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Impacto da incapacitação e do ableísmo nas pessoas incapacitadas em Portugal: 'Fado', cidadania e o eu corporizado

The impact of dis/abl(e)ism on disabled people in Portugal: *Fado*, citizenship and the embodied self

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SUMÁRIO

Pela ausência de um campo de Estudos sobre a Incapacidade em Portugal, a investigação na área da incapacidade é escassa e carece da perspectiva das pessoas incapacitadas. Esta dissertação pretende alargar o estudo da incapacidade física no nosso país numa perspectiva sociopolítica, focando-se na compreensão do impacto da incapacitação e do ableísmo nas vidas das pessoas incapacitadas, nomeadamente na sua qualidade de vida, corporização e identidade.

A investigação enquadra-se nos paradigmas sociopolítico, do ableísmo e da corporização e inclui três estudos que envolveram metodologia quantitativa e qualitativa. Cada estudo está incluído em três artigos científicos que foram publicados ou aceites para publicação. Para além destes, é apresentada uma proposta de mudança na área da incapacidade constituída pelas sugestões dos participantes.

O 1º. artigo inclui um estudo qualitativo com seis líderes associativos no qual se procurou aceder à perspectiva de especialistas no que se refere ao contexto português na área da incapacidade. O 2º. artigo contém um estudo sobre qualidade de vida e discriminação com 217 pessoas incapacitadas. A validação do questionário *QoL.Q* (Schalock & Keith, 1993) e da *Escala de Suporte aos Direitos das Minorias* (Nata & Menezes, 2007) foi realizada através de procedimentos de análise factorial confirmatória. Análises estatísticas descritivas e de correlação foram também efectuadas. O 3º. artigo compreende um estudo qualitativo com sete pessoas com deficiências físicas visíveis. O impacto e a resistência aos discursos ableistas acerca de corpos com deficiência e a relação da corporização com a identidade foram analisados através da teoria da corporização e dos conceitos ableísmo (Campbell, 2001) e capital físico (Bourdieu, 1990).

Os resultados mostram que a incapacitação e o ableísmo têm um impacto profundo na qualidade de vida das pessoas incapacitadas, assim como na sua corporização e identidade. Um ciclo paradigmático vicioso de tragédia é dominante, sendo contestado por uma minoria que se suporta numa tríade de factores baseada na consciência dos direitos. Mais do que isso, as pessoas incapacitadas manifestam formas corporizadas de resistência que contrariam as normatividades ableistas que constrangem o seu capital físico e o reconhecimento de uma identidade.

SUMMARY

An understanding of disability and the perspective of disabled people in Portugal has hardly yet been reached, mainly due to the lack of a field of disability studies. This dissertation aims to extend the study of physical disability in Portugal within a sociopolitical perspective by focusing on the understanding of the impact of dis/abl(e)ism on disabled people's lives, specifically their quality of life, embodiment and identity.

The research was designed within sociopolitical, ableism and embodiment paradigms and consists of three studies that combined qualitative and quantitative methodologies. Each study is included in three scientific articles that were published or accepted for publication. Besides the papers, a proposal for change in regard to disability provided by participants' suggestions is presented.

The first paper includes a qualitative study with six leaders of disability associations and attempts to get insights from these experts about disability in regard to the Portuguese context. The second paper contains a quantitative study on quality of life and discrimination with 217 disabled people. Validation of the *QoL.Q* (Schalock & Keith, 1993) and the *Minorities' Rights Support Scale* (Nata & Menezes, 2007) was carried out with CFA procedure. Then descriptive and correlational statistical procedures permitted the analysis of quality of life in disability and the impact of discrimination. The third paper comprises a qualitative study with seven people with visible physical impairments. The impact of and resistance to ableist discourses about impaired bodies and the relation of embodiment with identity are analyzed within embodiment theory and the concepts of ableism (Campbell, 2001) and physical capital (Bourdieu, 1990).

Findings suggest that dis/abl(e)ism has a profound impact on disabled people's lives, embodiment and identity. The prevalence of a tragic vicious cycle paradigm is challenged by a minor group of disabled people through a rights awareness-based triad of factors composed by financial and personal resources and social support system. Beyond that, disabled people manifest embodied forms of resistance that contradict the ableist normativities that undermine their physical capital and that impact on the recognition of a disability identity.

RÉSUMÉ: En raison de l'absence d'une filière d'études sur l'incapacité au Portugal, la recherche dans ce domaine est rare et ne présente pas le point de vue des personnes handicapées. Avec ce travail on prétend élargir l'étude de l'incapacité physique dans notre pays, à travers une perspective socio-politique qui met l'accent sur la compréhension de l'impact de l'incapacité et de l'*ableism* dans la vie des personnes handicapées, notament leur qualité de vie, leur *embodiment* et leur identité.

La recherche s'inscrit, donc, dans les paradigmes socio-politique, de l'*ableism* et de l'*embodiment* et comprend trois études qui ont utilisée une combinaison des méthodologies quantitative et qualitative. Chaque étude a été objet d'un article scientifique publié ou accepté pour publication. Une proposition de changement dans le domaine de l'incapacité composée des suggestions des participants suit la présentation de ces études.

Le premier article comprend une étude qualitative avec six dirigeants associatifs dans laquelle on a cherché à accéder au point de vue des experts à l'égard du contexte portugais dans le domaine de l'incapacité. Le deuxième article porte sur une étude quantitative auprès de 217 personnes handicapées versant la qualité de vie et la discrimination. La validation du questionnaire *QoL.Q* (Schalock & Keith, 1993) et de l'*Escala de Suporte aos Direitos das Minorias* (Nata & Menezes, 2007) a été réalisée par moyen des procédures d'analyse factorielle confirmatoire. Des analyses statistiques descriptives et de correlation ont également été réalisées. Le troisième article comprend une étude qualitative avec sept personnes ayant des handicaps physiques visibles. L'impact et la résistance aux discours *ableist* sur des corps avec un handicap et la relation de l'*embodiment* avec l'identité ont été analysés par moyen de la théorie de l'*embodiment* et des concepts d' *ableism* (Campbell, 2001) et de capital physique (Bourdieu, 1990).

Les résultats montrent que l'incapacité et l'*ableism* ont un profond impact sur la qualité de vie des personnes incapacités, ainsi que sur leur l'*embodiment* et leur identité. Un cercle vicieux paradigmatique de tragédie est dominant, quoiqu'il soit contesté par une minorité qui, à travers multiples facteurs, prend conscience de ses droits. Plus que cela: les personnes incapacités manifestent des formes "corsées" de résistance contraires aux normes *ableist* qui nuisent à leur capital physique et à la reconnaissance d'une identité.

Aos meus pais,
meus verdadeiros anjos da guarda.
To my parents,
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CONTENTS

INTRODUCTION

Disability is a complex matter. It calls into question a web of biological, cultural, economic, political and embodied discourses and practices that are historically and contextually situated. Over time, it has been interpreted and consequently treated or managed differently by societies, producing significant impacts on how individuals experience impairment and disability. Indeed, more than just being medical entities, impaired bodies are shaped materially and culturally (Ghai, 2006) and this influences greatly the experience of disability. Disabled embodiment is thus molded by medical, cultural, political, biological, contextual and individual factors – as it happens with non-disabled embodiment. However, by conceiving impairment as a conditional feature of human life, society simultaneously creates disability and makes it disappear into the normative order (Michalko, 2009).

Moral/religious positions were the first ways of interpreting impairments: a reflection of God's dismay (in Antiquity), a sin/evil or a God's creation (in the era of medieval Christianity). The medical model followed in the classical period with their scientific explanations and 'treatments' of impairments. Its power overstepped the borders of medicine and combined with the moral model, has constituted the 'personal tragedy theory' (Oliver, 1990, 1996; Barnes et al., 2005) that pervades language, cultural beliefs, research, media representations, policy and professional practice (French & Swain, 2004).

Meanwhile, with the two World Wars, the rehabilitative model arose with the promise of normalizing disabled people through the support of technology and the ideas and practices of rehabilitation. It was then society's responsibility to compensate or integrate those who were injured in the service of their country by means of normativity devices. Rehabilitation was thus on disabled people and not on society. Today, rehabilitation is the major device for social inclusion and the biopsicossocial model used by the World Health Organization found their basis on this model.

Surprisingly (or not), it was only in the end of 1970s that we heard disabled people's voices on this matter. With the influence of civil rights' movements, the Disabled

People's Movement emerged, challenging the social exclusion of disabled people through their politics. Right after that, Disability Studies developed in order to accompany this politicization in which the British (structural-materialist) and the USA (minority/cultural) social models have been influential.

While disability studies have been concerned with sociopolitical, cultural, economic and relational environments associated with disablism, post-modernism perspectives contest the exercise of power within cultural, linguistic and discursive practices that maintain the ideal of the inherently stable non-disabled body or mind (Garland-Thomson, 2002, p. 5). Within this perspective, critical disability studies goes further in terms of embodiment of difference and the processes and production of ableism; plus, disability is linked to other identities. By the influences of the feminism, post-structuralism and phenomenology perspectives, the significance of human corporeality is finally analysed outside the borders of medicine. Also, 'psychologisation' (Goodley, 2011) is contested with the evaluation of the effects of dis/abl(e)ism through the notions of the 'psycho-emotional effects of disablism', the 'internalized oppression', the demands of 'emotional labour', the pathologic culture of 'disavowal and individualization' and the ideas 'against the tragedy of impairment'.

Due to the lack of a disability studies field in Portugal, research on disability in our country is scarce and often lacks the perspective of disabled people. This thesis aims to extend the study of physical disability in Portugal within a sociopolitical perspective by focusing on the understanding of the impact of dis/abl(e)ism on disabled people's lives, specifically their quality of life, embodiment and identity.

Overall, this dissertation consists of a theoretical framework, three studies that are included in scientific articles and a general discussion of these where there's also a proposal for change in regard to disability.

The theoretical framework provides the reader with a comprehensive context for the current project and to rationalize the three empirical studies. It includes a literature review on the theoretical and historical perspectives on disability as well as a brief review on the topic of disability identity. While the disability models are introduced, a succinct historical account is given in order to contextualize their emergence over time. At the end, the section about 'disability identity' starts with a brief review on Erikson's work on identity, followed by an analysis of disability identity according to the disability models and the 'politics of recognition'.

Following the theoretical framework, there's an overview of the three studies that makes up the research and which are then included in each of the articles.

The first paper is entitled 'Views of disability in Portugal: '*fado*' or citizenship?' and includes a qualitative study with six disability leaders of associations in Portugal in which interviews sought to get insights from experts on disability in regard to the Portuguese context.

The second paper is entitled 'Quality of life in disability: validation of the Schalock's multi-dimensional model in the Portuguese context/ Qualidade de vida na incapacidade: validação do modelo multi-dimensional de Schalock ao contexto português' and includes a study on quality of life and discrimination with 217 disabled people (mostly with physical impairments). First, validation of the *Quality of Life Questionnaire* (Schalock & Keith, 1993) and the *Minorities' Rights Support Scale* (Nata & Menezes, 2007) was carried out with CFA procedures. Secondly, descriptive and correlational statistical procedures permitted the analysis of quality of life in disability (with 5 dimensions: satisfaction in life, competence in work/training, empowerment, equality of rights and positive discrimination), as well as the impact of discrimination.

The third paper is entitled 'Disability, embodiment and ableism: stories of resistance' and comprises a qualitative study with seven people with visible physical impairments. The impact of and resistance to ableist discourses about impaired bodies are explored and the relation of embodiment with identity is analysed, both within embodiment theory and the concepts of ableism (Campbell, 2001) and physical capital (Bourdieu, 1990).

Finally, there is a general discussion of the main findings of the three studies by drawing on three themes: *fado*, citizenship and the embodied self. We find that Portuguese disabled people have been following either a dominant tragedy model, or a citizenship perspective that tries to secure their *formal* integration. A further model is an experiential embodied perspective that links their impaired bodies to their identity/ies and which accounts for their resistance to dis/abl(e)ism.

And to end, a proposal for change regarding disability with participants' suggestions is presented.

Before starting with the theoretical framework, two notes are made in regard to the language and the researcher's personal positioning with regard to the topic and process of the research.

A Note on the Language

Charlton (1998) argues that attitudes towards disability are universally negative, yet there are cultural differences between countries under three themes: value and meaning of the body and physical characteristics; religion, particularly the messages that religious doctrines convey about disability; and language through which concepts are transmitted.

While the first two themes might be covered by the studies included in this thesis, the language used in Portugal in regard to naming 'disability', 'impairment', 'disablism' and 'disabled/impaired people' needs to be the object of reflection. Just because this thesis is written in English, this topic should not be left out, even more when the second article has a Portuguese version. Therefore, those who read in Portuguese might find it useful to have a clarification of the terms used. Also, even for the English language, this clarification might be convenient to the reader so that the concepts used in this thesis are clearly understood.

'Impairment' and 'impaired people' are the most common words used when people talk about disability in Portugal. There is no consensus in regard to the concept of 'disability' and because of that, people either use these terms in an individual way, which alert us to the fact that individual models are preponderant in Portugal, or else they find some difficulties in talking about the subject as a social oppression/construction due to the fact that they lack a word for it. We use the term 'disability' for 'incapacidade' when we refer to the social construction/oppression; we use ‘impairment’ for ‘deficiência’, and ‘disablism’ for ‘incapacitação’. ‘Disabled people’ is translated to ‘pessoas incapacitadas’ so that there’s a distinction with ‘impaired people’ that we translate to ‘pessoas com deficiência’. Even though the term ‘the impaired’ – ‘os deficientes’ - is currently used, as Teixeira (2012) explains, there are not half people or defective people but instead people are people with different bodily features. To be clear, impairment/deficiência conveys the medical conceptualization and the bodily difference - even on this we (also in English language) should have different words in order to distinguish between the medical concept (within the medical/deficit model) and bodily difference (as part of human differences).

As Olkin (2002, p. 136) argues ‘language not only mirrors but creates reality’ and ‘these considerations of language are not merely about cosmetics’. The concepts used have a value-based dimension (Vehmas, 2004) more than being purely scientific or descriptive. Even with regard to the post-modernist deconstruction of the disabled/non-disabled dichotomy, we find ‘the implications of the historical sedimentation of language which we use’ (Derrida, 1970, p. 271). Therefore we, in Portuguese, should use language that conveys adequate information about how we consider the object/subject/individuals.

The Researcher’s Personal Positioning

> *“The social scientist is not some autonomous being standing outside society. No-one is outside society, the question is where he [sic] stands within it . . .”*
> Mills (1959, p. 204)

Acknowledgement and examination of researcher’s location or ‘invested positionality’ (Lather, 1991, p. xvii) is important as this shapes research approaches and understandings (Brown & Strega, 2005). Postmodernism, political and critical psychology, critical race theory and feminism have contributed to the development of an anti-oppressive theory by which research processes are examined through a political frame (e.g. Kagan, Burton, Duckett, Lawthom & Siddiquee, 2011; Fox, Prilleltensky & Austin, 2009; Prilleltensky & Nelson 2002; Sloan, 2000). The ideas of value-free science, the researcher's powerful position, and the processes of reflexivity or self-reflexivity are among the issues discussed by this critical theory, to which critiquing and transforming existing social relations is the main goal of research. Critical researchers reflect upon both the real forces that impinge on the lives of groups and individuals as well as their interpretations in regard to these forces and the experiences they engender (Brown & Strega, 2005).

Harold Hahn (1985b, n.d.) argues that 'many of the difficulties confronting citizens with disabilities probably can be attributed to a pervasive tendency of researchers to ask the wrong questions'. With this in mind, critical/feminist research contends that every piece of research is ideological and choices of research topic, of methods and of study group population are always political acts (Letherby, 2003). Actually, 'the questions we ask, and the way we choose to ask them, often determine the answers we get' (Letherby, 2003, p. 3).

Rosi Braidotti (1994, p. 168) writes: 'accountability and positionality go together'. In regard to accountability, I am personally committed to social justice and the politics of disability. As a researcher my intention is to produce knowledge that can make a difference to disabled people's lives through social and individual change. In this process, I hope that my 'footprints' in the fieldwork were sensitive to respondents and to their own questions. As far as positionality is concerned, I can say that my 'que(e)rying the thresholds of passages' (herising, 2005) was part of the research process as I experienced continuities and discontinuities between myself and those who have participated in this project. I underscore the ways "bodies ... are essential to accounts of power and critiques of knowledge" (Grosz, 1993, p. 196). Therefore, I won't go into autobiographical revelations, which I personally find inadequate and oppressive for myself, but I manifest my bodily position that I present below.

‘*I am always on the side of my body’*
Merleau-Ponty (1968, p. 133)

Pity and curiosity won’t be feed. Also, heroic visions won’t be allowed – heroes belong to the cartoons. The obvious will be revealed: I am a wheelchair user. Perhaps more obvious for myself than for the majority of people: I am a cyborg[1] - my body is half human and half technology. Less obvious than what I’ve just revealed, I have experienced different embodiments in my life. I was once a hybrid[2] who became a cyborg. Still today I experience different embodiments as a cyborg. It depends essentially on the people who I am with and the places I find myself in. It became clear to me that contexts, with their physical features and where people are actors and producers, have a significant effect on my embodiment. Yet, I am also part of people’s world and of course part of my embodiment.

With these embodied experiences, I have kept wondering since my early years as a cyborg, why the majority of people – impaired or not – have to see and treat impairment in such a negative cultural and material way, to a point that we have a name for it: disability (as social oppression). And more importantly, why does this still happen and is perpetuated?

Obviously, I don’t have a neutral position in regard to disability. Who does anyway? I am committed to disability politics in my research as ‘I am always on the side of my body’.

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[1] [2] Cyborg and hybrid are concepts associated with the work of Donna Haraway (1991).

THEORETICAL FRAMEWORK

1. Theoretical and historical perspectives on disability

As a result of a long historical process, disability and impairment have been understood differently by a variety of models. The individual models – moral and medical – due to their long existence and influence on how society interprets disability, are still the dominant models of disability today, and present a 'personal tragedy' perspective. This domination has been challenged by the social models – the British structuralist-historical and the North American minority models – which have been the foundations of Disability Studies. Nevertheless, with the post-modernist perspective, Critical Disability Studies has shown the limitations of the former, in a new space of reflection on the significance of human corporeality where ableism and even cyborgs and hybrid bodies emerge. The truth is that disability has been understood in more profound ways over time.

1.1. The Individual Models

1.1.1. The Moral or Religious Model: *'God gives us only what we can bear'*

The moral model is the oldest model of disability and is still nowadays the most prevalent worldwide. It was prevalent in Antiquity and is apparent in the Bible.
As signs of the anger of Gods in Antiquity, in association with sin and evil in the Old Testament and with God's creation in the New Testament, physical impairments have been interpreted differently through the ages.

In Athens, Sparta and early Rome we found that different impairments had different meanings and were subjected to different practices: visibly deformed newborns were subjected to public exposure due to the fact they were signs of embodiment of the anger of the gods and possibility of misfortunes (Stiker, 1997; Albrecht, 2006); blind and deaf people were considered as having special features – who 'enjoy the pleasures of the dark and the silence' (Avan Louis & Stiker, 1988 cited in Stiker, 1997); and impaired and impoverished war veterans could have a pension in Greece (Braddock & Parish, 2001). In times of slavery and combats, strong physical constitution was extremely important and the ideal of bodily perfection was manifested in classical Art (Albrecht, 2006). In these times, a primitive system of assistance coexisted with infanticide (Barnes, 1997), demarking the acquired or congenital conditions. Even though deformity was linked to biological fears of collective sterility, of the extinction of the species, its interpretation was connected to the divine and the wrongdoing of the group (Stiker, 1997). From early times, biological abnormality was thus projected onto the social and moral level.

In the era of medieval Christianity, physical impairments were in the Old Testament associated with sin that signaled a profane nature of impurity and a source of evil or demons (Stiker, 1997; Barnes, 1997; Braddock & Parish, 2001). Only wholesome bodies were natural ones. Disabled people were subjected to purification rituals performed by priests and were made to bear the burden of sin since it was they themselves who were to blame. The idea of blame was eradicated in the New Testament where disabled people were part of God's creation or in whom people recognized God (Braddock & Parish, 2001). By this time, a system of charity had emerged: the rich assured their salvation by giving alms to the poor and Church fathers established charitable works and hospices that were supported by alms (Braddock & Parish, 2001; Albrecht, 2006; Barnes, 1997). Nevertheless, with the great epidemics, ideas of sin and demonology associated with disability reappeared. To sum up, in the Middle Age period, disability was mixed with other aspects of misery and suffering; it was lumped together with illness, poverty and other marginalized groups (Braddock & Parish, 2001; Barnes, 1997). Disabled people were spiritually integrated with the practice of charity but they were never integrated as they were always on the social fringes (Stiker, 1997).

Nowadays, the moral or religious model leaves its marks in the cultural perception regarding disability. In this perspective, disability is a sign of moral flaws, a sign of retribution of the individual's moral failures or his/her progenitors (e.g., Garland, 1995; Silvers, 1998b; Stiker, 1999). At the same time, disabled people have a special relationship with God, and therefore they have to accept their condition. Disability has a greater purpose in life than the condition itself, therefore people think: 'There's a reason I was chosen to have this disability'.

The benefits of the model, such as spiritual or divine acceptance, are however contrasted by the great negative effects of this model. Shame, ostracism and the need to conceal the disability or person with disability (Olkin, 2002) have contributed heavily towards a history of oppression, exclusion and stigmatization of disabled people.

1.1.2. The Biomedical Model: *'This is how the world is. Take it or leave it.'*

In the classical period, the (hi)story is different with the advent of medicine and philosophy - it is a time of distancing from Christian morals (Barnes, 1997). Thinkers were searching for natural causes and not moral ones. Ideas of heredity and of contagion substituted the theory of demonology, inaugurating a direction of empirical observation, away from theology (Stiker, 1997; Braddock & Parish, 2001; Albrecht, 2006). Scientific knowledge started to prevail.

With that, a new form of power emerged: the medical power. In the Age of Enlightenment, the thought was 'biologized' (Stiker, 1997). Administrations became dependent on the expertise and medical opinions; therefore the medical power became a political power (Stiker, 1997).

In the eighteenth century, with the use of appropriate technologies, there appeared specialized institutions for the education and rehabilitation of sensory impaired people. In this way training was aimed at drawing them out of inactivity and lack of education rather than integrating them back into society (Stiker, 1997; Braddock & Parish, 2001). Even though disabled people could be cared by their families that assumed new missions, such as caring for their children, the more common option would be internment in a hospice or asylum that would allow them to survive and at the same time permitted society to hide and regulate human misery (Stiker, 1997).

To sum up, the classical centuries retained the biological perspective, introduced ideas of health and debility and thus acquired principles of classification, which called for an act of separation (Stiker, 1997).

Nowadays, in the western world, the medical model is a powerful lens to understand disability. This model, filled with scientific credibility, explains disability in the language of medicine, and thus provides a great explanatory power. It sees disability as an individual's physiological or mental deficiencies, which are the inevitable product of the individual's biological defects, illnesses or characteristics (Kristiansen, Vehmas, & Shakespeare, 2009). The pathologizing, the objectification, the individualization, and the categorization of disability are key aspects of this model (see Smart & Smart, 2006).

For this model, impairment is an objective condition, a result of pathology that should be the focus of medical experts. This is a model of experts in control (Smart, 2001, 2004), leaving disabled people to the role of passive and compliant patients. Disability is individualized: the definition, the 'problem' and the treatment lies within the individual. Therefore the 'patient' responsible for the 'problem' should also be totally responsible for the solution (Kiesler, 1999).

In some textbooks, disability is even seen as 'a variable dependent upon characteristics of motivation and adaptability as well as the limiting residue of disease and injury' (Liachowitz, 1988, p. 12). Activists would then call this the "Try Harder" syndrome in which disabled people are subjects. Also, people are seen and categorized according to their pathology or impairment. Besides that, the use of clear-cut normative criteria by the biomedical model, leads to consider impairment as a biological inferiority, malfunction, deviance, pathology when compared with (or normed on) non-impaired individuals (McCarthy, 2003).

Even though the biomedical model came to contradict the moral/religious model, there are some influences of the latter on the ideas of biological wholeness and full functionality, which are viewed as virtue and righteousness for the moral model and constitute the norm for the medical model (Bickenbauch, 1993).

