup>. Since then, several laws have been created addressing equality of rights and employment. Funding received from the EEC has been allocated towards financing of training programmes for people with disabilities. Currently, Portuguese laws incorporate a juridical regime of prevention, qualification, rehabilitation and participation of people with disabilities. Some of the rights to equal opportunities include access to support services, education, training and work, as well as prohibition of discrimination based on disability and mandatory accessibility in public spaces. It is relevant to point out that most of this legislation was approved relatively recently, going only as far back as 2007, for example with the Plano Nacional de Promoção da Acessibilidade (PNPA) to public spaces, buildings, transport and information technology.

In 2016, in what is considered to be a incredibly significant step in the disability rights movement in Portugal, the Independent Living Movement (ILM) programme saw its first centre being established in Lisbon<sup>2</sup>. The

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<sup>1</sup> The PNPA, in English: the National Plan of the Promotion of Accessibility. For further reading, consult the official state guide: “Guia prático dos direitos das pessoas com deficiência em Portugal”, at: [http://www.inr.pt/documents/11309/283719/guia\\_pratico\\_acessivel\\_4\\_2\\_2020.pdf/6cc43949-c5f9-4658-9f9c-5b055b61ee97](http://www.inr.pt/documents/11309/283719/guia_pratico_acessivel_4_2_2020.pdf/6cc43949-c5f9-4658-9f9c-5b055b61ee97).

<sup>2</sup> Read the mission statement for Centro de Vida Independente in Lisbon here: vi-

Independent Living philosophy which grew out of the disability rights movement in the 1960s states that:

It is a movement of people with disabilities who work for self-determination, equal opportunities and self-respect [...] that every person, regardless of disability, has the potential and the right to exercise individual self-determination. We expect the same choices and control in our everyday lives that everyone else takes for granted [...] the same freedom to try, and fail, and learn from our failures [...] to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and abilities, start families of our own [...] achieving equal access through reducing and removing barriers and assure full community participation for persons with all disabilities<sup>1</sup>

In essence, the ILM is dedicated to the advancement of social systems in which all people with disabilities have the prospect of leading productive, meaningful lives as integrated and valued members of their communities. This philosophy clearly breaks from the traditional medical model of disability which chooses to focus on “what is wrong with the person” and endeavours to “fix what is broken”. Like the social model of disability, the ILM maintains that choices are limited due to barriers; societal, physical, expectational, and emotional. The aim of such centres is not to rehabilitate the person with an impairment but rather to focus on lessening and altogether removing barriers that limit choices.

## **8. “A luta continua”<sup>2</sup>**

Undoubtedly, the human body in all its vicissitudes has become a universal theme of both popular and commercial culture in Western [daindependente.org/o-que-e-o-centro-de-vida-independente/](http://daindependente.org/o-que-e-o-centro-de-vida-independente/). This ILM programme has now been implemented in some other cities in Portugal.

<sup>1</sup> A definition of the Independent Living philosophy from a Center for Independent Living in Illinois, USA. Available at: <https://www.lifecil.org/about/philosophy/>

<sup>2</sup> Of cultural interest, this Portuguese expression meaning “The struggle continues” was the uniting cry of the FRELIMO movement during Mozambique’s war for independence from their Portuguese colonizers. The leader of FRELIMO, Samora Machel, used this war cry to rally popular support against the colonial oppressors. Since then, this phrase has appeared in various instances of protests and causes throughout the African continent, and beyond. It is the title of a Mozambique inspired song made popular by the famous South African singer Miriam Mabeke. The song “Aluta continue” can be heard here: [https://www.youtube.com/watch?v=Mtl62-6pY\\_I](https://www.youtube.com/watch?v=Mtl62-6pY_I)

societies over the course of the past few decades, Portugal notwithstanding. Various social changes and movements have been at the forefront in firmly establishing the cultural conceptualisation of the body in contemporary society. Such changes and movements include; remarkable advances in medical procedures and technologies, the gay or women's liberation movements, along with changes in the commercial use of the body as an icon of modern-day consumerism. These experiences have helped to establish commercial activity as one of the leading authorities on defining the ideal human body – the gauge by which to measure aesthetic excellence. Thus, the parameters for ideal female beauty have become buxom breasts, thinness and ageless skin; while the ultimate symbol of masculinity is the athletic frame of imposing height and well-toned muscles. There is an endless bombarding of advertising in every imaginable nook and cranny of our daily lives – billboards, magazines, internet pop-ups, and book titles boast countless publications from miraculous slimming manuals, to handbooks on seven easy steps to muscle building and dietary regimes.

Granted that different cultural values will influence the manner in which people appraise their bodies, all this may serve as an excellent gauge of this narcissistic behaviour that contemporary culture has espoused. Michael Bury advances an interesting explanation for this: “the relevance of the body [...] begins to emerge, not simply as part of an analysis of the health correlates of lifestyle and consumer culture – important though these are – but to the more deep-seated issues that disease and illness pose for human beings” (Bury 1997: 173). In other words, what is particularly significant is not so much the increasing consumer culture of Botox, breast implants, tattoos or Western-sculptured facial features, for instance, but rather the underlying, deep-set fear that old age and illness maim – they disable.