Also worth mentioning, today the power of the medical model still transcends the field of medicine and invades other areas of knowledge. Before the 1980s, individualistic explanations linked to the medical model predominated within social sciences (Barnes, 2004). The American sociologist Talcott Parsons (1951) viewed short- and long-term 'sickness' as a deviation from the 'normal' state of being, which constituted a threat to economic and social activity or functioning. For him, ill and impaired people had a 'sick role' social status and therefore they had certain rights and responsibilities. They are relieved of the roles and obligations of non-disabled but they were expected to seek help from the medical and rehabilitation professionals.

Nowadays, the medical model is still very powerful by influencing greatly the social perceptions regarding disability with all the consequences that come from that. This deficit-treatment lens leads to an interpretation of the disabled individual as defective with reference to normative physical, behavioural, psychological, cognitive, or sensory being (Gilson & DePoy, 2002). According to this model, interventions are aimed solely at the 'abnormal' individual while the surrounding environment is left intact (Kristiansen et al., 2009). Resources are directed to 'improve' or 'repair' the individual through medical interventions. Practices and social arrangements do not consider impaired people's needs and consequently many physical and attitudinal barriers are erected, which undermine participation of disabled people in society. In fact, the medical model legitimizes the way society is relieved of any responsibility because disability is the individual's flaw and tragedy; it's the individual's bad luck (Smart & Smart, 2006).

1.1.3. The 'Personal Tragedy Theory': *Two in One*

As individual models, the moral and the medical models consider that disability resides within the individual and is always determined by his/her impairment (Olkin, 2002). But more than this, each model imprints a degree of stigma or pathology (Olkin, 2002). For this reason, these models form the 'personal tragedy theory' of disability (Barnes, Mercer, & Shakespeare, 2005; Barnes, Mercer, & Shakespeare, 1999; Oliver, 1990, 1996; Priestley, 2003; Silvers, 1998b).

This theory sees disability 'as a deficit, a personal burden and a tragedy' (Darke, 2004, p. 103), something to be avoided at all costs (Oliver & Barnes, 1996, p. 66). According to this theory, disability robs any enjoyment from life and is a burden to the society (Saxton, 2000).

The high prevalence (French & Swain, 2008) and dissemination across cultures (Coleridge, 1993; Insgtad & Whyte, 1995; Stone, 1999) of the 'tragedy personal theory' can be explained by its endurance in history (Stiker, 1997; Longmore & Umanski, 2001; Borsay, 2005). Its dominance spreads throughout language, cultural beliefs, research, media representations, policy and professional practice (French & Swain, 2004). It uses the term 'sufferers' to designate disabled people and they are represented by the media for dramatic purposes.

This theory conveys perceptions of disabled people as inferior, inadequate, sad, evil and causing pity and disgust (French & Swain, 2008). Impairment and disability are all about loss, and so disabled people want to be other than they are: 'normal', with no exception (Swain, French, & Cameron, 2003).

Dominant policies, practices and intervention, which are based on this theory, constitute intrusive and invalidating experiences for disabled people. They are expected to be 'independent', 'normal', to 'adjust' and 'accept' their situation (French & Swain, 2004), whatever the cost to themselves (French, 1994), which constitutes the 'try harder syndrome'.

While definitions of disabled people as 'sufferers' or 'victims' are spread by influential organizations and institutions, such as the Church, the medical profession, charities and the media, this creates and maintains the tendency to put disabled people in an inferior position in society (French & Swain, 2008). Also, these organizations tend to make ‘universal’ assumptions about disabled people and their lives and to ‘predict’ the amount of tragedy a disabled person will experience, by neglecting disabled people’s voices on their own lives and by perceiving impairment as the cause of all problems.

This theory has been severely criticized, especially the medical model. On the one hand, disabled people are reduced to an ‘abnormal’ and ‘lesser than’ medical condition. By being seen essentially as ‘deficient’ and unable to function ‘normally’, segregation policies are legitimized for them. Additionally, non-disabled expertise dominates the lives of disabled people and these are rendered to passive targets in separate and ‘special’ care environments. Services are made for disabled people but not by them, and all this tends to promote benevolence, charity and paternalistic attitudes and practices (Olkin, 2002). Kristiansen et al. (2009, p. 3) claim that ‘part of paternalism is a kind of expert system where the authorities of relevant knowledge and craft determine how the phenomenon in question should be understood and dealt with’. Paternalism allows non-disabled people to make decisions on behalf of disabled people for their own good, even if contrary to their own wishes.

Adding to that, the long history of the two-outcome paradigm of medicine—total cure or death of the individual – does not work for disability or chronic conditions in terms of treatment and policy considerations (Smart, 2005). Consequently, disabled people are subjected to dehumanization treatment when pathology is the only focus of intervention (Albrecht, 1992). Assisted suicide, euthanasia and antenatal termination are medical frames of a disabled entity that reflect the hegemony of the medical model (Goodley, 2011). And when disability is medicalised, interprofessional collaboration is rarely implemented (Smart & Smart, 2006).

1.2. In Between: the Rehabilitative and the Biopsicossocial Models

> *"How does disability arise? It arises from the fact that the environment where the individual who suffers an illness or an accident lives, judges that it can no longer keep him/her."* (Stiker, 1997, p. 158)

Comprising the functional and the environmental models, the rehabilitative model emerged in the twentieth century at the time of World War I. This model provides the basis of one of the most contemporary models, the biopsicossocial model, which is considered by Smith (2009) to be the second medical model.

With the 'Great War', a very large number of men were discharged, injured for life. Rather than being seen as aberrant, war-impaired people had suffered a catastrophe in the service of their country. For that reason, they deserved to be rehabilitated and integrated in society (Eldar & Jeliċ, 2003).

Ideas of compensation, collective responsibility, state involvement, normalization and social insurance had first appeared with work-related accidents in the last decades of the nineteenth and first decades of twentieth century (Assouly-Piquet & Francette, 1994 cited in Stiker, 1997). These ideas and practices were then reinforced for the war-injured and then, in post-war years, rehabilitation was made available to all disabled people (Stiker, 1997; Eldar & Jeliċ, 2003).

In the third decade of the twentieth century, the principle of the empirical norm appeared, by which the impaired person was evaluated and also evaluated him/herself with reference to a norm, to the able-body norm (Stiker, 1997). A whole collection of normalization devices tried to help disabled people to reoccupy a 'normal' place in the abled society (Eldar & Jeliċ, 2003; Sink, Field, & Gannaway, 1978). The goal was to adjust to a society as it was presently constituted. Returning to ordinary life, to ordinary work demanded identicalness as close as possible to the ordinary citizen (Stiker, 1997). Therapies and compensatory training were corrections that were intended primarily to facilitate reabsorption by the social body and only secondly for valorization or advancement: 'The plan is not one of equality but one of identicalness' (Stiker, 1997, p. 151). Consequently, disabled people were only integrated when their disability was erased (Stiker, 1997).

Today, rehabilitation refers to the collection of medical, therapeutic, social and professional actions directed to those termed disabled. They now have rights that are those that all citizens have but which have never been the object of any formal declaration: the right to work, the right to education, the right to parenting, for example. The narrow norms of society, such as requirements of schooling, the production imperative as well as the excessive medicalization are too restrictive and therefore disabled people are established as a category to be rehabilitated and reintegrated (Stiker, 1997).

Goodley (2011) points out that the main goal of this perspective is to manage (and control) disabled people in order to maintain the social order, by being therapeutically treated (controlled) by professionals allied to medicine, such as social work (Oliver, 1983) and psychology (Goodley & Lawthom, 2005b).

When such integration is impossible, disabled people are entitled to subsidies or allowances, and in this way society is exempt from having to change its structure to permit social inclusion and equality of rights for disabled people (Stiker, 1997). With monetary assistance, society forgets disability, making it socially invisible (Stiker, 1997).

To sum up the main idea of the rehabilitative model is that an impaired person, despite their individual medical deficiencies, can function 'normally', at least to some extent, in certain social contexts, if the latter are changed to accommodate them and if he/she has proper rehabilitation (instead of treatment or cure). This model is included in the 'part-essentialist individual deficiency' interpretation of the medical model (Smith, 2009) because it still uses an essentialist interpretation of normality to distinguish disabled and non-disabled, considering that 'normality' conveyed by a medicalised understanding of disability is the 'ideal' or the 'best' state. Still, the non-disabled professionals are seen as guardians and experts of the normalization process and therefore know best how to facilitate a better social functioning. Most contemporary mainstream policy-makers, including the World Health Organization (WHO) that uses the biopsicossocial model, adopt this paradigm.

The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) published by WHO in 1980 was highly criticized by disability scholars and activists, who even ignored or dismissed it as little more than a modified medical classification (Pfeiffer, 1998, 2000). Even though its aim was to challenge the medical model (Bury, 2000), ICIDH referred to the disadvantage of handicap resulting from the individual's 'being unable to conform to the norms', as if the 'problem' lied exclusively with the individual rather than with the norms. Additionally, ICIDH was deficient in being able to measure the influence of environments, facilities and policies in the way an individual with impairment is able to function and fulfil their role (Edwards, 2005).

In 2001, the International Classification of Functioning, Disability and Health (ICF) replaced the ICIDH. The ICF considers disability as constructed through the interaction between the individual and the environment. According with this new classification, disability is categorized by impairments of body function or structure, activity limitations, and participation restrictions and is an outcome of interactions between features of the person, including background health condition, and environmental factors. The latter are classified in general categories of the physical, human-built, social, and attitudinal world that may either create disability (and, in particular, participation restrictions) by acting as barriers or lessen (or eliminate) disability by acting as facilitators.

Despite the inclusion of environmental factors to evaluate disability, the ICF, like its 'mother' ICIDH, still received some criticism, particularly in regard to the same environment factors. In fact, the extent of the person's participation in his/her current environment is not well described when compared to the biomedical phenomena inherent within the physiological function of the person. The physical and attitudinal contexts have a great impact on disabled people's lives and this dimension should be well measured by an instrument with such an international usage. Locker (1983, p. 90) explains:

> *"The immediate context is handicapping where it presents barriers which must be negotiated, consuming reserves of time, money and energy in the process, or where the effort is such that the person decides not to bother and retreats into an enforced passivity. It is also handicapping to the extent that it leaves the individual with no option but to rely on the help of others."*

Gross and Hahn (2004) argue that there's an increased need for instruments that attempt to measure the interaction between the individual and the environment. For them, examples of questions that might be addressed include the following: 'What percentage of street intersections has curb cuts on all corners? How many restaurants have Braille menus? Do public events include sign language interpreters?' (Gross & Hahn, 2004, p. 132)
David Pfeiffer (1998, 2000) claims that the ICIDH and the ICF medicalises disability to a great extent, as their foundation is a functional framework of disability. He argues that with these instruments, empowerment is on the side of medical professionals who make decisions about the quality of life of disabled people, which then lead to the implementation of the principles of eugenics.

Tom Shakespeare (2006) has created an interactional approach that can be related to the biopsicossocial model of WHO. It includes relevant individual and contextual factors for the understanding of the experience of disability for each person. His approach considers an interaction between individual - the nature and severity of impairment, own attitudes to it, personal qualities and abilities and personality - and contextual factors - the attitudes and reactions of others, the extent to which the environment is enabling or disabling, and wider cultural, social and economic issues relevant to disability in that society.

1.3. The Social Model(s) and the Disability Studies: *'Nothing about us without us'*

> *"The social model goes against deep-seated intuitions and appears to defy logic"* (Shakespeare, 2006, p. 31).

Getting back to history, towards the end of the 1960s and beginnings of 1970s, in USA and the UK, the disability movement came into being. In the 1980s, the social model began to be theorized by academia and in this way disability studies as a discipline was created.

Previously, in 1972, a group of American disabled people (including Ed Roberts, John Hessler, and Hale Zukas), known as the Rolling Quads, living together in Berkeley, California, had inaugurated the birth of the modern independent living movement.

A year later, the Rehabilitation Act of 1973 was passed, and which became the first major nationwide anti-discriminatory legislation designed to protect disabled Americans. However, its section 504, which prevented discrimination based on disability in programs or activities that received federal funding, was only implemented five years later after intense lobbying and protesting (e.g. protest of 1st April 1977 in San Francisco), when the American Coalition of Citizens with Disabilities (ACCD) won the release of regulations that allowed this Section to be implemented.

In the tradition of other civil rights movements, ADAPT, the American Disabled for Attendant Programs Today, originally called the American Disabled for Accessible Public Transit, had used tactics of civil disobedience for the passage of the Americans with Disability Act (ADA) in 1990. ADA is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States. They conducted one of the largest disability rights protests:

> *"The 'Wheels of Justice March' is one of the largest disability rights protests to date (600 demonstrators), during which dozens of protesters throw themselves out of their wheelchairs and begin crawling up the 8 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day 150 ADAPT protesters lock wheelchairs together in the Capitol rotunda and engage in a sit-in until police carry them away one by one. George H.W. Bush signs the ADA on July 26."* (Albrecht, 2006, p. 35)

In the United Kingdom, in 1972, the work of Paul Hunt regarding the views of residents and potential residents of institutional homes for the disabled in the country resulted in the establishment of the Union of the Physically Impaired against Segregation (UPIAS). This organization controlled by disabled people, published a paper in 1975 that redefined the term *disability,* which became known as the social model of disability. In 1982, Disability Studies emerged with the formation of the Society for the Study of Chronic Illness, Impairment, and Disability. In 1986, it officially changed its name to the Society for Disability Studies (SDS).

The disability movement was then in motion. Rather than relying on legislative shifts, which turned out to be ineffective, disabled people used a wide-range of political action and mobilization, in order to bring disability to the attention of the general public as a matter of social relations (Barnes et al., 2005). Disability politics was now in disabled people's hands. A shift to self-organization took place. At long last, disabled people were able to assume the control of organizations, with the use of campaigns, self-help and activism (Barnes et al., 2005). Rather than a therapeutic orientation, a political orientation was adopted with the aim of influencing the behaviour of groups, organizations and institutions. Before that, disabled people were expected to conform to and change their behaviour according to traditional expectations, as stipulated by the previous models of disability. Shakespeare (2006, p. 30) recalls:

> *"Rather than a demeaning reliance on charity, disabled activists could now demand their rights; rather than pursuing a strategy of cure or rehabilitation, it is better to pursue a strategy of social transformation."*

From now on, the disability movement created internally a context for solidarity and mutual support; and externally worked on the campaigning for anti-discrimination legislation, independent living and a barrier-free society (Barton, 2004).

Within the confluence of sociological viewpoints with a strong political commitment to the self-empowerment of disabled people, the ontological and epistemological foundations for disability studies were created (e.g., Linton 1998b; Oliver, 1996; Priestley 2003). The social model replaces biological determinism in disability to recognize the construction of the social and political ways in which disabled people have been oppressed (Meekosha, 2004). For many disabled people, prejudice and discrimination found in society is a more significant obstacle than are medical impairments or functional limitations (Smart & Smart 2006). The social model rejects medical diagnoses and categories and assumes self-definition, self-determination, the elimination (or reduction) of the prejudice and discrimination, with full equality and civil rights as its hallmarks (Smart & Smart 2006). This model considers that the medical categorization has isolated people with disabilities from their own community and robbed them of a collective history (Hahn, 1985b, 1988). This collective history is now constructed within the disability movement.

Due to the close proximity of the disability movement with academia in the form of disability studies, the social model has the capability to explain and describe more of the day-to-day life of disabled people (Smart & Smart 2006). Barton (2004a, p. 287) writes that:

> *"Recognizing the centrality of institutional, ideological, structural and material disabling barriers within society is fundamental to a social model of disability".*

Nowadays, we can consider that there's not one social model but a 'family of social contextual approaches to disability' (Shakespeare, 2006) or 'social constructivist approaches', that pursue the understanding of social difference and inequality in disability (Meekosha, 2004). These have in common the rejection of an individualistic understanding of disability and the emphasis on the social construction or creation of disability issues, and consequently, they all locate the disabled person in a broader context (Shakespeare, 2006). Also, there's a political commitment to improve disabled people's lives, by promoting social inclusion and removing the barriers that oppress disabled people (Shakespeare, 2006).

Due to a strong emergence and influence of the disability movement in the UK and the USA, disability studies in these countries have found a firm place in academia and have evolved in such way that new understandings of disability have emerged. There are, however, some differences in disability studies in the two countries. Concerning the social model elaboration, in the UK we find a 'strong' structural-materialist model, whereas in the USA we find a minority (or cultural) model of disability. In regard to the scope of the disability studies field, Albrecht, Seelman, and Bury (2001) claims that in the USA 'disability studies' is not unique to writers and activists who coalesce around the social model of disability but designates a much broader field of study, one that encompasses a range of social scientific and rehabilitative disciplines as well as the perspectives of disabled activists. In contrast, in the UK, those who engage with disability without using the social model are generally associated with 'the sociology of chronic illness and disability', considering that disability is caused by illness and impairment that entail suffering and some social disadvantage; whereas 'disability studies' academics consider disability as centrally structured by social oppression, inequality and exclusion (Thomas, 2004c).

In Portugal, Disability Studies is not a firm discipline included in academia. Nonetheless, some academics have been working in this field, such as Joaquim Bairrão from the University of Porto who was responsible for several projects in the field of early intervention and that has been followed by Pedro L. dos Santos, Ana Isabel Pinto, Teresa Leal and Catarina Grande; Orquídea Coelho from the

University of Porto who has been working extensively on Deaf studies; a group of academics who have been working on inclusive education such as David Rodrigues, Luis de Miranda Correia, José Morgado, Margarida César, Sérgio Niza, Vitor da Fonseca e Vitor Franco; Jerónimo de Sousa and team members of Centro de Reabilitação Profissional de Gaia who made research contributions on the field of work inclusion and quality of life; Fernando Fontes and Bruno Sena Martins from Centro de Estudos Sociais at the University of Coimbra; Paula Campos Pinto from the New University of Lisboa; Pedro M. Teixeira from the University of Porto; among others.

Even though we will give a greater focus to the social models of disability in the UK and the USA - due to their great influence in the 'state of art' of disability studies -, the relational model of Nordic countries will be briefly mentioned so we can have a picture of how the social and political climate of the country has an important influence on the development of a social model. Finally, new understandings of disability within the post-modernist perspective will be presented, denoting the evolution of knowledge within disability studies in the last decade.

1.3.1. The Nordic Relational Model

Nordic researchers have relied on a relational understanding and have concentrated on evaluating welfare services (Gustavsson, Sandvin, Traustadóttir, & Tøssebro, 2005). For them, services and professionals ought to have positive influence on the lives of disabled people. Since the 1970s, disability has been associated with an 'environmental turn' as it became clear that society also has to adapt the environment to disabled people. This 'reversed adaptation' grew into a definition of disability that stressed a mismatch between the individual and the environment (Tøssebro, 2004). In fact, the conjunction of individual and environment is reflected in language since, in the Nordic languages, it is not possible to translate into separate words impairment and disability. The term *funksjonshemming* describes 'disability' and assumes a neutral valuation with regard with both the person and the environment (Shakespeare, 2006).

Due to their history of generous welfare states, Disability studies are less connected to the Disabled People's Movement, with leadership often being found in academia (Vehmas, 2008). Also, rather than being primarily focused on oppression and discrimination, the emphasis is on the interactions of bodies, minds and environments and the dis/empowering contributions of services and their practitioners (Goodley, 2011). Individualized models of disability are adopted in the welfare system or in education and are particularly influenced by the principles of normalisation (Stromstad, 2004).

1.3.2. The UK Structural- Materialist Model

The British disability studies, developed in the 1980s, was heavily influenced by historical materialism (e.g. Finkelstein, 1981a, 1981b, 1996, 2001; Abberley, 1987; Barnes, 1990, 1991, 1998; Oliver, 1990, 1996; Zarb, 1992; Morris, 1993; Gleeson, 1999; Thomas, 1999, 2007; Barton, 2001). As it was influenced only by Sociology, the British social model focuses on issues of equality in political and material participation (Phillips, 1993, 1995). This model is called the 'strong' social model, the 'politics of disablement', the 'social oppression theory' (Oliver 1990, p. 1) or the 'political economy of disability' (Thomas, 2004d). Finkelstein (1980), Oliver (1990), Barnes (1991) and Barton (1996) are some of the academics who developed this model by using a perspective that draws upon a Marxist and materialist interpretation of the world.

According to this perspective, social inclusion of impaired people has its roots in capitalist ways of production. 'Normal' and 'average' labour power became the only means to obtain independently the means of subsistence and it constituted the basis of social standing, merit and personal identity in modern society (Oliver, 1990; Gleeson, 1999). Because disabled people cannot have 'average' or 'normal' performances required by capitalism, their economic life, which is closely linked to their political life, is greatly damaged. For them, political life is an economic life wherein discrimination, exclusion, and disenfranchisement are experienced as an increased probability of substandard wages and poverty (Gilson & DePoy 2002). Professionals are part of the system because they rule ideologies that medicalise disabled people's lives and uphold class inequalities; the maintenance of the status quo of these professionals turns disabled people into passive recipients of state intervention (Goodley, 2011). The position and experiences of disabled people must be thus understood by the analysis of the socio-economic conditions and relations in which disabled people are oppressed (Barton, 2004).

The 'strong' social model views disability as a matter of oppression and research serves to a large extent to clarify how people with impairments are actually oppressed (Kristiansen et al., 2009). The study of disability is thus about a political-ethical dimension through addressing material needs via increased socio-political participation and socio-spatial inclusion (Gleeson, 1999, p. 150).

This model strongly opposed to the medical model by affirming that discriminatory attitudes, rather than functional impairments, lie at the heart of disability (Barnes et al., 2005). One of the discursive strategies used to criticise and demark its difference from the individual model consisted in a conceptual distinction between 'impairment' as a functional limitation and 'disability' as a socially generated system of discrimination (Meekosha, 2004). As a result, the personal experience disappears 'in favour of a macro-sociological focus on the social system' (Turner, 2008, p. 34).

The analysis of the system of discrimination is thus primordial for this model, which culminates in the struggle with politicization of disabled people through civil rights and equal opportunities campaigns, and social policy responses (Barnes et al, 2005). This system is erected with the barriers and constraints produced by a disabling society that creates systematic inequalities between disabled and non-disabled people, with the latter being always in a privileged position. Architectural, attitudinal, educational, occupational, legal and personal disabling barriers are continually being erected in the lives of disabled people. The built environment, housing and transport are only made to provide physical access to non-disabled people.

In education there are low expectations of success and the ideology of 'special educational needs' and a segregated education system dominate. The exclusion of mass public education regarding disabled learners undermines their access to a proper formal education but also the access to the 'hidden curricula' of schools by which the values, rituals and routines of the wider society are acculturated within students (Goodley, 2011).

This will lead to a lack of a proper formal education, which constitutes only one of the factors that prevent disabled people from being included in the job world. Inaccessible buildings, work processes and public transport systems, and employees' attitudes are key factors behind the massive unemployment rates among disabled people (Honey, Meager, & Williams, 1993 cited in Barnes, Mercer & Shakespeare, 2005), and which have a crucial impact on their social and material well-being in terms of income, class, influence, social relationships and personal identity (Barnes et al., 2005). Economic disadvantage is a very visible aspect in disabled people's lives. They often have low incomes due to their inability to work or/and exclusion from work; they are not able to reverse this situation because opportunities are denied; and they have additional costs to access an exclusionary society (Zaidi & Burchardt, 2009 cited in Goodley, 2011).

Added to this, we find that discrimination 'extends from these 'public' domains to the more 'private' sphere of family life, and moral issues about what sorts of lives are valued and devalued' (Barnes et al., 2005). The system of discrimination has spread to all areas of disabled people's lives. For this reason, and with the strong campaigning of disabled activists, disability has turned into a human rights issue in global public discourse. With the International Year of Disabled People (1981) disabled people's basic rights were proclaimed: education, employment, economic security, services, independence, culture and recreation, as well as influence and political participation. Subsequently, the 'right to life' and the 'right to parenthood' were added to this list at a meeting of disabled people across Europe (CSCE, 1992 cited in Barnes, Mercer & Shakespeare, 2005).

To conclude, the British social model is particularly useful for the understanding of the impact of the socio-economic conditionings imposed by society and provides important insights about the role of the non-disabled hostile world on disabled people's lives. Vic Finkelstein provides a good concrete example to reflect on. He describes a reversed world, one that is friendly for disabled people and hostile for non-disabled:

> *"Vic Finkelstein (1981a) illustrated the disablement of modern culture by describing an imaginary community where wheelchair users were the majority and the environment was designed accordingly. In this 'disability culture' (as opposed to a 'disablist culture') able-bodied people were marked by bruises from banging their heads on lowered entrances (made for wheelchair users) and suffered backache from stooping down. They were helped by able-bodied equipment such as helmets, neck braces and, 'best of all', limb amputation, and money was collected for them in up-turned helmets with, 'Help the able-bodied', imprinted upon them."* (Goodley, 2011, p. 11)

1.3.2.1. Critical observations concerning the British social model

Even though the replacement of the traditional deficit approach to a social oppression understanding of disability was and is an empowering and liberating process for disabled people (Barnes et al., 2005; Shakespeare, 2006), the British structuralist social model has been criticised by some academics, informed by postmodernist and poststructuralist theoretical perspectives, who began to question the focus on socio-structural determinants (e.g. Shakespeare, 1997; Corker, 1998; Corker & French, 1999; Corker & Shakespeare, 2002). Tom Shakespeare is one of the academics that has been the most outspoken critic of the British social model. His critiques draw on feminist, postmodernist and poststructuralists sources (Crow, 1996; Morris, 1996; Corker & French, 1999).

Following Smith (2009), even though the structuralist model conceptualizes normalization in a different way than individual models, ordinary citizenship is the main goal as it focuses on the struggle for the same participation in the same ideal and normal state as 'the non-disabled' already are, supposedly, enjoying. Within this idea, it assumes falsely that all non-disabled people are independent and also that independence is a desirable 'state of being' (Smith, 2009).

Also, the linear relation of the subordination of disabled people in relation to non-disabled is questionable since other factors might inverse these positions – 'we all have the capacity to oppress people who are situationally less powerful than us' (Tregaskis, 2003, p. 3; Vernon, 1999). As Erving Goffman (1963, p. 163) puts it: 'The normal and the stigmatized are not persons but rather perspectives'. By considering disabled people as a homogeneous group (based on oppression), the structuralist model fails to engage adequately with the complex intersections of other social identities and disability. For example, social class or having more access to financial and community resources has a great influence on how well one can cope with a disabling society (Shakespeare, 2006; Blackmore, 2007).

Even though material oppression is an important factor in disabled people's lives, it is not the only one. Many face oppression of a socio-cultural, communicative and discursive order (Goodley & Lawthom, 2005a). In fact, disablement is often felt in the relational dynamics between non/disabled people (Tregaskis, 2003). Therefore, relational, cultural and extra-material factors should also be taken into account in disabled people's oppression.

As far as barriers are concerned, Shakespeare (2006) argues that the structuralist model places great faith, perhaps unrealistically, on the removal of barriers. Even though barriers are a major factor for social exclusion and the physical obstacles approach has a powerful symbolic role for the understanding of disability, Shakespeare (2006, p. 44) claims 'that it is not enough to address buildings and products without addressing money and power'. Additionally, a free-barriers environments approach is effective to highlight the human- created obstacles to participation in society, but it doesn't work entirely in nature environments for example (Shakespeare, 2006). Also, incompatibility problems still emerge even when we apply the principles of universal design. For example, wheelchair users may have problems with tactile paving that gives locational cues for visually impaired people (Grey-Thompson, 2005). Finally, practicality problems arise because it is impossible to remove every obstacle; disabled people won't ever have the same freedom of movements and means as non-disabled people have, so in practice, access is often a compromise, and depends on goodwill and flexibility (Shakespeare, 2006).

Regarding the neglect of impairment by the structuralist model, Paul Abberley was one of the few materialist disability studies theorists who brought up the body or the impairment into the discussion about disabled people's oppression. He said:

> *"It is crucial that a theory of disability as oppression comes to grips with this 'real' inferiority, since it forms a bedrock upon which justificatory oppressive theories are based and, psychologically, an immense impediment to the development of political consciousness amongst disabled people."* (Abberley, 1987, p. 8)

Later on, Shakespeare and Watson have written about the 'absent presence' of impairment in (British) disability studies (e.g. Shakespeare & Watson, 1997, 2001a, 2001b; Shakespeare, 2000; Watson, 2002), arguing that disability politics must engage with impairment and not ignore it (Shakespeare, 2006). Beyond barriers, impairments also create difficulties for disabled people. Shakespeare (2007, p. 12) gives an example:

> "*People with intellectual impairments or dyslexia are disadvantaged by living in societies based on written information and expecting high levels of literacy and education. But this does not constitute oppression, any more than snow and ice or floods constitute oppression for people with mobility impairments. Not all barriers are discriminatory."*

Indeed, the marginalization of the personal experiences of impairment contributes for the maintenance of the individual model of disability (Marks, 1999b) by leaving the impaired body a 'property' of the medical model (Hughes & Paterson, 2006; Hughes, 2004; Thomas, 1999).

Adding to that, while the struturalist model fails as a social constructionist model when it neglects impairment, and turns into a reductionist or biologically determinist model (Shakespeare, 2006), its over-emphasis on social constructionism creates problems for people with hidden impairments, such as dyslexia or chronic fatigue syndrome, who might prefer a realist and medically based approach to defining and understanding impairment (Shakespeare, 2007). Shakespeare (2007, p. 13) says:

> *"Many disabled people long for a diagnosis to entitle them to welfare benefits and other exemptions, and it is hard to see a practical alternative to administering the complex entitlements consequent on disability."*

For him (2007), it is not medicine, but inappropriate medicalization that is the root of the problem. As a final example, Shakespeare (2007) argues that the employment situation of disabled people is more complex than discrimination of employees or existence of barriers. He (2007, p. 10) explains:

> *"Incidentally, I think that the employment situation of disabled people is complex. While there is considerable evidence of extensive unfair discrimination, it is also the case that many disabled people are limited in the type of work they can do, or the amount of work they can do, because of their impairments. Additionally, some disabled people lack the training, confidence or motivation to work, while others would prefer to rely on welfare benefits than enter the labour market. Thinking solely in terms of employer discrimination rather than this wider range of factors limits our understanding of the stubborn and persistent nature of disabled people's exclusion from the workforce."*

To conclude, for Shakespeare (2006), a social model must not essentialise disability but signal that the experience of disabled people is dependent on the social context, and differs in different cultures and at different times. Disability is a complex, scalar, multi-dimensional phenomenon and disability studies should include socio-political issues as well as questions of impairment and the body in order to better understand the complex dialectic of disability (Shakespeare, 2007).

1.3.3. The USA Minority (or Cultural) Model

Due to influences of identity politics and the corresponding academic disciplines emerging from the liberation movements of the 1960s—feminism, race and ethnic studies, gay and lesbian studies – the minority model of disability emerged afterwards (Hahn, 1985b, 1988, 1996; Kleinfield, 1979).

The field of disability studies in the USA has been influenced by sociology and by the humanities. North American researchers have been influenced by a minority group conception of disability, and latterly have been focused on cultural representation and meaning. Therefore, issues of psychology, identity, personal affirmation and moral development are matters of research (Gilligan, 1982; Olkin, 2002, 2003; Olkin & Pledger, 2003).

Early academic writings on the social psychology of disability had already identified the disability experience with that of other minority groups that have endured discrimination (Barker, 1948 cited in McCarthy, 2003). And today, the designation of the disability community as an oppressed minority is prevalent (Charlton, 1998). As debated in feminist and race studies, disabled people are considered a minority group, a sub-culture (Charlton, 1998; Silvers, 1998a). By 'minority', researchers don't mean to refer to numbers but the experience of prejudice, stigma, discrimination and oppression; it's about the vantage point of a prevailing perspective, of a majority, which is considered normative (Olkin, 2002). From this perspective, disability is a matter of prejudice and discrimination of a minority group that have to be combated through civil rights legislation, which will guarantee individual rights (Hahn, 1985b). Rather than correcting impairments to the maximum extent possible or encouraging disabled individuals to strive to approximate standards set by nondisabled majority, this socio-political paradigm assumes that equal rights have to be extended to disabled citizens (Hahn, 1996).

Harold Hahn (1985ab, 1986, 1988) was particularly influential in the development of the minority group model of disability. For him (1988), the environment demands a non-disabled functionality that people ought to possess in order to survive or to participate in community life. Because this functionality request is fundamentally determined by public policy, this suggests that public attitudes are a crucial component of the surroundings with which disabled people must contend (Hahn, 1988). Therefore, the attitudinal environment of society is the principal problem facing disabled people (Hahn, 1985a).

Hahn (1988) considers that the prevalent emphasis on disabled people's functional limitation and the pervasive features of an unaccommodating environment disguise widespread feelings of bias or prejudice. The attitudes towards disability are composed by two concepts that were included in the positional inventory developed by Livneh (1982) and were developed by Hahn (1988, 1996). These are the 'aesthetics' and 'existential' anxiety, with the former referring to the fears engendered by persons whose appearance deviates markedly from the usual human form or includes physical traits regarded as unappealing; and the latter, referring to the threat of potential loss of functional capabilities by the non-disabled and how this interferes with the pursuit of a satisfactory life (Hahn, 1988).

Personal appearance and individual autonomy are two critical values in 20th-century western society. Hahn (1988) claims that people who fail to meet prescribed standards of physical attractiveness and functional independence not only are assumed biologically inferior, but they are also exposed to a stigma that depicts them as 'not quite human' (Goffman, 1963, p.5). This assumption has been significantly influential in the treatment of disabled people by society.

Whereas 'existential' anxiety is connected to the functional-limitations model (or the medical model), 'aesthetics' anxiety is closely related to the minority-group model (Hahn, 1988). The pervasive cultural emphasis on personal attractiveness is associated to the 'aesthetics' anxiety, and those who are perceived as different or strange are placed in a subordinate role (Hahn, 1988). The equivalence of freedom with personal autonomy and the high primacy of liberty (rather than equality) are associated with the 'existential' anxiety that emanates from the personal identification with the position of a disabled person, in which the apprehensions aroused by functional restrictions often seem overwhelming (Hahn, 1988).

Unlike the reaction to other minorities, many non-disabled people are reluctant to openly acknowledge their aversion to disabled people and often express feelings of sympathy and paternalism, rather than displays of bigotry or hostility as experienced by other minorities. Regarding disability rights, politicians have often been inclined to provide sympathetic endorsements for the goals of disabled persons, even when they have shown strong resistance to the claims of other disadvantaged groups (Hahn, 1996). Consequently, paternalistic feelings of sympathy and pity have frequently shaped disability policy (Shapiro, 1993), and the functional limitations paradigm appears to be implied by laws and practice which have either sought to assist disabled people in striving to approximate the physical and behavioural standards established by the nondisabled or to compensate them with transfer payments (subsidies) for their inability to fulfil these requirements (Hahn, 1996). This is evident in the rehabilitative model. The prevalent assumption is that the inequality of disabled people is ascribed to an innate physiological inferiority and to personal misfortunes or maladjustments. Paradoxically, the passive acceptance of disability benefits and programs may comprise an even more formidable obstacle to the attainment of equal rights than intense conflict about legislation reflecting overt bigotry and animosity (Hahn, 1996). For the plight of disabled persons, while feelings of aversion and discomfort are disguised with sympathy and pity, segregation and inequality of disabled people is perpetuated and the effectiveness of antidiscrimination laws is undermined (Hahn, 1996).

Similar to what happened with the concept of homophobia, in which the term 'phobia' (a symptom or a condition of psychopathology) received some critical objections (e.g. Blumenfeld, 1992; Davies, 1997), we can also argue if the term 'anxiety' used by Hahn is accurate to capture the prejudice of non-disabled people towards disabled people. The first point is that the word 'anxiety' should only convey a pathologic condition. And furthermore, the notion of 'anxiety' might allow people to lose any sense of responsibility about their own prejudices. And this in turn reinforces the individual/medical interpretation of the phenomenon, leading to a neglect of the social, cultural and political mechanisms.

Nevertheless, Hahn's perspective is particularly important because it highlights how the segregation of disabled people can be traced back to the cultural origins of prejudice towards disabled people (as violators of important cultural norms and values). Indeed, the minority model of disability has a more eclectic approach regarding the socio-cultural formations of disability.

Within minority studies, we find some similarities or parallels between women's liberation, gay rights, disability rights and anti-racism movements. They all focus on identity politics and challenge the biologisation of difference (Shakespeare, 2006), comprising an alliance of academia with activism. As an example, attributes made to black people and other ethnic minorities by the colonizers, such as sinful, uncivilised, wretched, ugly, immoral, savage, innocent, sexual, exotic, im/potent and social dead, can also be identified for disabled people (Fanon, 1984).

However, Shakespeare argues that the oppression that disabled people suffer is different from and more complex than sexism, racism and homophobia, by considering how the biological difference of disabled people influences their lives:

> *"Women and men may be physiologically and psychologically different, but it's no longer possible to argue than women are less capable by their biology. Similarly, only racists would see the biological differences between ethnic communities as explanations for their social differences. Nor is it clear why being lesbian or gay would put any individual at a disadvantage, in the absence of prejudice and discrimination. But even in the absence of social barriers or oppression, it would still be problematic to have an impairment, because many impairments are limiting or difficult, not neutral."* (Shakespeare, 2006, p. 41).

Even though we might consider that impaired bodies have more functional and biological limitations than other minorities' bodies, nevertheless women's and gays' bodies have also been objects of medicalization over time. To illustrate this, the objectification of gays' bodies lead to corrective measures (Morgan & Nerism, 1993) and to put them under surveillance as they were considered as having biological specificities (Birke, 2002). And objectification of women's bodies has brought many implications for women's lives as their bodies were understood as 'breeding machines reproducing the species' (Meekosha, 1998b, p. 170). Even in regard to organic functionality, there are parallels between the embodiment of disability and the embodiment of gender when 'women's bodies and disabled male bodies are reduced to their biological (lack) of functioning: as deficient, as not able-bodied males' (Meekosha, 1998b, p. 170).

Following the argument of Hahn regarding the ineffectiveness of anti-discrimination laws on disability, we should look at the doctrine 'separate is not equal' laid down in the U.S. Supreme Court to combat racial segregation. In that time, the signs 'White' and 'Coloured' were used. Today, in a similar way, disabled people have separate entrances, separate buses, separate bathrooms, separate classrooms with the respective signs (Olkin, 2002).

Hence, the fight against disability oppression has distinctive features when compared with racism. Hahn (1986) considers that this also has to do with its link with paternalism whereby non-disabled people exercise their power and superiority:

> *"Paternalism enables the dominant elements of a society to express profound and sincere sympathy for the members of a minority group while, at the same time, keeping them in a position of social and economic subordination. It has allowed the nondisabled to act as the protectors, guides, leaders, role models, and intermediates for disabled individuals who, like children, are often assumed to be helpless, dependent, asexual, economically unproductive, physically limited, emotionally immature, and acceptable only when they are unobtrusive."* (Hahn, 1986, p. 130)

In fact, the exercise of power and control over disabled people is a mode of domination that is matched by the subtler rubric of protection or benign concern for others, which limits their autonomy (Shildrick, 2009).

Another distinctive feature of the disabled people community, when compared with other minority groupings, is their involvement with a great number of health and welfare professionals who 'continue to exercise significant power and control over disabled people' (Thomas, 2007, p. 59). Adding to that, the 'pathologization of the disability "problem" has meant an acceptance and awareness of internalized ableism' (Campbell, 2008a, p. 154). Nonetheless, this reminds us of what occurred to gays when homosexuality was included in the Diagnostic and statistical manual of mental disorders as a personality disorder or a sexual pathology deviance.

Also, isolation and a lack of minority culture are similar aspects when we compare disabled people with gays and lesbians. Both are often the only member of the family and in their neighbourhood (Olkin, 2002; Morris, 1991), undermining the possibility of a minority culture provided by their primary support group – the family -, which may in turn even exacerbate their experience of discrimination and prejudice. In fact, barriers (environmental and attitudinal) are likely to be encountered at home, in one's place of refuge, which can have a particularly pernicious effect on disabled people (Olkin, 2002).

More importantly than the analysis of similarities and differences between minority groups, new understandings on disability have been emerging. For instance, more recently a new activism from minority bodies, behaviours and abilities (McRuer & Wilkerson, 2003, p. 6) has appeared which have led to the inclusion of disability in queer studies (McRuer, 2006). But before we get to that, the central question of the minority (cultural) model is how disabled people can refute the presumption that their subordinate status in society can be ascribed to an innate biological inferiority (Hahn, 1996) and finally 'be allowed to board the diversity train' (Olkin, 2002, cited in Goodley, 2011, p. 34).

1.4. The Post-Modernism Perspective

Despite the significant challenge posed by the social model to medical frameworks of understanding disability, which has resulted in some considerable material gains for disabled people insofar as many western countries have passed new legislation to combat discrimination, the social model remains problematic and insufficient. It has focused on the socio-economic oppression of disabled people, and has neglected the other side of the 'bivalent social injustice of disablism' (Christensen, 1996): the cultural oppression of disabled people.

Even though the minority (cultural) model of disability represented a pioneering work about cultural oppression, the post-modernism perspective brings a deeper understanding of this oppression. For this perspective, dis/ability is understood in the exercise of power through forms of knowledge, within cultural, linguistic and discursive practices (Thomas, 2004a). The materiality of the body and the dichotomy of identities abled/disabled and dis/abled-bodies are thus best understood as a sign system that differentiates and marks bodies and minds and maintains the ideal of the inherently stable non-disabled body or mind (Garland-Thomson, 2002, p. 5).

The modern grand narratives of scientificity, certainty and progressive human emancipation are now contested by post-modern conditions (Lyotard, 1979). Due to a history of modernist progress, the 'normal individual', the 'able-bodied', or better, the 'non-disabled', is 'the body of a citizen' (Davis, 1995). Fiona Kumari Campbell (2009, p. 7) explains:

> *"Whether it is the 'species typical body' (in science), the 'normative citizen' (in political theory), the 'reasonable man' (in law), all these signifiers point to a fabrication that reaches into the very soul that sweeps us into life."*

The modernist understanding of the embodied self as autonomous and stable is thus questioned by the 'postmodernist insistence that the self is always interdependent, fluid and endlessly in process' (Shildrick, 2009, p.10).

Dichotomies between essentialism/constructionism, biology/society, nature/culture (Thomas, 2001) and impairment/disability (Corker & Shakespeare, 2002) are modernity's pearls that contribute towards the privileging of *one* (abled, independent) over the *other* (disabled, dependent) (Goodley, 2011). For Mitchell and Snyder (2006) disability is a discourse of cultural diagnosis, a 'narrative prosthesis' where characterisation or opportunistic devices signal social or individual collapse and disruption in literary (and other) discourses. Fundamentally, disablism is a culture of disavowal, produced by dominating modes of cultural production, in which 'disabled people are cast as other by the able-bodied subjectivities' (Goodley, 2011, p. 58).

Understandably, as in any socio-political challenge, strength is often related to a unified group definition and a common cause. But within post-modernist perspectives the instability of oppositional differences is exposed. The dominance of binary thinking may be deconstructed, yet their power is too real (Shildrick, 2009).

Even though the social model has undoubtedly promulgated a more inclusive organisation of social life and tremendous strides towards the *formal* integration of disabled people into the rights, obligations, and expectations of normative citizenship are made, a counter-trend of segregation is equally in play (Shildrick, 2009). The underlying attitudes, values, and subconscious prejudices and misconceptions that figure an enduring, albeit often unspoken, intolerance (Shildrick, 2009, p. 5) are not necessarily contested. This intolerance is directed towards those that threatens our sense of what Kristeva (1982, p. 71) calls 'the self's clean and proper body'.

1.4.1. The significance of human corporeality

Within the post-modernism perspective, debate about the body and impairment has been inspired, mostly, by three theoretical traditions: feminism, post-structuralism and phenomenology (Hughes, 2004).

Garland-Thomson (2005, p. 1582) argues that feminist disability studies 'deeply engage with the question of what it means to have a dynamic and distinct body which witnesses its own perpetual interaction with the social and material environment'. Feminist academics such as Jenny Morris (1991), Carol Thomas (1999, 2001), Sally French (1993), Susan Wendell (1996) and Helen Meekosha (1998b) have brought 'the experiences of our own bodies' to disability studies. For them, oppression is not only manifested in the material form of discrimination but also in the form of anger, frustration or even pain.

Recognition of impairment takes place when Thomas (1999, p. 43) introduces the concept of 'impairment effects', which refers to the 'restrictions of activity which are associated with being impaired but which are not disabilities'. For her, impairment has thus a direct and restricted impact on people's social lives:

> *"While impairment is not the cause of disability, it is the raw material upon which disability works. It is the embodied socio-biological substance – socially marked as unacceptable bodily deviation – that mediates the social relationships in question. Further, the particular character of the impairment plays a critical role in shaping the forms and degrees of disablism encountered".* (Thomas, 2004a, p. 25)

Within the relational model of Thomas (1999), disability is an oppression that refers to the relationship of 'those socially constructed as problematically different because of a significant bodily and/or cognitive variation from the norm and those who meet the cultural criteria of embodied normality' (Thomas, 2004b, p. 28). The understanding of impairment is thus appropriated by feminists who argue that disability is about both the individual's body, and the social categorisation of difference (e.g. Thomas 1999, Wendell, 1996; Morris, 1991).

Within the post-structuralism perspective, the body and the impairment is understood in terms of discourse or cultural representation. In modern times, impairment has been located in a negative language of defect and deficit. However, this is the product of a historically contingent product of power, particularly the medical power that produced diagnostic practices (Price & Shildrick, 1998). The impaired body is viewed in an anti-essentialist way, a cultural representation, a metaphor (Mitchell & Snyder, 2006), produced by meaning and interpretations. Shildrick (2002, p. 120) claims that 'as the body is discursively materialised in both language and practice, that materialisation is never value-neutral'. Following Tremain (2000, p. 296), the impaired body has no pre-given materiality and is only materialised through discourse, one that constructed in ways that deny access to the normal life of the community (Tremain, 2002, 2006).

In phenomenology, disability is placed at the level of embodiment (Hughes & Paterson, 1997, 2000; Paterson & Hughes, 1999; Hughes, 2002a; Michalko, 2002;

Titchkosky, 2003), where the body is the material basis of everybody's experience (Hughes, 2004). At the intersections of the corporeal and institutional (Sherry, 2006), the body is the place where self and society interact (Shilling, 2005). Merleau-Ponty (1962) was one of the most important scholars of this field, which is termed carnal sociology.

The dichotomy of impairment (biology) vs. disability (structural oppression) conveyed by the social model is thus contested by Hughes and Paterson (1997, 2000; Hughes, 1999, 2000, 2002a, 2002b, 2004; Paterson & Hughes, 1999; Hughes & Paterson, 2006) who argue that impairment is social and disability embodied. Impairment is a particular sort of experience produced in a world dominated by the carnal and emotional needs of non-impaired people, therefore the oppression (disability) is in the concrete world of lived experience and the everyday world of mundane social relationships (Hughes, 2004). Hughes (2004, p. 66-67) explains:

> *'We live in a world that is characterized by a carnal hierarchy. (…). The social and physical world has been made by and in the image and likeness of non-disabled people. It is a home for their bodies'.*

In the 'intercorporeality' space (Merleau-Ponty, 1962) bodies become social bodies due to a sharing of discursive circulation and inter-subjectivity (Hughes & Paterson, 2006). The impaired body is both discourse and material/spatial location, both political and physical, and it structures intercorporeal encounters (Hughes & Paterson, 2006). Stigma, prejudice, anxiety, etc. are part of the world of embodied encounters; oppression is embodied as pain and 'suffering' (Hughes & Paterson, 2006).

Tyrannies of perfection (Glassner, 1992), the belief in normality (Darke, 2004), the association between bodily normativity, agency and autonomy (Shildrick, 2009) are among the discourses that shape the social meaning of impairment. The belief in normality defines an essentially correct way to have been born, look like and be. This normativity in terms of morphological form and function is associated with agency and autonomy: 'to be a self – and more significantly a subject – with effective agency is, in every sense of the word, to be capable of exercising autonomy' (Shildrick, 2009, p. 19). The ideal body's neutrality, 'the absent body' (Leder, 1990), is a body over control, one that possesses an agency and autonomy with neutral emotional and social meaning and significance (Shildrick, 2009). The presence of an impairment or disease undermines this comfortable absence and the body is forced into the consciousness (Shildrick, 2002). It now attracts 'unwelcome attention and becomes the locus of a devaluation that extends far beyond the materiality of any real or perceived deficit' (Shildrick, 2009, p. 19). Corporeality is then in the self–other relation: the impaired body is experienced as other, which inextricably is reflected in the embodied subject. Due to its falling away from the putative neutrality of the normative, impaired people constitute the otherness, the abject humanity bordering on inhumanity (Darke, 2004).