It may be argued that the overriding view of disability has, for some time, been one in which bearers of impairments have been denied basic qualities of humanity. The person's apparent incompleteness is seen as a shortcoming that requires intercession on the part of others to correct such inadequacies. This approach brings to mind Paulo Freire's banking concept in education; that of the subject-object relationship that identifies “the teacher [as] the Subject of the learning process, while the pupils are mere objects” (Freire 1993: 54).

In such an instance the object would be the person with an impairment while the subject might be the therapist, doctor, nurse or teacher who attempts to correct, fix or adjust the impairment to suit socio-cultural expectations

of what suitable behavior or appearance for the body is. The weight of objectiveness is made heavier when the bearer of such impairment is labeled as paraplegic, or mentally challenged, for example. Somehow that body is depicted as lacking in something, as being fragmentary, or incomplete.

Oftentimes, people with impairments are deemed as fragile and lacking; needing someone to take care of them, and requiring protection at all times, and in Portugal it evidently still very much remains the responsibility of the family. Freire maintains that such human existence puts elite concepts of culture to the test. In other words, culture prevails in the potential of individuals to alter their own reality when they do not confine themselves to those whose thoughts and actions are traditionally followed are seen to be more advantaged. In essence, this means that not only does each individual already possess and reproduce culture, but he also has the capability to remake culture. Ira Shor expands on Freire's view:

The human power to make and remake culture [...] has profound meaning for disability as cultural production. This culture is not enshrined in canonical texts, although certain heroes of the literary canon embodied it [...] is not limited to the use of one or another discrete language, although it has produced rich languages such as American Sign Language. [...] is not limited by race, gender, class, or ethnic origin, and thus it represents one of the most democratic of human possibilities. Disability embraces the human power to adapt and accommodate, to make and remake ways of living to meet diverse needs and capabilities. Adaptations and accommodations are significant cultural products; making them and negotiating them are the praxis of everyday life for people who have disabilities (Shor 1992: 59).

To expand but a bit further on this line of thought, most people with impairments do not see their ordinary routine lives as constituting culture, neither do they see themselves as creating culture. In part, this could be because of the subordination forced upon them by the more dominant able-bodied culture. Freire goes on to explain this drive by dominating cultures as being motivated by a need for proficiency, speed and turnover, and that those who do not perform according to this mainstream culture are seen as a hindrance: "One of the greatest obstacles to the achievement of liberation is that oppressive reality absorbs those within it and thereby acts to submerge human beings' consciousness" (Freire 1993: 33).

Not only are impaired bodies not categorized as the norm, but their needs are also seen as added socio-economic burdens. Such stigmatization



leads them to become absorbed by the dominant cultures and their own potential to develop their own cultures is overshadowed. Inherently, disability is a state that has strong social coloring, as people with impairments cannot be regarded as being disabled outside a social context. Such people are incapable of performing some functions valued by the rest of society without difficulty and are, therefore, labeled by that society.

Culture is a mirror reflecting attitudes, morals and perceptions of a community; consequently, it registers even insignificant changes in a society's views. Ideas about disability expressed by people in different periods of human history show the evolution of human thinking. A society draws conclusions and outlines its perspectives on the future direction of its development. It is equally true of studies in disability and cultural aspects thereof. Western academic approaches to cultural studies employ a variety of scientific methods for understanding disability within a cultural framework. Certainly, the vast compilation of literature available within Disability Studies and Cultural Disability Studies in other countries reflects the burgeoning activity. However, in what concerns Portugal, Fontes argues that:

it is almost non-existent. Consequently, there is no critical *corpus* to be found in Portugal similar to the countless studies that have for a long time revealed the oppression and discrimination faced by disabled people in countries such as the United Kingdom and the USA. This epistemological lack of awareness is symptomatic of the tenacity with which medical concepts of disability have developed a hegemony that has been perpetuated within Portugal, despite the changes that have taken place in other socio-political contexts. In Portugal, the study of disability has been restricted to the fields of psychology, medicine and education sciences, all areas in which the medical model has been dominant. Disciplines such as sociology and anthropology, which are closely linked to disability studies in other countries, have only very recently directed their attention to this area of study in Portugal. We would argue that this is due to the prevailing historical, cultural, political and economic conditions in this southern European country and that they pose singular challenges to the development of emancipatory disability research (Fontes *et al.* 2014: 7)

It becomes readily evident that there is still a long way to go to overcome the many challenges facing the potential future of the placement of disability studies alongside cultural studies, and even greater efforts to allow for a novel field in Portugal of cultural disability studies. These challenges are not readily overcome and have many underlying causes such as the minimal

degree of political participation, insufficient democratization of interactions between the state and disability groups, a benefits mentality, the traditional practice transferring disability care to families, a lack of disability research from different academic contexts, insufficient engagement of people with disabilities in academic research, the yet to be defined disability related terminology in the Portuguese lexicon, long-standing stigmatizations and taboos, and finally, but equally important, lack of funding for non-traditional fields of knowledge.

*A luta continua.*

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