1.4.2. Ableism

> *"By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances."* Goffman (1963, p. 15)

> *"Ableism is a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human. Disability then is cast as a diminished state of being human."* Campbell (2001, p. 44)

Ableism is a kind of discrimination in favour of able-bodied people, in which disabled people are cast inferior (Linton, 1998b) due to their falling away from ableness, the perfectible body. Whereas disablism relates to the production of disability and fits well into a social constructionist understanding of disability, ableism goes a step further in rethinking not only disability but 'all bodies and mentalities within the parameters of nature/culture' (Campbell, 2009, p. 198). Thus, the focus is on the production, operation and maintenance of ableist-normativity: on the 'extraordinary other' (the abled) (Campbell, 2008b, p. 1). As Goffman (1963,

p. 152) puts it: 'It is not to the different that one should look for understanding our differentness, but to the ordinary.'

Following Shildrick (2009), the intolerance regarding physical difference emerges from a psycho-social imaginary that disavows morphological imperfection, which is shared by both non-disabled and disabled people. The normative desire to establish a certain security and predictability about the nature of human being is in play. In order to reiterate the 'truth' of the 'real/essential' human self, endowed with masculinist attributes of certainty, mastery and autonomy, the disabled body is thus a necessary symbolic construction (Campbell 2008b, p. 5). So rather than their difference, the disabled embodiment 'lays bare the psycho-social imaginary that sustains modernist understandings of what it is to be a subject' (Shildrick, 2009, p. 2).

Because both dis/abled share this psycho-social imaginary, normative and shared assumptions about the correspondence between bodily markers and the status of the self are displayed. The antagonists 'know their place' and this identification is a source of strength and stability that requires no further analysis. Some degree of disruption might emerge with the losses and gains to either side, 'but the fundamental binary of disabled/non-disabled are undisturbed' (Shildrick, 2009, p. 6). Campbell (2008a, p. 153-154) explains the processes of ableism:

> "*The processes of ableism see the corporeal imagination in terms of compulsory ableness, i.e. certain forms of 'perfected' materiality are posited as preferable. A chief feature of an ableist viewpoint is a belief that impairment (irrespective of 'type') is inherently negative which should, if the opportunity presents itself, be ameliorated, cured or indeed eliminated. What remain unspeakable are readings of the disabled body presenting life with impairment as an animating, affirmative modality of subjectivity. Instead of ontological embrace, the processes of ableism, like those of racism, induce an internalization which devalues disablement.*"

Standards of normativity are established and perpetuated on an everyday level by all people 'in a process of discursive othering' (Shildrick, 2002, p. 71). Ableism is a cultural project that is repeatedly performed, yet difficult to sustain because by their very nature all bodies are out of control (Campbell, 2009). Disability may be tolerated but in the final instance is inherently negative as it is an acute reminder of the temporariness of an able bodied ontology (Campbell, 2008a). Therefore, the categories dis/abled are deeply converged. Activists refer to non-disabled as 'temporarily able-bodied' (TAB) to remind them of the impermanence of their morphological status due to processes of ageing, unexpected trauma or incapacitating disease. But this threat is even deeper due to the indistinctness and permeability of the boundaries of disabled category. Stiker (1999, p. 8) puts it: 'Each of us has a disabled other who cannot be acknowledged'. And Shildrick and Price (1999b, p. 439) affirm that 'the spectrum of the other always already haunts the selfsame: it is the empty wheelchair that generates disease in the fully mobile'.

The insecurity of ablebodiedness is therefore manifested in a need to master the 'threat of disability to normative order' (Shildrick, 2009, p. 21). The privileged authority of biomedicine served this purpose. By promoting an image of individual pathology, 'it served to both legitimise, and settle, socio-cultural anxieties about the disruptive potential of disabled bodies' (Shildrick, 2009, p. 22). Illness, ageing and disability are 'medicalised in an attempt to re-establish corporeality as controlled and forgettable' (Shildrick, 2009, p. 32). Sutherland (1981, p. 75) says that: 'a crude and obtrusive imitation of a 'normal' body is held to be preferable to an elegant and efficient tool that makes no pretence of being anything other than what it is.' This reminds 'the imposition of a white mask in black bodies' (Fanon, 1984/1952).

Ableism is thus an internalization of the way in which the law, science and politics naturalize understandings of what is human and erases difference (Campbell, 2009). Following Garland-Thomson (2005, p. 1567), besides the great effects on disabled people's lives, prevailing narratives also limit the imaginations of non-disabled people. Both are constricted to some putative norm, being deprived of new possibilities of embodiment.

1.4.2.1. The effects of dis/abl(e)ism on dis/abled people's lives

> *'The body becomes a straitjacket or in extreme cases a prison.'*
> (Shilling, 1993, p. 193)

There are many effects of ableism and disablism on dis/abled people's lives. The *psycho-emotional effects* of disablism, the *internalized oppression*, the demands of *emotional labour*, the pathologic culture of *disavowal* and *individualization* are among the factors that come in the way of dis/abled people when they try to make sense of themselves and others.

The concept of '*psycho-emotional effects'* refers to the impact of disempowered social behaviours made by powerful non-disabled people on the ontological security or confidence of disabled people (Thomas, 1999). According to Reeve (2007, p. 4):

> *'Disabled people find themselves dependent on the goodwill of the service providers because, like homo sacer, they cannot rely on the law to fully protect them by ensuring that adjustments made to the environment restore independence and dignity and self-esteem to disabled people'.*

Avoidance, fear, help or curiosity, are common 'othering' responses chosen by non-disabled people to interact with disabled people, denying them scripts of everyday engagement and undermining their emotional well-being and feelings of worth (Reeve, 2002, forthcoming). Hughes (2012) argues that pity, fear and disgust are 'the major building blocks of the emotional infrastructure of ableism'.

The concept of *'internalized oppression'* is also very important for the understanding of psycho-emotional oppression of disabled people. For Campbell (2008a, p. 155), internalized ableism 'utilizes a twopronged strategy, the distancing of disabled people from each other and the emulation by disabled people of ableist norms'.

Penny Rosenwasser (2000, p. 1) has defined internalized oppression:

> "*an involuntary reaction to oppression which originates outside one's group and which results in group members loathing themselves, disliking others in their group, and blaming themselves for the oppression – rather than realizing that these beliefs are constructed in them by oppressive socio-economic political system.*"

Disabled people labour under the expectations of the non-disabled culture where their self has to act in ways that fit these expectations – this is called '*emotional labour*', a term coined by Hochschild (1983) and discussed by Williams (2003). As Olkin (2002) explains, a prescription of affect regulation occurs: certain emotions such as cheerfulness and gratefulness are desired and other affects such as anger and resentment are prohibited. In response to demanding publics, disabled people's self is assaulted – they learn to act as the passive disabled bystander, the grateful recipient of others' support, the non-problematic receiver of others' disabling attitudes (Goodley, 2011).

Thus, disabled people live in a *'culture of disavowal of disability'*, in which, Olkin (2009, p. 6) says: 'it just cannot be psychologically healthy or easy to have a part of oneself that is simultaneously so tangible and undeniable, yet so unacceptable'. In fact, disabled people labour under the burden of violence that is epistemic, psychic, ontological and physical and that leads to an ontological vulnerability (Campbell, 2008a). Goodley (2011, p. 96) explains that:

> *"Common experiences of hostility or pitying stares, dismissive rejection, infantilisation, patronising attitudes, altruism, help and care on the part of non-disabled people, can be understood as a process of splitting (separating good (desired) and bad (not desired) areas of one's psyche), introjection (internalising those aspects of the good life (desired) that you want to keep dear to you) and projection (making sure you project out the bad (not desired) away from yourself on to others).*"

Nonetheless, people deal with these imposed 'othering' responses in different ways. People have some power to use their agency and include it in their personal narrative and identity, even though this agent-based respect has been sidelined when people are reduced to tragic and passive victims of circumstances and experiences beyond her control (Smith, 2009). Goodley (2011, p. 93) says that:

> *'Some are productive (embracing disability activism, challenging the public, joking about it, kicking the cat), others potentially destructive (avoiding social settings where such questions may arise, internalising these comments as indicators of psychological flaws, feeling powerless).'*

As disabled people point out, they are the repositories of other's ontological anxieties (Marks, 1999a, p. 188). For this reason and the others exposed, Goodley (2011) argues that the understanding of the psychologies of 'able society' are equally or even more important than the psychologies of disabled people.

In regard to the effects of dis/abl(e)ism on non-disabled people, the idea of 'against the tragedy', specifically 'against the tragedy of impairment' might be particularly useful for changing the ableistic culture. Tom Shakespeare (2006) has reflected on alternative ways of seeing or considering impairment, as something different than the tragedy that the dominant models (moral and medical) have put on it. He puts it:

> *"Impairment is not the end of the world, tragic and pathological. But neither is it irrelevant, or just another difference."*
> Shakespeare (2006, p. 62)

Shakespeare (2006) starts by considering two truths about humans and impairments:
- Non-disabled people generally perceive impairment to be far more negative and limiting than those who experience it directly (Young, 1997);
- The human capacity for accommodation and adaptation to adverse circumstances is extraordinary (Albrecht & Devlieger, 1999).

Following Shakespeare (2006), impairment can be seen as a predicament: a difficulty, a challenge, something which we might want to minimize but which we cannot ultimately avoid, which involves hardship that can be overcome; although negative, it is not an inescapable tragedy or a defining flaw. Impairment can be seen simply as a 'fact of life' (Swain & French, 2008).

On one side, as a more complex and different corporeal-embodied minority, disability is often associated to lower levels of health, function or ability when compared to non-disabled. This only proves that human beings are not all the same, and do not all have the same capabilities and limitations. Need is variable, and disabled people are among those who need more from others and from their society (Shakespeare, 2006).

On the other side, impairment can have benefits such as being able to escape role restrictions and social expectations, the possibility of empathy with others and better relationships (Swain & French, 2008). Smith (2009) argues that there are certain valuable forms of self-development that cannot be reproduced in the absence of physical and mental diversity. These are characteristics that are produced *because* of the medical or physical condition and not *in spite* of it.

Due to and in a 'productive tension', the self is not a fixed entity or essential being but rather a non-essential 'becoming' which often reacts to unpredictability in non-imagined and positive ways (Smith, 2009). This capacity for human agency involves what might be termed an active engagement with experiences and is based on a capacity a person has to decide what kind of meaning to give to his/her experience (Smith, 2009). Many times, disabled people are creatively responsible-subjects who actively engage with their condition and environment. And by their immediate experience of being an 'outsider', they might be able to convey new possibilities for living unconstrained by ableist norms, which can be particularly useful for themselves and for non-disabled people who might be assisted by these particular insights. These qualities underpin a much more inclusive and a much richer society than exists now.

1.4.3. Critical Disability Studies

The questioning and the productive critique of the limitations of disability studies led to the emergence of critical disability studies as a new space of reflection on disability. According to this field, disability is a disruption of the perceived stability of normative expectations; a disability politics directed to the reform of external social structure is insufficient (Shildrick, 2009). (Re)forming negative attitudes, assimilating disabled people into normative civil society and providing compensatory initiatives and safety nets in cases of enduring vulnerability are the strategic options of disablism in order to facilitate social change (Campbell, 2009). Nonetheless an assimilationist imperative of society is reflected in these options leading disabled people to adopt culturally valued roles to blend into society (Campbell, 2009). Essentially, they develop a disablist 'epidermal schema' (McRuer, 2002) and enter into a paradox: while they are cast as the dependent other, when they try to enter the non-disabled world, they are expected to demonstrate extra-special, hyper-individual forms of being (Goodley, 2011). They have to be more normal than normal people (Freidman-Lambert, 1984, p. 15 cited in Goodley, 2011).

More than the processes and the production of disablism, critical disability studies goes further 'in terms of both the embodiment of difference and the unease that disability so often generates' (Shildrick 2009, p. 4). The main questions posed by this field are if we should keep persisting with the existing system and 'what it is that continues to impede the evolution of equitable conditions of possibility' (Shildrick, 2009, p. 2).

A critical disability studies perspective explores the limits of liberal tolerance of disability and the interests of ableism (Campbell, 2008a). The 'giveness' of the 'natural body' is questioned and replaced by a corporeality that is fluid in its investments and meanings (Shildrick & Price, 1999a, p. 1).

The intersection of disability studies with feminist, queer and black studies places the body/mind as key sites for relational, discursive and cultural inscription (Goodley, 2011), and opens the question of transgression of those forms of 'anomalous embodiment that frustrate social, cultural, and legal normativities'

(Shildrick, 2009, p. 108). Disability is thus a queering performance of 'normative paradigms' (Shildrick, 2009, p. 5): 'queer perverts the logic of the normative' (Goodley, 2011, p. 161).

Therefore, disability unsettles, disturbs and challenges normative ways of living by refuting the standard of (ableist) culture, the myth of self-reliance and the condemnation of 'regressive dependency' (Mintz, 2002, p. 167 cited in Goodley, 2011). Following this perspective, the standards of citizenship are questioned (Overboe, 2007) and the limits of the straight, non-disabled body are exposed within queer theories (McRuer, 2002, p. 224). The study of disability is now turned into a study of its *alter ego*: ability (Goodley, 2011).

Dan Goodley (2011, pp. 160-161) explains the three characteristics of critical disability studies – transgression, performativity and affirmation:

> *"Critical disability studies open up spaces for rethinking self and other. The first seeks transgression, describing identities that shift norms, straddle standards and shake up the dis/ability distinction. The second, performativity, explores how regulated selves might, nonetheless, offer embodied alternatives. Is disability 'a gift' – not (necessarily) an act of God – but the promise of 'a deep ontology of learning' (Michalko, 2002: 153)? When a disabled mother changes her kid's nappies with her teeth (see Reeve, 2008), does this unsettle normative notions of motherhood and expand conceptions of parenting? The third, affirmation, recasts disability as a positive identity (Swain & French, 2000). This connects with queer: subversive, unruly and enabling aspects of being non-normative."*

To summarize, critical disability studies is about rejecting the stereotypical disabled-body-as-deficient (Overboe, 2007), and contesting the privileges of corporeal integrity by refiguring it as an impermanent mode of embodiment; it's about revaluing disability as a variable mode of becoming (Shildrick, 2009). It's about new ways of seeing and feeling bodies, where cyborgs and hybrids emerge.

The concept of *cyborg* is a concept associated with the work of Donna Haraway (1991), who writes about a paradigmatic figure for postmodern hybridity that destabilises evolutionary, technological and biological narratives (Shildrick, 2002). The cyborg relates to the enmeshing of technology and subjectivities, the mixing of human and machine*;* 'it denotes the ways in which corporeal identities carry the marks of technological change' (Meekosha, 1998a, p. 26).

The distinction between human and machine, nature and society, self and other, able and disabled, all become hard to sustain (Goodley, 2011, p. 168) within the critical disability studies perspective. Biological bodies are not given but exist only in the constant processes of historical transformation (Shildrick, 2002). Consequently, a number of bodies exist: 'hybrid bodies, vulnerable bodies, becoming-bodies, cyborg bodies' (Shildrick, 2002, p. 121) - ones that resist definition, both discursive and material.

By pushing the margins of the idea of the embodied self, the disabled body is already a cyborg (Shildrick & Price, 1999a, 1999b). By contrast, the 'perfect' body, 'the temporarily able bodied is a hybrid - an able body that will *become* disabled' (Goodley, 2011, p. 169).

Far from being merely a metaphorical invocation, the cyborg is a referent for the *actual* bodies of disabled people (Garland-Thomson, 2002, p. 9). Haraway (1990, p. 220) asks: 'why should our bodies end at the skin?' and Olkin (2009, p. 23) explains the idea of impaired body as cyborg:

> *'When I use crutches I feel connected to them as if they are one of my limbs. When I set them aside and get on the wheelchair I disconnect from the crutches and take on the wheelchair as part of me. I don't like anyone to move my crutches without my permission, or to lean on the arm of the wheelchair or rest their hand on the back of it unless it is someone I feel comfortable touching me."*

To conclude, this subject extends the ideas of ableism and the production of disability by connecting issues of ontology, humanness and the place of technology (Campbell, 2009, p. 35). It speaks about 'an intimate experience of boundaries' (Haraway, 1990, p. 223), which annihilates the modernist notions about fixed substance and full presence. However, as Shildrick (2002, p. 129) argues, 'the promise is not one of unproductive, limitless fragmentation, but of dynamic new incorporations'.

2. Disability Identity

> *"The more one writes about this subject [identity], the more the word becomes a term for something as unfathomable as it is all-pervasive. One can only explores it by establishing its indispensability in various contexts"*
> Erikson (1968, p. 9)

'Identity' as we now know it derives mainly from the work of psychologist Erik Erikson (1959/1980) who described identity formation in his theory of developmental stages that extends from birth through adulthood. Considered as the 'identity's architect' by his biographer Lawrence Friedman (1999), Erikson had embraced human universality amid particularities, in which individual identity, dignity, recognition and respect for human diversity were his concerns; also, he was related to the politics and the cultural of post-war America.

'Identity crisis' was also coined by Erikson (1976) and although this term was initially popularized in connection with adolescence, it is not limited to this time frame: Erikson himself initially formulated the concept in connection with World War II veterans. When a crisis is presented in consequence of a variety of changes that affect one's work, status, or interpersonal relationships, people are forced to redefine themselves in terms of values, priorities, and chosen activities or lifestyle.

For Erikson (1976), identity involves a conscious sense of individual singularity, an unconscious struggle for continuity of experience and a harmony with the ideals of a group. According to him, there's a genetic continuity on the representation of the self, starting from the 'mothering' individual in early infancy and extending to humanity by adolescence. Also, identity development occurs in two phases: a developmental individual phase and a historical one – which reflect the complementarity between biography and history (Erikson, 1976). Additionally, the youth crisis is a crisis of a generation and of the ideological solidity of society, reflecting the complementarity between identity and ideology. Therefore, interactions between the psyche and the social, between development and history, contribute to identity formation that can only be conceptualized within a psychosocial relativeness (Erikson, 1976).

Identity formation is "located *in the core of the individual* and yet also *in the core of his communal culture"* (Erikson, 1968, p. 22, italics original). Erikson argued that, "identity formation employs the process of simultaneous reflection . . . by which the individual judges himself . . . [and how] he (sic) perceives the way in which others judge him in comparison to themselves." This process is, "luckily, and necessarily, for the most part unconscious except where inner conditions and outer circumstances combine to aggravate a painful, or elated, 'identity consciousness'" (1968, p. 22). Erikson described this in regard to Gandhi's work in India and to the black liberation movement, for whom the recognition of difference and the contestation of oppressive dominant notions of themselves were claimed. A 'latent identity' was demanded in which a sense of unity between selves and the environment was found and where human revolt permitted an internal alignment with historical reality (Erikson, 1976). For him, activists were prophets of 'identity confusion'.

The centrality of the co-development of the individual and society on identity within a developmental theory is Erikson's main contribution to the field. Identity implies a sense of personal continuity and singularity where simultaneously people also acquire a social identity based on their membership in various groups. Marian Scott-Hill (2004, p. 87) argues that identity 'might be thought as mediating between the personal, private world of everyday life and the collective space of multiple cultural forms and social relationships'. We all are an amalgam of multiple aspects of identity and members of different socially divided groups (Swain & French, 2004). Sameness, difference and recognition are keywords for identity as this lies between the individual and the social. People define themselves in the eyes of both others and themselves. In other words, identities are social products, produced through interaction and shaped in part by the definition of others (Huang & Britain, 2006, p. 353).

These definitions of others are thus particularly crucial with respect to identity formation of disabled people as well as other minorities. In regard to disability identity, the impact of different models of disability on its formation will be discussed below, as well as the subject of recognition as this is an important topic on disability.

How our culture interprets our body is highly influential on our identity (Scott-Hill, 2004). As with other bodily attributes such as skin color, gender or aging, so too physically disabled people are 'marked' because of their visible impaired body (Hahn, 1985b).

The biomedical model with the assumption that impairment is inherently negative and is the source of the problems has a pernicious effect on disability identity. Because disability identity is an outcome of physical impairment, it is therefore negative and in need for adjustment, mourning, and coming to terms with loss (Shakespeare, 1996). For this model, this identity must be eradicated or normalized, therefore it is often denied by disabled people whenever it's possible. Disability identity is in fact an 'impairment identity' as it refers only to the specific impairment and abnormality, which marks divisions between impairment categories and, of course, the non-disabled 'normal' people (Scott-Hill, 2004).

With the social model, disability identity is restored. Impairment categories are refused because they are a source of discord and fragmentation in disabled community. For this model, negative self-identity is not about bodily deficiencies but is a result of the experience of oppressive social relations (Shakespeare, 1996).

Within the disability movement disabled people are provided with a collective context where they can find a political identification that challenges views of them ‘as incapable, powerless and passive; and it establishes disabled people as the experts on disability and disabled people's definitions as the most appropriate approaches to disability, rather than the traditional domination of professionals’ (Shakespeare, 1996, p. 101). Similar to what happened with other minority movements, an ‘identity politics’ has emerged: ‘a politics based on the particular life experiences of people who seek to be in control of their own identities and subjectivities and who claim that socially dominant groups have denied them this opportunity (e.g. Fox Genovese, 1991; Young, 1990). Similar to the gay rights movement (and others), there’s an escape away from the ‘pathology’ towards a self-defined identity (Carneiro, 2009).

Disability identity is thus about the experience of and resistance to structural oppression that should connect all disabled people (Scott-Hill, 2004) so that they would feel empowered and achieve a different self-understanding (Shakespeare, 1996). It is a product of personal and collective pride (Barton, 2004b) provided by a community and group identity, which the biomedical model does not take into account.

Even though the concept of a single disability identity is appealing for its political use (Huang & Brittain, 2006), it presents some difficulties that have been the object of discussion. While considering the individual (the impairment) as a residue of the biomedical/deficit model, this model homogenizes disability identity as something fixed or stable that ignores additional identities such as gender, class, and ethnicity (Huang & Brittain, 2006) that influence identity and the experience of disability. Additionally, the master status of disability identity – and impaired identity – transcends other identities, which, for example, has the power to de-sex people, so people are viewed as disabled, not as men or women, straight or gay (Shakespeare, 2006). Due to that, identity politics has a certain role expectations and has left very little room for individuality (Takala, 2009). For Shakespeare (2006), this identity diminishes the agency and the scope for positive engagement with impairment or society when, with an identity politics, disabled people adopt a victim position, as they became prisoners of an oppressive and excluding society. Hughes (2009) argues that the politics of disability are made up of two trends: the social model stalwarts that address structural exclusion; and the embodied health movements where 'biological citizens' embrace specialized medical and scientific knowledge associated with their 'condition'.

In the cultural model, 'ways of being' (cultures) emerge from the exclusion and segregation of people with impairments from mainstream social life (Scott-Hill, 2004). As bodily differences are considered cultural representations that are socially constructed by the normative gaze, impairment disappears within the cultural group or it is naturalized in such a way that it becomes the essence of cultural difference (Scott-Hill, 2004). Indeed, as Hahn and Belt argue (2004, p. 461): 'disability, and even functional impairment, is neither a "disease" nor a bodily attribute that can be removed by medical intervention'. And if people think of physical impairments as normative variations in the human condition, they become characteristics of population diversity like any others (Hahn, 1997 cited in Putnam, 2005).
Disability identity is thus a cultural identity, which pursues cultural autonomy and integrity. In fact, as Calhoun (1990, p. 28) argues, the politics of personal identity and the politics of collective identity are so inextricably linked that: "identities are often personal and political projects in which we participate, empowered to a greater or lesser extent by resources of experience and ability, culture and social organization".

Within the cultural model, there's one model that is particularly important for the construction of a positive disability identity: the affirmative/non-tragedy model, created by John Swain and Sally French (2000). In the affirmative model, a positive disability identity is generated, at least in part, by the disavowal of the limited, the status quo, stereotypes, the typecast, the predetermined (Swain & French, 2004). According to this model, rather than being subjected to discrimination or oppression as the social model argues, all disabled people are subject to a tragedy view of themselves and their lives, whether or not they feel or understand themselves to be subjected to that view. Tragic images and discourses of disability and impairment that convey and construct people and their lives are created (Swain & French, 2008). As a result, disabled people are 'imprisoned into the misconceptions of others' (Gray and Hahn, 1997, p. 395) and are artificially undervalued by society (Hahn, 1985a). The affirmative model stands in opposition to the dominant, 'commonsense' beliefs about disabled people's feelings about themselves, their bodies and their lives (Swain & French, 2008). French and Swain (2004, p. 185) explain:

> *"Affirmation is about being different and thinking differently about being different. It is about disabled people challenging presumptions about themselves and their lives in terms of not only how they differ from what is average or normal, but also about their assertion, on disabled people's terms, of human embodiment, lifestyles, quality of life and identity. (…) Impairment is part of human diversity, a phenomenon integral to the human condition, and reveals a significant understanding of humanity."*

Even when an affirmation of identity and disabled lifestyle is problematic due to impairment that is debilitating, painful or associated with premature death, the real problem for this model is the assumption that people will necessary, simply because of being impaired, experience their lives and themselves as personal tragedies (Swain & French, 2008). The affirmative model is thus a counter-narrative to the prejudices, expectations, actions and practices predicated on a personal tragedy model of disability (Swain & French, 2008).

In a paradox of a culture of disavowal, where a disabling social and political environment operates (Smith, 2009), an affirmative disability identity has been achieved particularly in disability arts where identity is politicized and challenges discrimination and stigma in a far more accessible way for the general public than the work of many academics (Brandon & Elliot, 2008).

Disability culture and particularly disability arts constitute sites where dominant discourses are rejected by bringing them to the light as hegemonic constructions within a disabling society (Cameron, 2009). As a force of resistance, 'the humor expressed in disability arts lyrics is observational, often highlighting the absurdity that characterises expectations held by the non-disabled about disabled people or the offence generated by the non-disabled in their interactions with disabled people'

(Cameron, 2009, p. 384). Within disability arts, the *truth* of disability experience is expressed through art forms and arts productions created by disabled people (Masefield, 2006, p. 22).

To sum up and following Shakespeare (2006), disability identity is complex and its process takes place on three fronts: the political (disability activism), cultural (disability arts), and personal (understanding of one's own experience). Political or cultural self-organization offers 'potential for subjectivity, for a changed self-understanding and an increased sense of personal power' (Shakespeare, 1996, p. 102), where embracing identity means coming to terms with one's political and cultural status in the world.

Within phenomenology or embodiment perspective, acknowledgment of the body is a crucial step toward the development of identity (politics). With that, besides the deconstruction of negative societal perceptions of the impaired body as well as the struggle to positive reframe (Abberley, 1987; Hughes & Paterson, 1997), individual experiences resulting from specific bodily impairments are taken into account (Huang & Britain, 2006). Relationships between cultural representations of bodies and people's experiences are fundamental to understanding how embodiment affects the structures of interpretation that people use to acquire their sense of self (Scully, 2003). For Merleau-Ponty (1962) human subjectivity is located in the body rather than the mind, and movement, or motility, is the critical factor in the construction of human identity - due to that, there is no perceived separation between body and self.

In social interaction, that occurs in the intercorporeal (Merleau-Ponty, 1962) and intersubjective space (Hughes & Paterson, 2006), identities are created and constructed through experience and intersubjectivity (Tsang, 2000 cited in Huang & Brittain, 2006). And because impairment 'enters the world of discursive circulation and inter-subjectivity' (Hughes & Paterson, 2006, p. 103), it becomes social. Physicality is thus embedded in social structures (Hughes & Paterson, 2006), influencing identity construction. Therefore, identity for disabled people is fundamentally embodied (Huang & Britain, 2006). As Hargreaves (2000, p. 185) indicates, “the impaired body immediately and conspicuously signifies difference and abnormality. Thus, the disabled body is tied to self and identity in a most intense and evocative way”. And due to their physiological difference from other bodies marked by difference (e.g., race, gender, and sexual orientation) (Promis, Erevelles, & Matthews, 2001 cited in Huang & Britain, 2006), it’s undeniable that impaired bodies play an important part in determining a person’s sense of self (Huang & Britain, 2006).

Hughes and Paterson (2006, p. 92) write that ‘forms of resistance and the struggle for bodily control, independence and emancipation are embodied’. For them (2006, p. 104): “black pride, gay pride, disabled pride: they are all forms of a politics of proprioception; a contemporary politics of bodies, in which aesthetic, as well as political and economic, tyrannies are deconstructed by excluded groups”.

When analysed from a post-modernism perspective, ‘claiming identities for ourselves and attributing particular identities to others is essentially a matter of power’ (Huang & Britain, 2006, p. 353). Jenkins (1996, p. 54) argues that ‘social identities exist and are acquired and allocated within power relations’. The medical gaze plays a crucial role in invalidating bodies that do not conform to the concept of normality and because of that an othering’s process occurs where disability as an identity is damaged (Huang & Brittain, 2006). Swain and Cameron (1999, p. 75) further indicate that “the social identities of those who consider themselves to be normal (or non-disabled or able-bodied) are secured only through a process which involves the systematic social exclusion and marginalisation of others (‘the disabled’), who are identified in terms of their deviance from an imagined ideal”.

Disability identity is thus in between the complex interaction of individual, biology and society (Shakespeare, 1996) in which disabled people ‘must continually negotiate the relationship between body, socially constructed disability, and identity’ (Huang & Brittain, 2006, p. 353).

Within disability studies, disability identity is not a consensual matter. For Nancy Fraser (1995) affirmative remedies and the politics of recognition can have negative effects as it might leave deep structures intact and may even stigmatize the disadvantaged class. She calls for transformational remedies – which deconstruct groupings and promote solidarity. Shakespeare and Watson (2001a, p. 24) argue that *everyone* is impaired, in varying degrees, denoting the fluidity of disabled identity. For them, this perspective, by offering a continuum of human experiences and bodies, can be a catalyst for dismantling socially constructed divisions between 'the disabled' and 'the normal'.

This fluidity is also denoted by Davis (2001, p. 536) who argues that fixing borders around identity is problematic due to the nature of physical impairment: anyone can become disabled and some disabled people can be 'cured' and become 'normal'. This malleability might have implications in terms of political concerns, making it different than gender, race, ethnicity or sexual orientation (Putnam, 2005).

Nevertheless, identity exclusion or non-recognition is a crucial matter in disabled people's lives. Smith (2009) argues that it's not only social and economic structural barriers that put disabled people in a position of discrimination, but they too suffer from identity exclusion, when their experiences and identity are effectively ignored or marginalized in favour of dominant constructions. Ikaheimo (2009) argues that basic rights, as an institutional form of inclusion in social life, are insufficient for our sense of well-being and sense of worth. For him, people's interpersonal recognitive attitudes and relationships towards one another (namely, with respect, love and/or contributing value) are fundamental for personhood, for being a person both socially and psychologically.

This move from basic rights to interpersonal recognitive attitudes has been worked within the 'politics of recognition'. This interpretation emphasizes the ideal of equality where recognition often means the attribution of equal status or standing (Jones, 2006). Within it, the politics of universalism developed by Charles Taylor (1994) has given way to the politics of difference. The ideal of uniformity sustained the idea that all human beings share something in common and, in virtue of their common humanity, are entitled to equal respect and a common set of rights (Jones, 2006). However, this was replaced by the ideal of authenticity where people are not recognized by their sameness but their uniqueness to which the recognition of 'the equal value of different ways of being' is required (Taylor, 1992, p. 51). Essentially, as Iris Marian Young (1990) argues, politics must recognize rather than repress difference due to the fact that denial of difference contributes to social group oppression.

Following Galleotti (2002), the 'old' toleration of society towards minorities is determined by the extension of their freedom through liberal rights that called for no more than non-interference. For her, minorities should have their full recognition as citizens and must also possess the same formal rights as other citizens. However, at the same time marginalization and domination/humiliation from society must cease so that the damage to their self-respect and self-esteem must also cease. In this respect, stigmatized minorities must have their identities positively and publicly recognized and this recognition is something that a society can give only symbolically (Galleotti, 2002).

Similar to the idea of Ikaheimo (2009), Axel Honneth (1995ab) identifies three forms of recognition that he believes to be essential to an individual's developing a positive relation-to-self: love, rights and esteem. On one hand, emotional attachments are essential to gaining basic self-confidence. On the other hand, systems of law that accord equal rights provide citizens with recognition as being morally responsible. This develops social respect, which in turn is essential for the development of self-respect (Honneth, 1995ab). For him, besides social respect, people also need social esteem, which is essential for the development of self-esteem. Therefore, universal and particular recognition are both important yet independent: social esteem requires an act of recognition that is separate from, and that needs to be added to, social respect (Jones, 2006).

However, due to ableist thoughts and practices, impairments often lead to non-recognition and social exclusion, or in other words, one is included in social life by others as a non-person (Ikaheimo, 2009). Disrespect and misrecognition in different ways motivate people to engage in struggles for recognition (Jones, 2006), where the sources of individuals' sense of self-respect and dignity are obviously relevant to understanding politics in many of its aspects.

In respect to these struggles for recognition, Iris Marian Young (1990) argues that autonomous organization of groups must be encouraged so that each group's voice is heard in public. She calls for a 'rainbow coalition' where social injustice can be tackled with a stronger consciencialization by means of a collective and shared sense of oppression. Young (1990) explains:

> *"In a Rainbow Coalition each of the constituent groups affirms the presence of the others as well as the specificity of their experience and perspective on social issues (Collins, 1986).(…) Ideally, a Rainbow Coalition affirms the presence and supports the claims of each of the oppressed groups or political movements constituting it, and arrives at a political program not by voicing some "principles of unity" that hide difference, but rather by allowing each constituency to analyze economic and social issues from the perspective of its experience. This implies that each group maintains significant autonomy, and requires provision for group representation."* (Young, 1990, pp. 188-189)

OVERVIEW OF THE THREE STUDIES

The main objectives of this thesis are to extend the study of physical disability in Portugal on a sociopolitical perspective with the understanding of the impact of dis/abl(e)ism on disabled people's lives, specifically their quality of life, embodiment and identity. The research was designed within sociopolitical, ableism and embodiment paradigms and sought to capture the multiple layers of significance and meaning of disability in Portugal. In fulfilling this ambition, the research comprises three studies that are sequential in their level of analysis: from a sociopolitical macro-perspective, where we include the first and second studies, to an embodied perspective in the third study. Each paper includes each one of the three studies. For the second study we provide both a Portuguese and an English version for the paper.

The **first study** has an exploratory character by using semi-structured interviews in which we sought to get insights from these experts in the field of disability in regard to the Portuguese context, specifically: the history, the views of society and politicians, the role of the sociopolitical model and the associative movement, the composition of the Portuguese community of disabled people, the barriers to their politicization and its link with disability identity. The selection criteria of the six disability leaders were their national representativeness, their role in the disabled associative movement and the target population of each association.

The **second study** addresses quality of life and discrimination. Quality of life offers a broad, overarching approach that is largely consistent with a sociopolitical perspective. For example, a great deal of what is understood as 'inclusion' meshes very well with a quality of life approach (Brown & Brown, 2003). Plus, as disability is largely understood with reference to medical, moral or aesthetic values, or ultimately to some view of what constitutes a good human life (Edwards, 2009), quality of life can be seen as a way to tackle the difficult task of evaluating the impact of disability (as social construction) on an individual's life.

By following the assumption that all aspects of life are interconnected and also affected by and connected to all parts of the environment in which the person lives, a comprehensive type of quality of life is adopted in order to have a strong potential for being meaningful, relevant and applicable to disabled people's lives. It also looks at the processes – such as exercising individual choice – that act as the means of achieving quality in life.

As such, Schalock's multi-dimensional model of quality of life (QOL) (Schalock 1996) was used. He proposes a multidimensional QOL model with eight core domains: (a) emotional well-being, (b) interpersonal relations, (c) material well-being, (d) personal development, (e) physical well-being, (f) self-determination, (g) social inclusion and (h) rights. In line with that, the definition of quality of life by Schalock and Verdugo (2003) was adopted. For them, quality of life is the promotion of equality, regardless of the physical condition of the person. Also, by assuming a sociopolitical perspective, it would seem vital to make a closer analysis of the impact of discrimination in quality of life.

Participants include 217 disabled persons, mostly with physical impairments. An adaptation of the questionnaire was conducted in which most of the items were from the *Quality of Life Questionnaire (QoL.Q)* (Schalock & Keith, 1993). Two new dimensions – equality of rights and positive discrimination – were adapted from the *Minorities's Rights Support Scale* (*Escala de suporte a direitos das minorias,* Nata & Menezes, 2007). First, the adequacy of this model to the Portuguese context was evaluated by using confirmatory factor analysis and internal consistence procedures; and secondly, quality of life combined with discrimination was analyzed with the use of statistical descriptive and correlation procedures.

The **third study** attempts to understand how ableist discourses about impaired bodies have impacted on and been resisted by disabled people and how embodiment is related to identity. In pursuit of these aims, a qualitative study was conducted with seven people who have visible physical impairments. The study was designed within embodiment theory and the concepts of ableism (Campbell, 2001) and physical capital (Bourdieu, 1990). For Turner (1992), embodiment is an understanding of the body as biological or corporeal, which is simultaneously, entwined with society. Merleau-Ponty (1962) argues that motility means that human identity and consciousness are embodied experiences, which can be enhanced by moving the body in skilful and intentional ways. Framing this theory within the field of disability, we find that the concepts of ableism used by Campbell (2001) and of physical capital used by Bourdieu (1990) are particularly useful for the understanding of the context-specific interrelationships between bodily expression and social structure and agency. The experience of disability is thus analyzed through the prism of ableism and embodiment where an analysis of the body bears upon an understanding of the social inequalities which are at the core of the lives of disabled people.

STUDY 1

VIEWS OF DISABILITY IN PORTUGAL: *'FADO'* OR CITIZENSHIP?

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Views of disability in Portugal: '*fado*'[3] or citizenship?

ABSTRACT. Disability research in Portugal is scarce and often lacks the perspective of disabled people. This paper tries to bring insights from leaders of disability associations about the community of disabled people in Portugal, the barriers to their politicization and links with disabled identity. It seems that most disabled people get trapped in a tragic paradigmatic vicious cycle due to a system-induced disempowerment which is sustained by a dominant individual and remediation model that extends to families, society, policies and politicians. The disabled associative movement has been unable to reach the majority of disabled people. Suggestions are thus made in order to transform this social reality by disseminating politically aware alternative disability paradigms and the possibility of a positive disabled identity, as well as by generating societal involvement in disability as a public matter.

Keywords. sociopolitical model, politicization, identity, disability associations, disabled community, barriers.

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[3] *Fado* literally means fate and is a type of Portuguese singing with a nostalgic or a melancholic tone that speaks about loss or the harsh realities of life, sometimes with a sense of resignation (Britannica online encyclopedia).

Introduction

An understanding of disability and the perspective of disabled people in Portugal has hardly yet been reached, mainly due to the lack of a field of disability studies. As occurs widely, disability has been predominantly interpreted through the prism of a 'personal tragedy theory' (Oliver 1990) and, within a disabled associative movement that emerged only after the democratic revolution of 1974. Moreover it has been sparsely informed by a socio-political approach that highlights the barriers and constraints erected by a disabling society (Barnes, Mercer and Shakespeare, 2005).

A recent study (Sousa et al 2007) that included 15.005 Portuguese disabled people concluded that these have lower qualification levels than the national average and are subject to several kinds of social inequalities such as access to work, training, school and income, which reveals the existence of discrimination and prejudice in Portuguese society. Surprisingly, the same study has found that disabled people do not feel discriminated against, a situation that might be explained by a conformism at the frontier of social exclusion and scant social consciousness about their social condition as disabled (Sousa et al 2007).

In view of these huge social disadvantages experienced by Portuguese disabled people, the significance of a politicization that highlights civil rights and equal opportunities and social policy responses (Barnes, Mercer and Shakespeare 2005) is immense.

However, by identifying disability experience with that of other minority groups that have endured discrimination and by designating the disability community as an oppressed minority, as is prevalent in the disability studies literature today (Batavia 2001; Charlton 1998), we intend to understand if the politicization of disabled people is a matter of positive self-identification with the disabled people's community and consequently of a political and social identity as disabled.

Calhoun (1990:28) argues that "identities are often personal and political projects in which we participate, empowered to a greater or lesser extent by resources of experience and ability, culture and social organization". Disability is an announcement of identity due to the intensity and visibility of their mark on the body (Stoer, Magalhães and Rodrigues 2005) but it is the social stigma of having a disability that pervades the disabled identity, as associated with dependence and abnormality (Oliver 1993), that has to be challenged (Linton 1998). For that, the development of a positive disabled identity might be reached by political (disability activism), cultural (disability arts), and personal (understanding of one's own experience) experiences (Shakespeare 1996). The existing literature reveals the association of a political disabled identity with feelings of self-worth and pride, shared experience of discrimination and identification with a common cause, acknowledgement of policy alternatives, and engagement in political action (Putnam 2005).

So, the central question we want to address in this paper is: have the Portuguese disability associations been able to reach disabled people in order to transform their stereotyped negative disabled identity, and to get them involved in politicization for the transformation of their social reality?

Methodology

The research methodology used was qualitative with a "purposive" (Portney and Watkins 1993) and "expert sampling" (Trochim 2002), considering the national representativeness, the role in the disabled associative movement and the target population of each association.

We have tried to obtain insider perspectives of the disability experience to get to know how disabled people view historical developments and future issues that affect their lives as citizens (McCarthy 2003). To this effect we used exploratory (semi-structured) interviews with six leaders of disability associations in Portugal (four are disabled, one is a physiotherapist and one is non-disabled) to explore their views on social and political discourses about disability and their impact on the lives of disabled people; ableistic practices and attitudes; the responsiveness of organizations regarding the needs of disabled people; empowerment; social participation; quality of life; and the 2020 prediction for disabled people's lives. We have done content analysis of the *verbatim* transcripts of the audio-taped interviews, which took place during March-June 2008.

In order to describe the associations, the typology of disability organizations constructed by Oliver (1990) was used. This typology considers the scope and the degree of control of disabled people in the organization. As described in Table 1, four associations – the Portuguese Disabled Association (APD); the Military Disabled Association (ADFA); the Work Disabled National Association (ANDST); and the Self-mobilized Citizens Association – have adopted a populist/activist model, with three (APD, ADFA, ANDST) simultaneously adopting a consumerist/self-help model (Oliver 1990); the Portuguese Foundation for Physical Impaired uses a partnership/patronage model (Oliver 1990); finally, the National Confederation of Disability Organizations is an umbrella/co-ordinating organization (Oliver 1990).

Table 1. Characterization of the associations with their year of origin, the interviewees, their target population and adopted model according to Oliver (1990).

Association	Year of origin	Interviewee	Target population	Adopted model
Portuguese Foundation for Physical Impaired (LPDM)	1952/ 1954	Coordinator of Centre of social resources/ non-disabled physiotherapist	Disabled people and disadvantaged people	Partnership/patronage (Oliver 1990) & environmental
Portuguese Disabled Association (APD)	1972	Representative of Porto Delegation / disabled person	Disabled people	Consumerist/self-help – populist/activist (Oliver 1990) & socio-political model
Military Disabled Association (ADFA)	1974	Representative of Porto Delegation / disabled person	Disabled Ex-soldiers and civilians	Consumerist/self-help – populist/activist (Oliver 1990) & socio-political model
Work Disabled National Association (ANDST)	1976	President/ disabled person	Work injured	Consumerist/self-help – populist/activist (Oliver 1990) & socio-political model
National Confederation of Disability Organizations (CNOD)	1980	President/ disabled person	Disability associations	Umbrella/co-ordinating (Oliver 1990) & socio-political model
Self-mobilized Citizens Association (ACA-M)	1998/ 1999	President/ non-disabled person	Road injured and their relatives	Populist/activist (Oliver 1990) & socio-political model

Note: the abbreviations used for the associations are the Portuguese ones.

Disability in Portuguese history: is there social evolution?

During the last 30 years, 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 marginalized and segregated in their homes or in special institutions. In 1919 the first laws about social insurance and work accidents were passed, but during the 2nd World War laws relating to the field of disability were not passed in Portugal as happened in other European countries (Veiga et al 2004) – obviously, the nature of the authoritarian regime of fascist inspiration that ruled the country from 1926 to 1974 explains this gap.

In this historical context, the Portuguese Foundation for the Physically Impaired (LPDM) was founded in 1952/54. It is an organization for both disabled people and disadvantaged people and is run as a charitable body. At the beginning, the medical model was adopted because Portugal had a poliomyelitis outbreak in the 50s. Nowadays it has adopted the rehabilitation and the environmental model; and it provides services for disabled children and adults. It also has a consultative and advisory role for other institutions.

During the dictatorship, Portugal became involved in a colonial war in Africa (Angola, Mozambique and Guinea) from 1961 to 1975, in which 25 thousand persons acquired impairments and 10 thousand died. During this period, the State created some services to respond to the needs of these war-impaired people, such as the Professional Rehabilitation Service (in 1966) (Veiga et al 2004), and sent many physically and sensorially impaired people to foreign specialized rehabilitation centres, a situation that was negatively evaluated by disabled people. This dissatisfaction led to the creation of the Portuguese Disabled Association (APD) in 1972. In the beginning it comprised disabled civilians and former soldiers that had been injured in the colonial war and who could not have their own association as this was forbidden by the regime. Today, the APD is the biggest national association with 22 delegations around the country and 25 thousand associates. It is an organization of disabled people aiming for political activism but it also provides services to meet the self-defined needs of its members, including for example, juridical, psychological and social services. Additionally, it promotes sports with a basketball league.

In 1974 Portugal experienced a revolution that restored democracy. Disabled former military personnel were part of the associative movement which flourished in the civilian society and was characterized by values of solidarity, autonomy/independence, democracy/citizenship and volunteer work (Martins undated) and by creating "*spaces where people can exercise and claim their rights: of reunion, of association, of culture, of sport, of leisure, of protest and of indignation*" (Malheiro 1996:14). In this context disabled former military personnel have demanded the constitutional recognition of the specific condition of disabled people; the responsibility of the State in the creation of policies to promote social integration of disabled people; and treatment as a citizen instead of charitable aid. The Military Disabled Association (ADFA) was created by an impaired former military personnel group who were very politically active in the beginning in their struggle for rights such as rehabilitation and social integration. Moreover they rejected the pity paradigm used by charity institutions and aimed to try to change mentalities. Soon the association had created self-help projects (like prosthetics training) and other services aimed at problem-solving.

By then, two important State organisms were created: in 1977 the National Rehabilitation Secretary; and in 1979, the Employment and Training Institute (Veiga et al 2004).

In 1976 the National Work Disabled Association (ANDST) was created because Portugal was (and is) the only European country where work injuries are the responsibility of the insurance companies, which then try to minimize expenses related to accidents at work. Therefore the aims of the association were (and continue to be) to fight for justice with the insurance companies, and to provide services that help work-impaired people become more informed and prepared when they negotiate with insurance companies. In fact, Portugal has a high rate of work injuries. A recent study (ANDST/ISPA/IEFP 2006) about work accidents found that 40% of the workers had more than 2 work accidents, which means that companies are not committed to prevention.

In order to have more influence in the political arena, in 1980 the National Confederation of Disability Organizations (CNOD) was formed as a result of the amalgamation of 35 organizations of disabled people (2 federations and 33 associations). Hence it is an umbrella/coordinating organization (Oliver 1990) which works toward the full social integration of disabled people.

Afterwards, Portugal became a member of the European Economic Community in 1986 and since then there has been an influence of the European Union in Portuguese policies and legislation (e.g. Recommendation 86/379/CEE). Furthermore, the European Social Fund has been a financial resource for policies about equality of rights and employment and training opportunities for disabled people (Veiga et al 2004). In this context the 1st Law of Bases of Prevention, Rehabilitation and Integration of disabled people - Law nº. 9/89 was created.

Due to the high rate of road mortality and injury in Portugal compared to other European countries, in 1998/1999 the Self-mobilized Citizens Association (ACA-M) was founded with a petition called "Against the civil war on Portuguese roads". It is an association with uniquely socio-political aims.

Nowadays, Portuguese legislation includes a juridical regime of prevention, qualification, rehabilitation and participation of disabled people – Law nº. 38/2004 — that considers equality of opportunities; promotion of opportunities for education, training and work throughout one's lifetime; promotion of access to support services; and elimination of barriers that prevent full participation of disabled people. Moreover, there is the Law nº. 46/2006 regarding prohibition of discrimination based on disability; and the Executive Law 163/2006 that requires mandatory accessibility in public and private buildings and public spaces. There is also the 1st Plan of Action for Integration of disabled people (PAIPDI) (2006-2009) which takes into account citizenship and human rights, accessibility and qualification; and a National Plan of Promotion of Accessibility (PNPA) (2007) to public spaces, buildings, transport and information technology.

So the history of Portuguese disability since 1940 shows us that charity and family assistance, social segregation and exclusion were contested by a group of disabled soldiers who had participated in the associative movement and had reclaimed a citizen treatment for disabled people. Subsequently this socio-political model was adopted by a number of disability associations and State organisms were created. Additionally, European Union membership encouraged Portugal in the creation of specific-disability legislation. This history explains why there has been an evolution in the way society views and responds to disabled people in the last decades:

> *"Twenty years ago you didn't see disabled people in the streets, or those you saw were begging. When I went downtown in Lisbon, I saw persons showing their wooden prosthetic. And today, we don't see that, and that's the biggest sign of change. This might happen because we have employment, other social supports... but this also helped to change mentalities, so that way to look with pity, at the excluded or the cripple (doesn't happen so often.)"* LPDM

> *"Forty years ago people with disability didn't go out of the home. They were hidden from society and didn't even open their mouths. Today they speak, and they participate.*" ADFA

So what about the current situation?

Despite this social change regarding disabled people, the current situation presents extreme difficulties highlighted by the interviewees: accessibility and mobility issues, but also discrimination in many important areas such as school, job, economic situation, which prevent disabled people from participating in society.

> *"We have an extremely physically disorganized society. Disabled people find barriers on a daily basis."* ADFA

> *"(…) it functions as an octopus: if we have physical barriers, then we'll also have social barriers, cultural barriers. So we don't have a society that is equal for everyone*." APD

> "*I do think that is still the way people look. (…) it's how we look at diversity, how we think if we are black or white, or we use a wheelchair or not, (…) I think that's a huge burden for disabled people, not only physical barriers.* " LPDM

> "*We know that a job is not for everyone, we know that environments are not for everyone, we know that school is not for everyone, that economic power is not for everyone*". LPDM

And even the interviewee from the non-political orientation association has mentioned that attitudinal issues are crucial even to architectural changes:

> *"When I talk about friendly environments, I don't mention only physical barriers but also attitudinal ones. People are included in these environments and I have many examples to tell you, like a neighbour who didn't want a lift platform on the stairs because it took away room for plants."* LPDM

These obstacles reflect the heavy and lasting history that still persists. We continue to witness the marginalization of disabled people in current Portuguese society and if in urban centres there might be more architectural and attitudinal conditions for social inclusion and also more institutions and services available, within the country disabled people are still totally dependent on their families who frequently are not prepared to deal with disability.

> *"I believe it is ignorance, and not lack of love, because it must be very hard to know your child has a disability. But then parents get resigned and because it's not them who directly suffer, they don't change anything and let everything be the same. This happens more often in the inland regions of the country, where it's normal to hide them. (…)And when there is not faith in religion, I see a lot of abandonment."* CNOD

The community of disabled people: who are they?

Still, generally speaking, the social and political situation is a very hard one for most disabled people. And if at the beginning of the associative movement, people were more willing to fight for their rights, nowadays when we evaluate the current situation in Portugal, we find a great deal of resignation from disabled people or even a non-assumption of their social condition of being disabled. In fact, in the community of disabled people, interviewees identified two groups. The first is a major group of people who depend on subsidies or allowances. They are not integrated in society and show themselves to be resigned with their rights. Furthermore they lack participation in the associative movement, they lack information and awareness about their social condition as disabled, and finally they manifest passivity and disappointment. Secondly there is a minor group that includes those who, by their qualifications and job attainment, are able to break the myths. These people are conscious about their rights, and contribute to social and political change by their positive personality and positive actions, individually or collectively by participating in the associative movement.

> *"There are two groups: those who like to be dependant, who like to live off others, but there are also people with no disability who also like to live off subsidies and be victims; and we have disabled people who want to be independent and live on their own."* LPDM

> *"Before, people were more dynamic, more willing to participate, more hopeful. (Now) there's passivity, a disappointment that leads to no participation of disabled people, to resignation of their rights. We see people tired of promises that are not accomplished. And all this leads to lack of interest and takes them to isolation."* ANDST

> *"The study (done by CRPG) found that disabled people say everything is wrong but when they are asked about satisfaction with their reality, the level of satisfaction is very high. This means that disabled people are not aware of problems."* ADFA

> *"Not only has society changed but disabled people must have an active and participative role in change. And they should also have a posture of demanding but also of contributing to change. It must be a positive posture, not a posture of saying that everything is wrong but one which contributes to change on a daily basis, by their participation in the associative movement, by their actions and personality. Assuming the 'poor person' position doesn't integrate anyone in society. There are disabled people*

> *who like this position because it's more comfortable, because it takes less effort and that's extremely negative."* *ADFA*

This comfort trap referred by this interviewee is in fact caused by a system-induced disempowerment: non-accessible environments, unemployment issues which generate dependency on social subsidies and consequently on their families, isolation from the disabled community and self-identification issues regarding disability.

As we have seen before, Portuguese disabled people face many architectural and attitudinal barriers which prevent them from being integrated in society. For example, in a major field for social integration such as work – as mentioned by the National Plan for the Inclusion (2006) – because it brings financial security and social status (Barnes 1999) and power to achieve concrete social changes (Sutherland 1981), disabled people encounter inaccessible environments but especially prejudice from the employers who link disability with low productivity and sick leave (Pearson 1989, 1995). Adding to that there is also lack of professional training and relocation services.

> *"There's absence of professional training and professional relocation services. We have cases that get professional training and are hopeful to find a job but then reallocation services don't work because companies are not prepared to employ disabled people. There's no pedagogic intervention in the companies in order that they could start giving the same chances to disabled people."* ANDST

In this work context, disabled people have to request subsidies or allowances which constitute their only way to survive. Actually there are some policy discrepancies, such as if a disabled person works, he/she has no right to any social subsidy, not even the 3rd person help subsidy. So even if there is a job opportunity, many people decide in favour of the social subsidy rather than to risk getting into the job market, putting themselves at higher risk (than non-disabled) for unemployment and possibly losing social subsidy. Because these social subsidies are not enough to have an independent life, they have to live with their families, who have no other way to look at them besides the dependent and tragic one.

This explains some of the lack of political participation of disabled people:

> *"We asked them to participate, (…) we asked to come to a protest at the Republic Assembly, we have to demand our rights. Interviewer: Why there is weak participation? Interviewee: First of all because of their disability. If they don't have a car, it's very complicated. Second, their families never looked at them in a different way than a dependent way and don't help them to be independent. And third because most of them receive an allowance, which is very small, if they live with their parents, it helps but that's not enough."* APD

Beyond the economic dependency, we can also show that families are still the dominant caregivers of disabled people and there are few who are able to have a personal assistant for personal care, and even less for other daily activities.

> *"If a person is at home, and is retired, and never had training and has a social subsidy (200 Euros), and if the family has no economic capacity, the family can't buy a wheelchair so that person can't get out of home."* APD

Thus the majority of disabled people have no conscience about their social condition as disabled because they can only see themselves isolated living a dependent life. Isolation from other disabled people and from society is not only a result of oppression but reinforces it because it prevents people to counteract the discrimination and conditioning that affect them (Sutherland 1981).

Yet there are self-identification issues with other disabled people due to problems of functional requirements imposed by the existing environment and by the relative absence of positive sources of identity (Hahn 1985a). Therefore we notice an absence of sense of belonging to a minority group, because the predominance of the individual model prevents awareness and leads to conformism to unworthy situations. And as we see with other minority groups, disabled people have been internally oppressed by their conditioning (Oliver 2006), with feelings of unworthiness and inadequacy (Barnes, Mercer and Shakespeare 2005) similar to those held by the non-disabled world (Oliver 2006) that lead to despair and disappointment, and this constitutes a major barrier to political awareness (Abberley 1987).

Subsequently what we find is a vicious cycle sustained by the 'personal tragedy theory' (Oliver 1990) where disabled people, their families and society are involved, which serves to keep disability as an individual problem and hence to leave social and economic structures intact (Oliver 2006), by leading to disabled people's acceptance of poverty, unemployment, restricted life chances and social exclusion as a consequence of their own individual characteristics as someone inferior to the non-disabled (Oliver 1996). Despite the social change in the view of disability, the dominant one is still based on the individual and remediation model and not on one that questions the socio-political conditions in which disabled people live.

This negative stigmatization which society imposes on disability results in an understandable reluctance of disabled people to assume a disabled identity (Hahn 1985a; Sutherland 1981). Consequently, even if there is a chance to participate in the disabled community, this negative social load associated with disability might lead them to distance themselves from, or avoid other disabled people for fear of being discredited through association (Titchkosky 2006).

Therefore, the personal tragedy model, that is so ingrained in Portuguese society, is itself disabling because it denies disabled people's awareness and identity as disabled people (French and Swain 2004).

So in a society that constantly reflects a negative image of disability and which assumes that a life with disability is not worth investment (McCarthy 2003), and yet at the same time discriminates and excludes based on well-intentioned "protection" due to patronising attitudes, thus constituting an even harder way to identify and fight against, how can disabled people get out of the tragic paradigm cycle and stand for a disabled identity and involvement in collective action to protect their rights? And how have the associations and the State and politicians been addressing disability issues?

Associations and the political power: is the socio-political model successful?

Even though the European Union acknowledged in 2002 that social inclusion of disabled people relates to the elimination of physical and social barriers and discrimination, and despite the 2003 European Year of disabled people regarding citizenship, discrimination and human rights' issues and the fact that between 2004 and 2010 we have seen the European Action Plan "Equality of opportunities for disabled people", what has been reflected in Portugal is a production of advanced legislation that is not implemented and that only serves to satisfy European directives.

> *"Unfortunately many laws are made in this country only because there are European directives."* (ACA-M)

> "*There is no echo here, especially in the accomplishment of legal norms.*" ANDST

> *"There is no capability for a political answer because the vision is totally party-specific, there are no national policies, there is not the ability to transcend the legislature, so there is no capacity to have a wide vision of the problem and disability is always a target for those who have to be in the spotlight, a victim of the political ´star system´."* (ACA-M)

The leaders of the associations highlighted non-operating State organisms and the almost complete absence of dialogue with the politicians or the government.

> "*There are no connections between areas. We have a job but then we don't have transport to get there, for example. "*APD

> *"There's a public organism which is named the National Rehabilitation Institute but it must have a more active role. And there's a State Secretary for Rehabilitation. I think disabled people should be more represented at the organizational structure of the State (…). And there should be a more direct channel between us and those who make policies."* ADFA

The most frequent response from politicians or the government has been no response. This absence of dialogue with the associations shows an unwillingness of political leaders to express clear opposition to the aspirations of disabled citizens, which leads us to consider that politicians (also) still believe that personal and unfortunate circumstances are holding disabled people back (Barnes, Mercer and Shakespeare 2005; French and Swain 2004), reinforcing the tragic vicious cycle explained before. Yet this absence of a clear opposition from the politicians may increase the difficulty of the struggle (Hahn 1985a).

> *"What have been the social and political changes in the disability area? None, unfortunately. It's very hard because sometimes we have to go to ten meetings with the minister and we change a comma. Even when we point out that there are lucrative solutions for the State, that we are not asking for money and we are looking to rationalize resources, nothing changes. There are processes that are not resolved for years and years. (…) A year ago we asked for a hearing with the parliamentary spokesperson for health and we have no answer. (…) And how do I explain this? I believe this is not only lack of interest or willingness to help or lack of willingness to participate in solutions, but it is a lack of respect." (CNOD)*

And if there is no dialogue with associations, decision-making processes regarding disability issues are left to professionals, which bring them to a supposed reality and not a real one.

> "*The associative movement is very weak. (…) we need a stronger associative movement, which would be capable to assess people's needs and be able to mobilize them for their rights. Otherwise the State gives what professionals tell them to give without consulting disabled people.* "ADFA

> *"Many of these policies which have been implemented have nothing to do with reality and we have to change that. We have to legislate for a reality, not a supposed reality."*
> ADFA

In this political context, in which despite consistent patterns of disadvantage there is a disregard of disability issues and ignorance about the social and economic causes of disability, it is understandable that the advanced Portuguese legislation is absolutely ignored and not accomplished at all.

> *"Changes have been few. There are many intentions, a big production of laws but then we don't see them implemented. If we think about accessibility, we have many laws but then something doesn't let them be implemented. (…) The executive Law 163/2006 that requires the State to make their buildings accessible was never implemented. So we still see enormous physical barriers, especially in public places."* ANDST

And for the accomplishment of legislation, disabled people depend on the sensitivity for disability issues of the person who is in charge, which reflects the way legislation is treated.

> *"I see change and the State is expecting associations to have proposals so the State can carry them out or include them in their policies. This is a condition of a democratic state and I think we have this. But of course this depends on the person who is in charge, like all things in life."* LPDM

In conclusion, we find that the lack interest of politicians regarding disability issues and the weakness of the disabled associative movement to prevent that is a major reason for the social segregation of disabled people. There is no integration of socio-political and civil rights approaches in the political power process, and these only show up as references in discourses and legislation but have no basis in reality.

> *"There are many people who can't get out of their homes because they live on a 3rd or 4th floor without elevator. There are those who live in old shelters or day centres. This is not life, this is not life! There are too many scandalous situations and politicians keep looking the other way."* ACA-M

In fact, the politicization of disability by associations has not been able to reach out to the majority of disabled people. Perhaps problems with disabled people's activism are implicated in that. We know that this activism has some special features compared to other minorities: architectural and mobility barriers; weak economic capacity; and self-identification issues. Additionally, even those who have more potential political capacity may find that this could politicize their life, rendering it even more different from the normal life initially denied them (Hahn 1985b).

> *"We need a stronger associative movement that would be able to equate disabled people's needs and rights, and get them mobilized and motivated for this fight (…)."* ADFA

Nevertheless the disabled associative movement has been losing its political strength over the years. Perhaps overturning the social oppression of disabled people is still an unreachable goal for associations since it seems that their achievements rest more on their capacity to transform their own association with self-help projects and services (Barnes, Mercer and Shakespeare 2005). Furthermore, a perennial lack of resources and financial dependency on the State might also explain the disabled associative movement's failure in reaching out to the disabled population as a whole (Barnes, Mercer and Shakespeare 2005).

> *"(In a meeting) I made a lot of demands about accessibility issues and I was the only one because the other leaders just lamented but didn't give solutions. And this happens because the only association that didn't receive financial support from Lisbon City Hall was ours. So, the State gives financial support to associations to silence them. The best way to control an association is giving money because then there is a self-censorship which prevents people from having the motivation to demand solutions for their problems."* ACA-M

At any rate, the disabled associative movement must be explored because there are some unanswered questions that might be included in future research.

> *"I am very critical about the associative movement of disabled people in Portugal, because I think they claim too much, and sometimes in the worst way, and are less active in creating answers. (…) I see claiming strategies that are linked to other interests."* ADFA

For the future

> *"There is a lot to do when we talk about inclusion and participation of disabled people in society, on equal terms.*" ADFA

How can disabled people and their associations transform this social reality which is characterized by segregation, marginalization and disrespect of human rights, such as the right to have an independent life, to attend school and obtain qualifications, to have a job and financial security, to constitute a family, to move freely in the community? Ultimately what is at stake is full social inclusion and a citizenship issue, as the interviewees have pointed out:

> *"Integration doesn't mean a burden, you give an allowance and the problem is resolved. We don't want that. As association, we want full inclusion and integration in all society areas, job, and school … as a full citizen who lives in our society."*
> APD

The association leaders have indicated some measures in order to promote social inclusion of disabled people:

- Fully accessible environments are absolutely essential so that disabled people have the chance to move around freely. For this, accomplishment of legislation is fundamental and perhaps disabled associations might need to carry out wide-ranging political action and mobilization, rather than relying on legislative shifts (Barnes, Mercer and Shakespeare 2005).

> *"We believe that we all belong to the same world. So, friendly environments are extremely important for all of us. Social policies have to be alerted to this fact (...)"* LPDM

- Appropriate social compensation but not exclusive ones: social policies regarding disability must promote autonomy, independency and empowerment instead of dependent protection.

> *"The State should support more disabled people with appropriate compensation, and create mechanisms that allow them to live with dignity and overcome economic barriers. I mean mechanisms that are not subsidy or allowance, but ones that would compensate but made people do more than that. "*ADFA

- Education about and involvement of civil society in disability issues in order to promote a critical political consciousness regarding oppressive social conditions and a full-rights citizenship perspective on disability. And if civil society is more attentive to disability, maybe the political powers will become more interested in this field. The disabled associative movement should influence the thinking and practices of the population at large, and not only of disabled people (Barnes, Mercer and Shakespeare 2005).

> *"(…) we have a society that is not prepared to accept a disabled person, who should be accepted as equal. (...) it has to start from elementary school, with education."* ADFA
> *"The change can occur if we sensitize the civil community, (…) when we will be able to make people think that we are all equal, and today I am in a wheelchair and tomorrow you might also be. This has to be more present in their lives."* CNOD

- Proper organisation of disabled persons groups (Oliver and Zarb 1997) in order to promote sociopolitical awareness of the unjust psychological and sociopolitical conditions which oppress disabled people.

> *"We have to create a new model of associativism for disabled people. I see also (for year 2020) associativism with more quality."* ADFA

Disabled people should be exposed to alternative models beyond the dominant individual one. Disability has to be considered by disabled people as a matter of social relations and not an individual defect in order to have the chance of getting into an empowering process (Barnes, Mercer and Shakespeare 2005) that would allow them a feeling of control, a proactive approach to life and a critical understanding of the socio-political environment (Zimmerman and Warschausky 1998).

- Development of a positive affirmative/political disabled identity

> *"It's possible to find ways that are not about diminishing yourself. The person can analyze his/her own situation and circumstances and find a solution and should be guided by someone who is more experienced."* ACA-M

Rather than absorbing the mainstream representation of impaired people as victims of personal tragedy (Cameron 2009), rather than assuming one's situation as personal failures, it is crucial that disabled people start recognizing their condition as a social one based on discrimination, prejudice and oppression (Shakespeare 1996). Disabled people's self-organization is a primary source of a strong disability identity (Barnes, Mercer and Shakespeare 2005) because it is an expression of group identity (French and Swain 2004), but disabled identity is also an individual process. What is at stake is to challenge the tyranny of the personal tragedy model (Swain and French 2004) and the dominant stereotypes of powerlessness and objectification (Shakespeare 2006), by adopting an affirmative disabled identity (Swain and French 2000) and by focusing attention on empowering disabled people and on the possibilities for changing society (Shakespeare 1996).

Conclusions

Disability in Portugal is still lived with physical and social barriers, discrimination, inequalities, identity shame, individual blame, remediation measures and weak politicization and citizenship. The sociopolitical model is a powerful tool for the understanding of disability on a wider level but also, in an individual analysis, to allow disabled people to make sense of their experience in a more positive way. Rather than living a "*fado*" (fate) imposed on us, we all pursue lives that we desire to be meaningful, worthy, joyful and full-filled as individuals and citizens.

REFERENCES

Abberley, P. 1987. The concept of oppression and the development of a social theory of disability. *Disability, Handicap & Society 2* (1): 5-19.

ANDST, ISPA, IEFP. 2006. *A reintegração sócio-profissional da pessoa com deficiência adquirida por acidente de trabalho* [Socio-professional reintegration of work-impaired people].

Barnes, C, T. Mercer, and T. Shakespeare. 2005. *Exploring disability: A sociological introduction,* 2nd edition. Cambridge: Polity Press.

Barnes, C. 1999. Disability studies: new or not so new directions? *Disability & Society* 14: 577-80.

Batavia, A. 2001. Oppression and disability: Are people with disabilities an oppressed minority? Special issue, *Journal of Disability Policy Studies* 12(2): 66-67.

Britannica online encyclopedia. July 2010. http://www.britannica.com/EBchecked/topic/200134/fado.

Calhoun, C. 1990. *Social theory and the politics of identity*. Cambridge: Blackwell.

Cameron, C. 2009. Tragic but brave or just crips with chips? Songs and their lyrics in the Disability Arts Movement in Britain. *Popular Music* 28(3): 381–396.

Charlton, J. 1998. *Nothing about us without us: disability oppression and empowerment.* Berkeley: University of California Press.

Veiga, C., Sousa, J. Nunes, N. & Fabela, S. 2004. *Contributos para um Modelo de Análise dos Impactos das Intervenções do FSE no Domínio das Pessoas com Deficiência em Portugal*

[Contributions for a model of analysis of the impact of the European Social Fund on the disability domain in Portugal]. Vila Nova de Gaia: CRPG.

Sousa, J. (C.G.) 2007. *Mais qualidade de vida para as pessoas com deficiências e incapacidades – uma estratégia para Portugal.* [More quality of life for people with impairments and disabilities – a strategy for Portugal]. Vila Nova de Gaia: CRPG.

French, S. and J. Swain, 2004. *Whose tragedy: Towards a personal non-tragedy view of disability.* Chapter 5 of *Disabling Barriers – Enabling Environments,* eds J. Swain, S. French, C. Barnes and C. Thomas. London: Sage.

Hahn, H. 1985a. Introduction: disability police and the problem of discrimination. *American Behavioural Scientist* 28: 293- 318.

Hahn, H. 1985b. Towards a politics of disability: definitions, disciplines, and policies. *Soc. Sci. J.* 22: 88-96.

Linton, S. 1998. *Claiming disability: Knowledge and identity.* New York: New York University Press.

Malheiro, J. 1996. *Associativismo Popular: Originalidade do Povo Português* [Popular associativism: originality of Portuguese people]. Almada: Câmara Municipal de Almada.

Martins, A. O movimento associativo popular e a democracia [The popular associative movement and democracy]. http://www.25abril.org/a25abril/get_document.php?id=259.

McCarthy, H. 2003. The disability rights movement: experiences and perspectives of selected leaders in the disability community. *Rehabilitation Counseling Bulletin* 46: 209–223.

Oliver, M. 2006. *Social policy and disability: some theoretical issues.* Chapter 1 of *Overcoming disabling barriers – 18 years of disability and society*, ed L. Barton. Oxon: Routledge.

Oliver, M. 1990. *The politics of disablement.* Basingstoke: McMillan.

Oliver, M. 1996. *Understanding Disability: From Theory to Practice.* London: Macmillan.

Oliver, M. and J. Zarb. 1997. *The politics of disability: a new approach.* Volume 2 of *Disability studies: past, present and future*, eds L. Barton and M. Oliver. Leeds: The Disability Press.

Pearson, V. 1989. Making a virtue of necessity; hospital and community care for the mentally ill in China, *International Social Work* 32: 53–63.

Pearson, V. 1995. *Mental Health Care in China: state policies, professional services and family responsibilities.* London: Gaskell Press.

Portney, L. and M. Watkins. 1993. *Foundations of clinical research: Application to practice.* Stamford, CT: Appleton & Lange.

Putnam, M. 2005. Conceptualizing disability: developing a framework for political disability identity. *Journal of Disability Policy Studies* 16 (3): 188-198.

Shakespeare, T., 2006. *Disabled people's self-organization: a new social movement?* Chapter 4 of *Overcoming disabling barriers – 18 years of disability and society*, ed L. Barton. Oxon: Routledge.

Shakespeare, Tom. 1996. *Disability, identity and difference.* Volume 6 of *Exploring the Divide,* eds C. Barnes and G. Mercer. Leeds, UK: The Disability Press.

Stoer, S. R., A. M. Magalhães and D. Rodrigues. 2004. *Os lugares de exclusão social: Um dispositivo de diferenciação pedagógica*. [The places of social exclusion: a device for pedagogic differentiation]. São Paulo: Cortez Editora.

Sutherland, A. 1981. *Disabled we stand.* London: Souvenir Press.

Swain, J. and S. French 2000. Towards an affirmative model of disability. *Disability and Society,* 15(4): 569-582.

Titchkosky, T. 2006. *Disability, Self and Society*. Toronto: University of Toronto Press.

Trochim, W. 2002. *Bill Trochim's center for social research methods: Knowledge base.* http://www.causeweb.org/cwis/SPT--FullRecord.php?ResourceId=92

Zimmerman, M. and S. Warschausky 1998. Empowerment theory for Rehabilitation research: conceptual and methodological issues. *Rehabilitation Psychology* 43(1): 3-1

STUDY 2

Qualidade de vida na incapacidade: validação do modelo multi-dimensional de Schalock ao contexto português

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Qualidade de vida na incapacidade: validação do modelo multi-dimensional de Schalock ao contexto português

RESUMO. Neste artigo pretende-se avaliar a adequação do modelo multi-dimensional sobre qualidade de vida de Schalock (1996) ao contexto português e analisar a qualidade de vida das pessoas incapacitadas, acrescentando uma dimensão política a este constructo e procurando entender o impacto da discriminação. A amostra é constituída por 217 participantes, os quais na maioria têm deficiência física, com idades compreendidas entre os 16 e os 81 anos. Realizaram-se procedimentos de validação do instrumento *Quality of Life Questionnaire* (Schalock & Keith, 1993) e de análise estatística descritiva e de correlação. A análise fatorial confirmatória revelou índices adequados no ajustamento local de cada fator e no modelo global, e a consistência interna das escalas revelou-se satisfatória. Propõe-se uma versão adaptada do instrumento composta por 5 escalas: satisfação, competência, empoderamento, igualdade de direitos e discriminação positiva. Os resultados do estudo revelam a importância dos direitos e do empoderamento para a qualidade de vida das pessoas incapacitadas e sugerem uma forte consciência crítica quanto à experiência da discriminação em diversos contextos, conduzindo-nos para a necessidade de mudanças sociais e políticas neste domínio.

Palavras-chave: qualidade de vida, incapacidade, discriminação, perspetiva sociopolítica, direitos.

Introdução

A incapacidade tem sido predominantemente vista segundo uma perspetiva médica/individual e colocada no campo da patologia e do défice na área da investigação sobre qualidade de vida. Assumindo que a ausência da condição médica constitui por si só uma maior qualidade de vida (Cummins, 2001; Huppert & Whittington, 2003), e no âmbito da dicotomia saúde vs. doença, atribui-se à incapacidade um estatuto de incumprimento da "normalidade" (De Mayer, Vanderplasschen & Broekaert, 2008; Pfeiffer, 2000).

A preponderância do modelo médico na interpretação e análise da incapacidade tem conduzido a um predomínio de estudos que usam o conceito de qualidade de vida relacionada com a saúde (*health-related quality of life*). Este conceito é acedido pela avaliação da "normalidade" da saúde mental e física e sua influência no funcionamento do indivíduo (Farquhar 1995; WHO, 2001; Ware, Kosinski & Keller, 2002; Cummins, 2000). Para esta avaliação, os instrumentos mais usados têm sido o *Short Form Health Survey -36* (SF-36) e o *Short Form Health Survey -12* (SF-12) (Sprangers et al., 2000; Ware, Kosinski & Keller, 1996; Garratt, Schmidt, Mackintosh & Fitzpatrick, 2002). Estes instrumentos atestam a "anormalidade" da condição física de pessoas com deficiência física (Tate, Kalpakjian & Forchheimer, 2002; Hays, Hahn & Marshall, 2002) uma vez que os dois itens que avaliam o funcionamento físico - mover uma mesa ou subir um lanço de escadas -, dificilmente serão realizáveis (Huppert & Whittington, 2003).

A ênfase na "normalidade" da capacidade física e mental negligencia a possibilidade de bem-estar em presença de uma deficiência. Da mesma forma, a medicalização da incapacidade e a consequente autoridade concedida aos profissionais de saúde, têm constituído um fator incapacitante na vida das pessoas (Pfeiffer, 2000). Evidências empíricas são reveladoras deste facto: relatos de pessoas incapacitadas mostram que, segundo a visão dos outros, uma vida com incapacidade não é de qualidade nem merece investimento (McCarthy, 2003), havendo ainda dados acerca da discrepância entre a qualidade de vida em presença duma deficiência estimada pelas próprias pessoas incapacitadas e pelo público em geral (Ubel, Loewenstein & Jepson, 2003). É ainda revelante constatar-se que a inferiorização medicalizada da qualidade de vida das pessoas incapacitadas tem reflexos profundos quer nas decisões políticas, baseadas em grande medida em fatores económicos, quer em decisões médicas. Os profissionais de saúde e os doentes atuam com base numa compreensão dos estados de saúde ou condições físicas que é filtrada pelo modelo médico da incapacidade (Ubel et al*.,* 2003).

Contrapondo-se a este quadro de avaliação médica e de trabalho académico que conduz unicamente à inferiorização da qualidade de vida na incapacidade, surgiu, paralelamente e desde há poucas décadas, uma forte reivindicação por maiores oportunidades de participação e de inclusão na sociedade por parte da comunidade das pessoas incapacitadas (Wehmeyer & Schalock, 2001; Wehmeyer & Schwartz, 1998). Este movimento social levou à emergência de outros modelos de análise e de compreensão da incapacidade – ambiental, sociopolítico e de direitos –, no sentido de garantir a aproximação da qualidade de vida das pessoas incapacitadas à dos outros cidadãos (Keith & Schalock, 2000).

A partir daqui, em alternativa às comparações normativas que serviam de base à interpretação dos resultados, privilegia-se uma avaliação da qualidade de vida que tenha em consideração as prioridades dos respondentes (Joyce, McGee & O'Boyle, 1999). Assiste-se assim a uma mudança de paradigma que assume a preponderância de um bem-estar pessoal, familiar, em comunidade e societal, e que vai além dos avanços tecnológicos, científicos e médicos. O modelo de *empowerment* substitui o movimento normalizador, ao enfatizar o planeamento centrado na pessoa e na sua auto-determinação (Verdugo, Prieto, Caballo & Peláez, 2005).

Neste novo quadro paradigmático encontra-se um consenso acerca dos domínios-chave da qualidade de vida (Schalock & Verdugo, 2002; Schalock, 2004). Curiosamente estes mesmo domínios apresentam uma consonância com os domínios de bem-estar propostos pela Psicologia Comunitária. O bem-estar é colocado num nível individual, relacional, comunitário e social (Nelson, Lord & Ochocka, 2001; Prilleltensky, Nelson & Peirson, 2001) e nestes níveis encontramos domínios que têm uma correspondência com os domínios-chave da qualidade de vida identificados por Schalock e Verdugo (2003) e Schalock (2004) em vários estudos[4]. Conforme o quadro 1, nota-se assim que os domínios-chave de qualidade de vida como a auto-determinação, o desenvolvimento pessoal, o bem-estar físico e emocional, e os direitos civis correspondem a domínios do bem-estar individual; as relações interpessoais, a família, a inclusão social e o lazer estão relacionados com o bem-estar relacional; e finalmente, as condições do meio (condições de vida e da residência), o bem-estar material e a segurança estão presentes no bem-estar comunitário e social.

Quadro 1 - Domínios-chave da qualidade de vida e domínios do bem-estar da Psicologia Comunitária

Domínios de bem-estar da Psicologia Comunitária (Nelson, Lord, Ochocka, 2001; Prilleltensky, Nelson & Peirson, 2001)	Bem-estar individual: controlo pessoal, escolha, auto-estima, competência, autonomia, identidade positiva, direitos civis; Bem-estar relacional: participação na vida social, comunitária e política; Bem-estar comunitário e social: oportunidade em adquirir recursos básicos através do trabalho, salário e educação e condições da residência.
Domínios-chave de qualidade de vida (Schalock & Verdugo, 2003; Schalock, 2004)	- Auto-determinação, desenvolvimento pessoal, bem-estar físico e emocional, direitos civis; - Relações interpessoais, família, inclusão social, lazer; - Meio (condições de vida e da residência), bem-estar material e segurança.

Na vastidão de conceitos de qualidade de vida existente na literatura, um dos mais usados é o definido pela Organização Mundial da Saúde (O.M.S.) que considera qualidade de vida como a perceção do indivíduo relativamente à sua posição na vida no contexto cultural e sistema de valores em que vive e de acordo com os seus objetivos, expectativas, padrões e preocupações (WHOQOL GROUP, 1998).

Em contraste com a perspetiva biopsicossocial veiculada pela O.M.S., Schalock e Verdugo (2003) definem qualidade de vida como a promoção da igualdade entre as pessoas, independentemente da sua condição física, assumindo assim uma perspetiva sociopolítica. O modelo de qualidade de vida de Schalock (1996), usado nesta investigação empírica, considera este constructo como um conceito

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[4] A revisão dos estudos de qualidade de vida compreendeu os estudos de Hughes *et al.*, 1995; WHO, 1995; Felce & Perry, 1996; Schalock, 1996; Cummins, 1997; Felce, 1997; Gardner & Nudler, 1997; Getting & Bradley, 1997; Renwick, Brown & Rafael, 2000; e Ferdinand & Smith, 2003.

multidimensional que abrange as seguintes áreas: bem-estar emocional, relações interpessoais, bem-estar material, desenvolvimento pessoal, bem-estar físico, auto-determinação, inclusão social e direitos.

No panorama nacional existe um estudo sobre qualidade de vida das pessoas com deficiências e incapacidades realizado pelo CRPG e ISCTE (Sousa et al., 2007), com uma amostra de 15.005 sujeitos, cujos resultados sugerem a relevância desta dimensão sociopolítica. Com o estudo referido, conclui-se que existem graves défices de qualidade vida na auto-determinação, desenvolvimento pessoal, bem-estar físico e material, direitos e inclusão social. E ainda que as desigualdades sociais encontradas no acesso à formação, trabalho e rendimento revelam sinais de discriminação e preconceito na sociedade portuguesa, que não é sentida como tal pelas pessoas incapacitadas, parecendo indicar um conformismo em relação à sua situação e uma consciência social reduzida, por não verem a incapacidade como uma condição social (Sousa et al., 2007).

Neste artigo é descrito um estudo empírico que pretendeu avaliar a qualidade de vida de pessoas incapacitadas, segundo uma perspetiva sociopolítica, tendo como objetivos:

1) Avaliar a adequação do modelo multi-dimensional de qualidade de vida de Schalock (1996) ao contexto português;
2) Avaliar a adequação da introdução de duas novas sub-escalas – igualdade de direitos e discriminação positiva - na escala de qualidade de vida;
3) Analisar os níveis de qualidade de vida nas suas várias dimensões (satisfação, competência, empoderamento, igualdade de direitos e discriminação positiva) e a relação entre elas;
4) Avaliar o impacto da discriminação na vida dos indivíduos através da análise de valores relativos à existência, aos motivos, aos contextos de experiências de discriminação e ao grau de desconforto sentido;
5) E finalmente, analisar a relação entre discriminação e qualidade de vida.

Método

Participantes

Conforme descrito na Tabela 2, a amostra é constituída por 217 participantes, dos quais 149 são homens (69,00%) e 67 são mulheres (31,00%), com idades compreendidas entre os 16 e os 81 anos (M = 35,86; D.P.= 12,60). Relativamente ao estado civil dos participantes, 148 são solteiros (69,80%), 55 são casados (25,90%) e 9 são viúvos ou divorciados (4,20%). A fonte de rendimento dos participantes inclui o emprego para 81 (39,70%), 95 (46,60%) vivem de subsídios ou pensões, e 28 (13,70%) têm outros rendimentos. Quanto ao grau de escolaridade, 11 (5,10%) não sabem ler nem escrever, 80 (37,20%) têm o ensino obrigatório, 82 (38,10%) o ensino secundário ou um curso técnico, e 42 (19,50%) um curso superior ou pós-graduação. Relativamente à situação profissional, 95 (44,60%) participantes estão empregados ou são trabalhadores-estudantes, 41 (19,20%) estão desempregados, 30 (14,10%) são não ativos e 47 (22,10%) são estudantes ou formandos.

No que se refere ao tipo de deficiência, 107 (49,30%) têm uma deficiência física, 6 (2,80%) deficiência intelectual, 49 (22,60%) deficiência sensorial, e 40 (18.40%) revelam ter multideficiências. Quanto à origem da deficiência, 89 (44,30%) dos participantes referem que a origem é congénita e 112 (55,70%) relatam uma origem adquirida.

Relativamente ao uso de ajuda técnica, 50 (31,10%) dos participantes referem que não usam nenhuma ajuda técnica, 25 (15,50%) usam ajuda técnica como canadianas ou próteses, 70 (43,50%) usam cadeira de rodas manual e 16 (9,90%) usam cadeira de rodas elétrica.

Quanto à autonomia nas atividades de vida diária (comer, vestir-se, tomar banho), nota-se que 23 (10,60%) apresentam autonomia reduzida, 23 (10,60%) têm autonomia média e 122 (56,20%) uma autonomia total nestas atividades.

Tabela 2 - Características sociodemográficas e relativas à deficiência, mobilidade e autonomia

Variável	N	Categoria	Média/Frequência (percentagem)
Sexo	216	Homens	149 (69,00)
		Mulheres	67 (31,00)
Idade	209		Média = 35,86 D.P. = 12,60 Mínimo = 16; Máximo = 81
Estado civil	212	Solteiro(a)	148 (69,80)
		Casado(a)	55 (25,90)
		Viúvo(a)/divorciado(a)	9 (4,20)
Grau escolaridade	215	Analfabeto(a)	11 (5,10)
		Ensino obrigatório	80 (37,20)
		Ensino secundário/curso técnico	82 (38,10)
		Curso superior/Pós-graduação	42 (19,50)
Situação professional	213	Empregado/trabalhador-estudante	95 (44,60)
		Estudante/formando	47 (22,10)
		Desempregado	41 (19,20)
		Não ativo	30 (14,10)
Fonte rendimento	204	Emprego	81 (39,70)
		Subsídio/pensão	95 (46,60)
		Outros	28 (13,70)
Tipo deficiência	202	Física	107 (49,30)
		Sensorial	49 (22,60)
		Intelectual	6 (2,80)
		Multideficiências	40 (18,40)
Origem deficiência	201	Congénita	89 (44,30)
		Adquirida	112 (55,70)
Uso de ajuda técnica	161	Sem ajuda técnica	50 (31,10)
		Canadianas/próteses	25 (15,50)
		Cadeira de rodas manual	70 (43,50)

		Cadeira de rodas eléctrica	16 (9,90)
		Não se aplica	47 (21,70)
Mobilidade	206	Viatura própria	87 (40,10)
		Viatura de familiares/amigos	50 (23,00)
		Transportes públicos	43 (19,80)
Autonomia geral	212	Reduzida	52 (24,50)
		Média	65 (30,70)
		Total	95 (44,80)
Autonomia nas actividades de vida diária	216	Reduzida	23 (10,60)
		Média	23 (10,60)
		Total	122 (56,20)
		Não se aplica	48 (22,10)

Instrumentos

Questionário de qualidade de vida (QQV). O QQV é uma versão adaptada de quatro escalas. A maioria dos itens é adaptada do *Quality of Life Questionnaire (QoL.Q)* (Schalock & Keith, 1993), tendo sido ainda adaptados itens das escalas *The World Health Organization Quality of Life - BREF* (OMS, 2004) e *Disability Assessment Schedule* (OMS, 2001), e que foram adicionados a três dimensões originais do *QoL.Q* (satisfação, competência, empoderamento) (cf. Quadro 2). Foram ainda adicionadas ao QQV duas novas dimensões - igualdade de direitos e discriminação positiva - adaptadas da *Escala de suporte a direitos das minorias* (Nata & Menezes, 2007) (cf. Quadro 2).

O *QoL.Q* é referido por Cummins (1997) como a escala mais usada na revisão de estudos que realizou. Importa ainda referir que esta escala foi concebida para pessoas com deficiência intelectual, sendo por isso usada maioritariamente nesta população (e.g.: Lachapelle et al., 2005), tendo sido já utilizado por pessoas com deficiência visual (Verdugo, Schalock et al., 2005). Ainda se deve referir que a versão original do *QoL.Q* usa uma escala de resposta ordinal (com três categorias).

A versão portuguesa foi adaptada pelas autoras e inclui 33 itens, usando uma escala de Likert de 1 a 5, em que 1 corresponde a "discordo totalmente" e 5 corresponde a "concordo totalmente", sendo que, em alguns itens, 1 corresponde a "Decidi completamente sozinho" e 5 a "Alguém decidiu completamente por mim". O questionário inclui as seguintes dimensões: satisfação (11 itens, $\alpha = .79$) (ex.: "De uma forma geral, a minha vida é como eu quero que seja"), competência/produtividade (10 itens, $\alpha = .86$) (ex.: "O meu trabalho ou o que faço diariamente é importante para mim e para os outros"), empoderamento/independência (6 itens, $\alpha = .687$) (ex.: "Posso sair e entrar em casa quando quero"), igualdade de direitos (3 itens, $\alpha = .74$) (ex.: "As pessoas com incapacidade física devem ter as mesmas oportunidades que qualquer pessoa") e discriminação positiva (3 itens, *mean inter-item correlation* = .231) (ex.: "As pessoas com incapacidade física devem ter direitos especiais porque são discriminadas (tratadas de forma negativa pelas pessoas ou sociedade)").

Quadro 2 - Dimensões, nº de itens e novos itens do Questionário de qualidade de vida

Dimensão	Nº itens	Novos itens e proveniência destes
Satisfação	11	Consigo movimentar-me bem no meio onde vivo. (Disability Assessment Schedule, OMS, 2001) Estou satisfeito/a com as minhas relações pessoais. (WHOQOL-BREF, OMS, 2004) Estou satisfeito/a com a minha aparência física. (Quality of Life Index, Ferrans & Power, 1984) Estou satisfeito/a com a minha vida sexual. (WHOQOL-BREF, OMS, 2004) Estou satisfeito/a com o acesso aos cuidados de saúde. (WHOQOL-BREF, OMS, 2004) Estou satisfeito/a com a minha saúde. (WHOQOL-BREF, OMS, 2004)
Competência	10	Considero que sou bom/boa no meu trabalho/formação. Os meus colegas de trabalho/formação tratam-me bem. Estou satisfeito/a com as capacidades e experiência que tenho adquirido no trabalho/formação. (Autoras do estudo)

Empoderamento	6	Quem decide as atividades que faz por lazer? (Autoras do estudo)
Novas dimensões		Escala EDM, Nata & Menezes, 2007
Igualdade de Direitos	3	As pessoas com incapacidade física devem ter as mesmas oportunidades que qualquer pessoa. Se uma pessoa com incapacidade física fizer um trabalho igual ao de outra pessoa, deverá receber o mesmo salário. As pessoas com incapacidade física devem ter os mesmos direitos que qualquer outra pessoa.
Discriminação Positiva	3	As pessoas com incapacidade física devem ter direitos especiais porque são discriminadas (tratadas de forma negativa pelas pessoas e pela sociedade). As pessoas com incapacidade física deviam ter um representante (um lugar) nos órgãos de poder (Assembleia da República, Câmaras, Juntas de Freguesia, …) porque são uma minoria. As pessoas com incapacidade física devem ter condições (subsídios por ex.) para ter uma vida independente.

Escala da experiência de discriminação; EED. A EED é uma versão adaptada pelas autoras da escala *The experience of discrimination scale* (Thompson, Noel & Campbell, 1996). Inclui 4 itens que se referem à existência de experiência de discriminação ("Alguma vez se sentiu discriminado/a (tratado/a de forma negativa pelas pessoas e pela sociedade)?"), ao motivo da discriminação (incapacidade, raça, sexo, idade, estatuto socioeconómico, religião, orientação sexual ou outros – com possibilidade de especificar), aos contextos nos quais ocorreu (escola, emprego, serviços de saúde, amigos, família, ou outros - com possibilidade de especificar) e ao grau de desconforto com a experiência, usando uma escala de 1-5 em que 1 corresponde a "nada" e 5 corresponde a "muito".

Escala da Autonomia (EA). A EA é uma versão adaptada pelas autoras dos questionários *Disability Assessment Schedule* (OMS, 2001) e *Participation Objective, Participation Subjective* (Brown, 2006). Inclui 7 itens, dos quais 3 se referem a atividades de vida diária (AVD) (comer, vestir-se, tomar banho) e 4 referem-se a atividades como realizar atividades domésticas, fazer compras no supermercado, preparar refeições/cozinhar e estar sozinho/a por uns dias. Para todos os itens é perguntado se os participantes conseguem realizar as tarefas de forma autónoma ou se necessitam de ajuda, se a ajuda é total ou parcial e se está disponível ou não.

Procedimento

Por se tratar de uma amostra que é difícil de aceder, o método de amostragem usado foi em bola de neve (Maroco, 2007), tendo-se usado contactos de associações ligadas à incapacidade e contactos pessoais no sentido destes divulgarem e incentivarem os seus contactos a preencherem e a divulgarem o questionário. Antes da administração, realizaram-se reflexões faladas com quatro pessoas com deficiência física, com diferentes características sociodemográficas, que deram indicações e sugeriram alterações relativas à compreensão dos itens.

Os critérios de inclusão dos participantes prenderam-se com a existência de uma deficiência (que no caso de adquirida teria de ter pelo menos 1 ano de existência) e com a idade superior a 16 anos.

O questionário foi administrado em dois formatos - *on-line* e em papel[5] - cumprindo-se normas de anonimato e de informação relativa à duração média do preenchimento do mesmo, ao objetivo do estudo e a quem era destinado, e à possibilidade de contactarem a equipa de investigação se necessitassem de esclarecimentos sobre este. A administração do questionário decorreu entre Agosto de 2008 e Fevereiro de 2009.

Análises estatísticas

Para procedimentos de validação da escala foi realizada uma análise fatorial confirmatória com o suporte do programa EQS 1.6. Começou-se por analisar o ajustamento local de cada uma das dimensões de qualidade de vida - satisfação, competência, empoderamento, pertença/integração social, igualdade de direitos e discriminação positiva. Seguidamente testou-se o ajustamento global de primeira ordem e o ajustamento global de segunda ordem do modelo no sentido de se perceber qual seria o modelo mais ajustado. Ainda se realizaram análises do *Alpha de Cronbach* e do valor *mean inter-item correlation* para testar a consistência interna do instrumento.

As análises estatísticas foram realizadas com o programa SPSS 19. Começou-se por realizar análises de natureza descritiva para as dimensões de qualidade de vida, com o cálculo das médias e dos desvios-padrão. A normalidade da distribuição da amostra foi testada com o uso do teste de *Kolmogorov-Sminorv* que revelou uma distribuição anormal para todas as dimensões com a exceção da satisfação. A anormalidade da distribuição da amostra levou à opção por análises de correlação de

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[5] 27% da amostra respondeu *on-line* e 73% respondeu em papel. Realizaram-se teste de qui-quadrado usando várias variavéis sociodemográficas, tendo-se verificado diferenças significativas entre o tipo de administração do questionário e a situação profissional dos sujeitos ($X^2(3) = 23{,}73$, $p < .001$) e o meio de transporte utilizado ($X^2(3) = 8{,}64$, $p < .05$). Verificou-se assim que os indivíduos não-ativos usaram mais o formato *on-line* (27,1%) que em papel (9,1%). No meio de transporte, os que usam transporte público (25,4%) ou viatura própria (49,2%) usaram mais o formato *on-line* do que em papel (17,7% e 36,7% respectivamente). Foram também realizados *t-test,* tendo-se encontrado diferenças significativas em duas dimensões: os sujeitos que usaram o formato papel (M = 3,60; DP = .64) têm uma média mais elevada que os que responderam *on-line* (M = 3,17; DP = .58) na dimensão da satisfação; na dimensão da competência no trabalho/formação também se verificou que os que responderam em papel (M = 3,99; DP = .82) tiveram uma média mais elevada que os que responderam *on-line* (M = 3,62; DP = .81). A magnitude das diferenças na satisfação foi moderada (eta squared = .09) e na competência foi baixa (eta squared = .04) (Cohen, 1988).

Spearman entre as dimensões de qualidade de vida. O impacto da discriminação na vida dos sujeitos foi examinado através de análises de natureza descritiva, com o cálculo de frequências e percentagens relativos à discriminação (experiência, motivo, contextos, grau de desconforto), e de análises de correlações de *Spearman* para aceder à relação entre discriminação e qualidade de vida.

Resultados

Análise fatorial confirmatória (AFC)

A versão original do *QoL.Q* (Schalock & Keith, 1993) inclui 40 itens e sugere a existência de quatro dimensões: satisfação, competência/produtividade, empoderamento/independência e pertença/integração social. De uma forma geral, a AFC realizada indica bons níveis de ajustamento local para cada uma das dimensões, com exceção da dimensão pertença/integração social que foi removida da escala, na medida em que apresenta índices ajustamento desadequados ($\chi^2_{(5)} = 72{,}06$, $p < .001$; CFI = .69; e RMSEA = .26) (cf. Tabela 3). Ainda nesta dimensão eliminaram-se seis itens, restando três que se referem à participação em clubes/associações ou em atividades recreativas. Foi assim necessário realizar procedimentos de depuração, *i.e*, eliminação de itens em todas as sub-escalas, sendo que esta baseou-se numa análise do baixo poder explicativo de cada item (saturação no fator), na sua redundância e/ou na sua ambiguidade. Os critérios para a eliminação foram a sua baixa saturação (inferior a .35) e o facto desta eliminação se refletir numa melhoria ao nível dos índices de ajustamento. Realizaram-se ainda correlações entre as variâncias erro de alguns itens, usando o critério da similitude semântica entre os itens em questão (Byrne, 2006). Por ser a mais indicada para amostras em que existem violações de normalidade das distribuições, optou-se por usar a versão robusta (Byrne, 2006) em todas dimensões.

Tabela 3 - Resultados da AFC: escalas; itens eliminados; índices de ajustamento; e descrição de alterações.

Escalas	*S-Bχ^2 (gl)*	*CFI*	*RMSEA*	*IC 90%*
Satisfação	67,02 (43)**	.93	.05	[.03-.08]
Alterações: eliminação dos itens sat8, sat9 e saud14 e correlação entre as variâncias erro dos itens sat2 e sat6.				
Competência	35,44 (33)*	.98	.05	[.00-.14]
Alterações: eliminação do item trab15 e correlação entre as variâncias erro dos itens trab18 e trab24 e entre trab20 e trab21.				
Pertença/integração social	72,06 (5)***	.69	.26	[.21-.31]
Alterações: eliminação dos itens soc33, soc34, soc35, soc37, soc38 e soc39.				
Empoderamento	10,05 (9)*	.98	.03	[.00-.09]
Alterações: eliminação dos itens quot24_R, quot28 e quot29_R.				
Igualdade de direitos	0,1257 (1) ns	1	.00	[.00-.13]
Alterações: correlação entre as variâncias erro dos itens dir40 e dir41.				
Discriminação positiva	1,64 (1) ns	.98	.06	[.00-.20]
Alterações: eliminação do item dir45.				

* p < .05; ** p < .01; *** p < .001; ns (não significativo)

Seguidamente testou-se o ajustamento global de primeira ordem do modelo, tendo-se procedido ao parcelamento aleatório de itens em algumas dimensões (em 2 ou 3 parcelas, conforme o nº de itens) no sentido de garantir um modelo parcimonioso e justificado (para detalhes relativamente às vantagens do uso de parcelas ver Little, Cunningham, Shahar & Widaman, 2002). O ajustamento global testado através da análise fatorial de primeira ordem revela bons índices de ajustamento ($\chi^2_{(17)}$ = 14,62 ns; CFI = .93; e RMSEA=.00) (cf. Tabela 4), sugerindo a multi-dimensionalidade do modelo. A figura 1 revela o diagrama do ajustamento global de 1ª ordem do modelo. Testou-se ainda o ajustamento global de 2ª ordem do modelo (cf. Tabela 4) e comparou-se os valores de AIC (Akaike's Information Criterion) dos dois modelos para analisar qual teria o valor de AIC mais baixo já que este indica o modelo mais ajustado (Hu & Bentler, 1995). Verifica-se que o valor de AIC do ajustamento global de 2ª ordem (-40,26) é superior ao do ajustamento global de 1ª ordem (-10,84), comprovando assim a multi-dimensionalidade do modelo.

Tabela 4 - Resultados da AFC: ajustamento global de 1ª e 2ª ordem; índices de ajustamento e valor de AIC

	X^2(gl)	*CFI*	*RMSEA*	*AIC*
Ajustamento global de 1ª ordem	14,6163 (17) ns	.93	.00	-10,84
Ajustamento global de 2ª ordem	103,74 (72)**	.92	.06	-40,26

** p < .01; ns (não significativo)

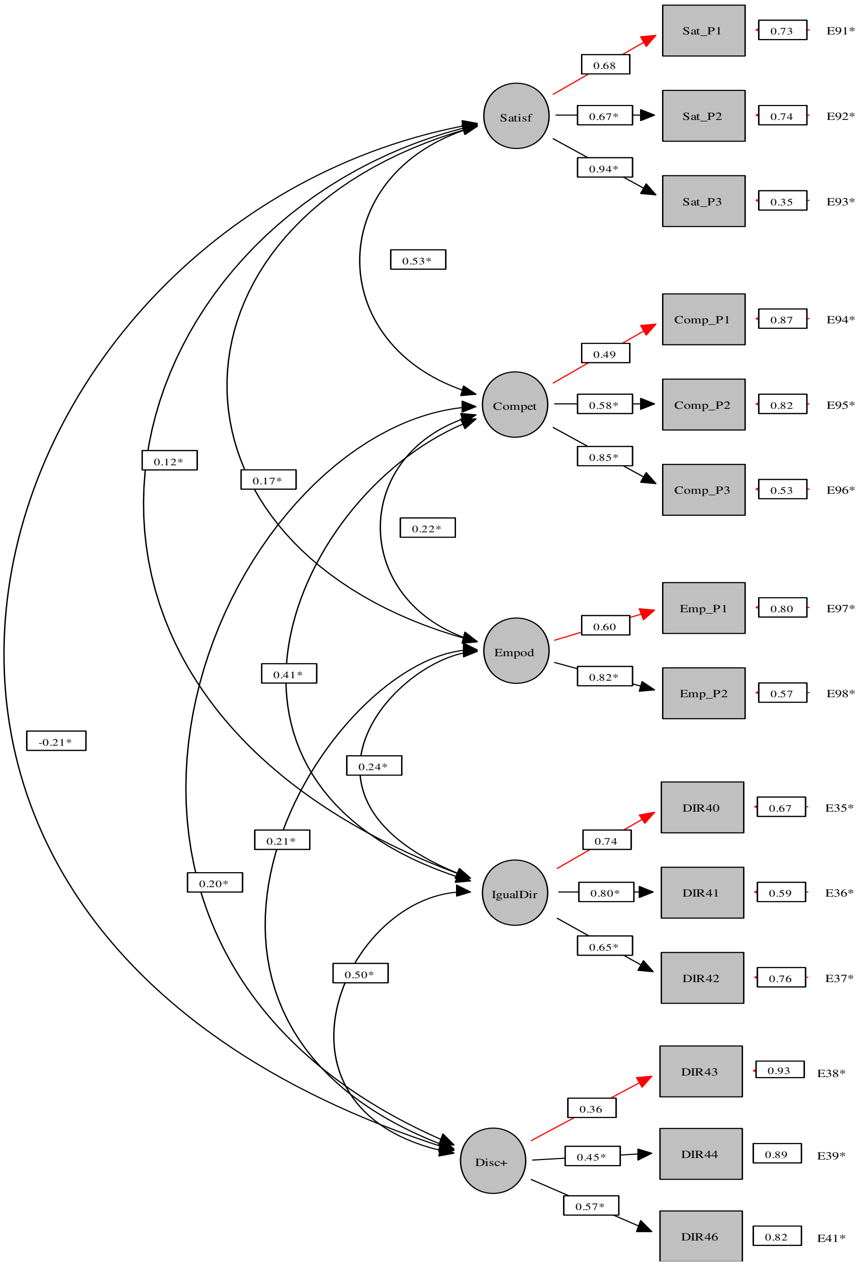

Figura 1 - Modelo global de 1ª ordem - estrutura em 5 escalas e respectivas saturações.

Nota: Satisf = Satisfação; Compet = Competência; Empod = Empoderamento; IgualDir = Igualdade de direitos; Disc+ = Discriminação positiva.

Análise de consistência interna

Os resultados da análise da consistência interna mostram que os *alphas de Cronbach* se situam entre .859 e .687 – sendo assim aceitáveis -, e que na dimensão da discriminação positiva o valor *mean inter-item correlation* está entre .2-.4, sendo por isso adequado (Briggs & Cheek, 1986) (cf. Tabela 5). Optou-se por usar o valor *mean inter-item correlation* na dimensão da discriminação positiva na medida em que sendo o *alpha de Cronbach* sensível ao número de itens da escala, é mais adequado reportar o valor referido (Pallant, 2001).

Tabela 5 - Valores de consistência interna (alphas de Cronbach) e de mean inter-item correlation, médias e desvios-padrão das dimensões

Dimensão	Nº itens	*Alpha de Cronbach/ Mean inter-item correlation*	*M*	*DP*	*n*
Satisfação	11	α =.794	3,49	.66	217
Competência	10	α = .859	3,89	.83	211
Empoderamento	6	α = .687	4,20	.75	217
Igualdade de Direitos	3	α = .737	4,67	.67	216
Discriminação Positiva	3	*Mean inter-item correlation* = .231	3,96	.88	215

Dimensões de qualidade de vida

Conforme se verifica na Tabela 5, as dimensões que apresentam as médias mais elevadas de respostas são a igualdade de direitos (M = 4,67, DP = .67) e o empoderamento (M = 4,20, DP = .75). A discriminação positiva surge seguidamente como a dimensão com a média mais elevada de respostas (M = 3,96, DP = .88). E finalmente apresentam-se a competência (M = 3,89, DP = .83) e a satisfação (M = 3,49, DP = .66).

Tabela 6 - Correlações de Spearman entre as dimensões

	1	2	3	4	5
(1) Satisfação	1				
(2) Competência	.447*** (n=211)	1			
(3) Empoderamento	.152** (n=217)	.107 (n=211)	1		
(4) Igualdade Direitos	.008 (n=216)	.183*** (n=210)	.277*** (n=216)	1	
(5) Discriminação Positiva	-.048 (n=215)	-.038 (n=209)	.119 (n=215)	.159** (n=215)	1

* p < .05; ** p <.01; *** p <.001

A análise de correlação de *Spearman* entre as dimensões revela que a satisfação está significativa e moderadamente correlacionada de forma positiva com a competência no trabalho/formação, sendo esta a correlação que apresenta maior magnitude (r=.447, p <.001) (Bryman & Cramer, 2003) de todas as encontradas (cf. Tabela 6). Assim se verifica que quanto mais os indivíduos se sentem satisfeitos com a vida, mais fazem uma apreciação positiva relativamente à sua competência no trabalho/formação. É ainda evidente uma correlação positiva e significativa entre competência no trabalho/formação e igualdade de direitos (r = .183, p < .001).

O empoderamento está correlacionado de forma significativa e positiva com a satisfação (r = .152, p < .01) e com a igualdade de direitos (r = .277, p < .001), demonstrando que quanto mais empoderados os indivíduos se sentem, mais satisfeitos se sentem com a vida e mais defendem a igualdade de direitos (cf. Tabela 6). E finalmente as dimensões relacionadas com os direitos – igualdade de direitos e discriminação positiva – estão correlacionadas de forma significativa e positiva (r = .159, p < .01) (cf. Tabela 6), notando-se assim que quanto mais os indivíduos defendem a igualdade de direitos, mais defendem a discriminação positiva. Acrescente-se ainda que à exceção do valor da correlação entre satisfação e competência no trabalho/formação, todas as outras correlações encontradas apresentam valores baixos (Bryman & Cramer, 2003).

Impacto da discriminação

Os resultados relativos à discriminação foram analisados através de estatística descritiva referente à existência, motivo, contextos e grau de desconforto das experiências (cf. Tabela 7). Procedeu-se ainda à análise de correlações de *Spearman* entre as dimensões de qualidade de vida e a discriminação (cf. Tabela 8).

Tabela 7 - Frequências e percentagens das respostas relativas à existência, motivo e contextos de discriminação; média e desvio-padrão do grau de desconforto com a discriminação

	Frequência	%
Existência:		
Sim	145	67,40
Não	70	32,60
Motivo:		
Incapacidade	125	57,60
Raça	1	.50
Idade	1	.50
Sexo	1	.50
Orientação sexual	1	.50
Estatuto económico	5	2,30
Contextos:		
Escola	53	37,90
Emprego	46	33,10
Família	8	5,80
Amigos	14	10,10
Serviços de Saúde	20	14,40
Grau de desconforto	Média	Desvio-padrão
	3,78	1,168

Os resultados mostram que 67,40% (n = 145) dos participantes relatam ter sido alvo de discriminação pelas pessoas ou sociedade, apontando a incapacidade como o principal motivo (57,80%, n = 125), notando-se que os outros motivos têm pouca expressão (n < 5). Os principais contextos de discriminação relatados pelos participantes são a escola (37,90%, n = 53) e o emprego (33,10%, n = 46), seguidos dos serviços de saúde (14,40%, n=20). As relações pessoais com amigos (10,10%, n = 14) e familiares (5,80%, n = 8) são os contextos nos quais sentem menos discriminação. O grau de desconforto com as experiências de discriminação tem a média de 3,78 (DP = 1,168).

Tabela 8 - Correlações de Spearman entre discriminação e dimensões de qualidade de vida

	Discriminação
Satisfação	-.209** (n = 215)
Competência	-.102 (n = 209)
Empoderamento	-.237** (n = 215)
Igualdade direitos	-.092 (n = 214)
Discriminação positiva	-.041 (n = 214)

*p <.05; ** p <.01; *** p <.001

A análise das correlações de *Spearman* entre as dimensões e a discriminação indicam uma correlação negativa significativa com a satisfação (r = -.209, p < .05) e com o empoderamento (r = -.237, p < .05), o que indica que quanto mais os indivíduos sentem discriminação, menos satisfeitos e empoderados se sentem (cf. Tabela 8).

Discussão

Esta investigação empírica tinha como objetivos avaliar a adequação do modelo multi-dimensional de qualidade de vida de Schalock (1996) ao contexto português e analisar a qualidade de vida das pessoas incapacitadas sob um prisma sociopolítico, tentando entender o impacto da discriminação.

Quanto ao primeiro objetivo do estudo, verifica-se que os procedimentos de validação do *QoL.Q* para uma amostra portuguesa resultaram satisfatoriamente. O bom ajustamento demonstrado pela estrutura fatorial, conseguida pelo procedimento de AFC efetuado, assim como os valores de consistência interna, permitem afirmar que a estrutura final pode ser considerada estável e válida. A remoção da sub-escala pertença/integração social é um aspeto relevante deste procedimento que vale a pena referir mais detalhadamente.

Tal como aconteceu no estudo de Verdugo, Schalock et al (2005), com uma amostra de espanhóis invisuais, no qual a AFC não indicou um modelo de 4 fatores com bons níveis de ajustamento e a análise fatorial exploratória subsequente veio a revelar uma estrutura de 3 fatores com a exclusão do fator pertença/integração social, no presente estudo esta dimensão foi igualmente retirada. Note-se que somente os itens relacionados com a participação em clubes/associações ou em atividades recreativas conseguiram obter cargas fatoriais aceitáveis, sendo que estes não nos pareceram demonstrar a pertença/integração social de um modo fiel e completo quando analisamos os hábitos sociais da população portuguesa. Um estudo comparativo com os 23 países da União Europeia acerca de atitudes perante a vida (Nata & Menezes, 2010) concluiu que Portugal é o país que regista maior sociabilidade, mas apresenta uma média negativa no envolvimento comunitário, entendendo-se este último como a participação em organizações de caridade ou de voluntariado ou em atividades organizadas na área da residência. Tal como se passa em Espanha, em Portugal não há uma tradição vincada de pertença a associações ou organizações cívicas, o que poderá estar relacionado com uma recente vivência democrática (Nata & Menezes, 2010). Conclui-se assim que, por questões de diferença cultural, a dimensão da pertença/integração social não se mostrou adequada à amostra portuguesa e que as restantes dimensões tiveram índices de ajustamento local adequados.

Duas importantes conclusões poderão ainda ser afirmadas em relação à validação do instrumento. A primeira terá que ver com a constatação de que o modelo testado (com cinco fatores) é multi-dimensional, visto que o ajustamento global de 1ª ordem indicou índices mais adequados do que o ajustamento global de 2ª ordem, quando se comparou os valores de AIC (Byrne, 2005). A segunda conclusão prende-se com o fato das dimensões igualdade de direitos e discriminação positiva - propostas pelas autoras – terem tomado espaço neste modelo. Desta forma, é possível propor um modelo multi-dimensional de qualidade de vida que inclui cinco dimensões: satisfação, competência, empoderamento, igualdade de direitos e discriminação positiva – comprovando-se a adequação do instrumento a uma amostra portuguesa e revelando-se a importância da adoção de duas sub-escalas de direitos na medição da qualidade de vida na área da incapacidade.

O segundo objetivo desta investigação tem a ver com a análise da qualidade de vida de pessoas incapacitadas segundo um prisma sociopolítico, considerando-se, por isso, o impacto da discriminação.

Poder-se-á iniciar esta análise a partir das dimensões que estão associadas à satisfação na vida. Destaca-se primeiramente a correlação com a competência no trabalho/formação, que apresentou a magnitude mais elevada das encontradas, e que parece indicar a importância de perceções positivas sobre a competência na área profissional/de formação para a satisfação na vida. Sendo o trabalho um dos fatores com maior impacto no bem-estar social e material das pessoas incapacitadas (Barnes, Mercer & Shakespeare, 2005), acrescentando-se a vantagem a um nível sistémico que tem a ver com a redução substancial de custos com subsídios e com outros serviços fornecidos pelo Estado (O'Brien & Dempsey, 2004), entende-se como a perceção de sentido de competência nesta área se relaciona fortemente com a satisfação na vida. Este mesmo resultado foi encontrado no estudo de Verdugo, Schalock et al. (2005) com espanhóis com deficiência visual, levando os autores a sugerirem intervenções aos serviços direcionados a pessoas incapacitadas que se focassem na promoção da perceção de competência na esfera laboral/de formação. Há, no entanto, grandes entraves à empregabilidade das pessoas incapacitadas que estão relacionados com a existência de barreiras arquitetónicas, a falta de conhecimentos e a existência de preconceitos (Instituto de Emprego e Formação Profissional, 2004). Neste estudo, foram encontrados resultados que nos parecem apontar para uma ligação entre uma dimensão política e o sentido de competência na esfera laboral/de formação, especificamente a correlação positiva e significativa entre competência no trabalho/formação e igualdade de direitos e o nível elevado de experiências de discriminação no contexto de trabalho. Estes revelam que uma focagem individual na promoção da empregabilidade ou da perceção de competência é insuficiente e deverá ser complementada fortemente por uma intervenção sistémica para a mudança nas práticas e atitudes dos empregadores e da sociedade em geral, e de garantia da igualdade de direitos, por parte dos serviços direcionados às pessoas incapacitadas (Wagner, Armstrong, Frase, Vandergoot & Thomas, 2006).

Para além da competência no trabalho/formação, também o empoderamento está relacionado com a satisfação na vida. Como revelado no estudo de Verdugo, Schalock et al. (2005), no qual a auto-determinação (que foi definida pelos autores e que incluía 5 itens da sub-escala original de empoderamento) está correlacionada com a satisfação, no presente estudo também constatamos como o empoderamento é uma dimensão relevante para a satisfação na vida das pessoas incapacitadas. Numa nota adicional, poder-se-á hipotisar que o tipo de deficiência tem influência na adoção de conceitos que melhor espelhem a realidade dos indivíduos e, como tal, no estudo de Verdugo, Schalock et al. (2005) com espanhóis invisuais foi adotado o conceito de auto-determinação que substituiu o de empoderamento. Na presente investigação, a dimensão do empoderamento revelou-se adequada para a amostra e mostrou-se relacionada com a igualdade de direitos, sendo que esta última se relacionou com a discriminação positiva. Estes últimos resultados parecem mostrar que o exercício de poder e controlo na vida está associado a uma dimensão política que, embora constasse no modelo teórico de Schalock (1996), parecia não ter expressão concreta no *QoL.Q*.

No sentido de avaliarmos o impacto da discriminação na qualidade de vida das pessoas incapacitadas, alguns resultados merecem ser objeto de discussão. Desde já, a correlação significativa negativa entre o empoderamento e a discriminação, leva-nos a tomar em conta a importância de uma dimensão de direitos (pela correlação acima explanada) na promoção e na avaliação do empoderamento das pessoas incapacitadas. Para além disso, verifica-se em simultâneo um alto nível de discriminação (com base na incapacidade) em mais de metade da amostra, em contextos tão importantes para a sua inclusão social como são a escola e o trabalho, e uma média elevada de respostas no empoderamento. Isto parece sugerir que a qualidade de vida das pessoas incapacitadas é determinada pelo empoderamento individual e não pelo usufruto de estruturas societais e atitudes sociais empoderantes.

De fato, a discriminação é de tal modo frequente no quotidiano das pessoas incapacitadas (e.g. Gilson & DePoy, 2002; McCarthy, 2003) que é considerada uma expressão de uma profunda violência estrutural, ao constituir formas sociais que colocam os indivíduos em risco, tendo assim um impacto negativo profundo no bem-estar das pessoas incapacitadas, das suas famílias e das comunidades (Stancliffe, 2001). Nesta investigação é revelada, por um lado, uma correlação negativa significativa entre discriminação e satisfação e, por outro, uma média elevada no grau de desconforto sentido nas experiências de discriminação, o que nos parece mostrar o impacto profundo da discriminação na vida dos indivíduos. É neste quadro de discriminação que se poderá entender a grande valorização da dimensão da igualdade de direitos, que revela um elevadíssimo consenso dos participantes nesta questão, e que nos aponta para uma necessidade saliente de verem os seus direitos iguais aos outros cidadãos.

Em jeito conclusivo, este estudo empírico mostra-nos que a qualidade de vida na incapacidade é caracterizada por relações entre a satisfação na vida e a perceção de competência no trabalho/formação e o empoderamento. Este último parece apresentar-se como um empoderamento individual, visto que mais de metade da amostra reporta altos níveis de discriminação em contextos essenciais à inclusão social, caracterizando-se ainda por um impacto psicológico significativo nos participantes. O elevadíssimo consenso dos participantes relativamente à igualdade de direitos, assim como a relação entre esta dimensão política e o empoderamento, deverão fazer-nos refletir acerca da necessidade urgente de se promover uma consciência política crítica sobre a qualidade de vida das pessoas incapacitadas e sobre a discriminação de que são vítimas.

É assim fulcral considerar-se a importância dos direitos e do empoderamento na promoção da qualidade de vida das pessoas incapacitadas, em vez de nos perdermos em perspetivas individuais, de tragédia pessoal (Oliver, 1990), de determinismo biológico (Barnes et al*,* 2005), que continuam a "culpar a vítima" (Nelson & Prilleltensky, 2005) e a estruturar formas sociopolíticas nas quais se constrói e se perpetua a opressão das pessoas incapacitadas (Meekosha, 2004). O poder e o controlo na vida - importantes para todos os seres humanos - não devem ser entendidos como uma questão de imposição de vontade sobre o outro, mas uma questão de responsividade, baseada na mutualidade, que deve ocorrer nos vários contextos de vida do indivíduo (Herrmann, 2005).

Importa então que nos questionemos acerca da adequação do modelo médico na promoção da qualidade de vida das pessoas incapacitadas (Vash, 2004; Van Campen & Iedema, 2007), reavaliando a medicalização da incapacidade (Barton, 1993), na medida em que as barreiras impostas a estas pessoas estão mergulhadas em políticas e práticas que se baseiam na abordagem médica/individual, pela insistência na crença de que são as circunstâncias pessoais e desafortunadas que as travam (Barnes et al, 2005). Os estudos sobre qualidade de vida na área da incapacidade devem ter em conta as barreiras e a discriminação que as pessoas incapacitadas poderão encontrar nas suas vidas e incluir uma dimensão política na avaliação da qualidade de vida, pois interessa entender as dimensões que influenciam a satisfação na vida e não somente avaliar as perceções acerca dela.

Algumas implicações e limitações deste estudo deverão ser objeto de análise. Desde já, o facto de se ter usado, junto de indivíduos com diferentes tipos de deficiência (na maioria física), uma escala de qualidade de vida que na sua origem foi concebida para indivíduos com deficiência intelectual. Embora a escala se tenha revelado adequada, é bem possível que o tipo de deficiência seja um aspeto importante para a qualidade de vida e, portanto, futuras investigações com amostras com indivíduos com deficiência física poderão ser importantes para a compreensão da qualidade de vida nesta população.

Como limitação deste estudo, poder-se-á considerar a anormalidade da distribuição da amostra e o possível viés que isso poderá criar no sentido da não representação do universo das pessoas com deficiência em Portugal. Este tipo de distribuição era expectável na medida em que é consequência das condicionantes sociais impostas às pessoas incapacitadas. A amostra deste estudo foi a possível de ser acedida, representando a franja da população com deficiência que tem algum contacto com a sociedade. Muito embora se tenha tentado colmatar uma das condicionantes impostas pela sociedade - como seja a inacessibilidade física - com o uso do formato eletrónico do questionário, na verdade não se conseguiu alcançar o grande número de pessoas com deficiência que não estão integradas na sociedade e que não têm acesso a tecnologias de informação. Estudos futuros deverão tentar ultrapassar esta limitação.

Em conclusão, este estudo mostra que a qualidade de vida deve ser entendida num contexto sociopolítico, de promoção de igualdade (Schalock & Verdugo, 2003), que conceba a incapacidade na interação entre indivíduo-sociedade e, consequentemente, responsabilize todos os cidadãos na promoção de qualidade de vida das pessoas incapacitadas e no respeito pelos seus direitos civis.

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REFERÊNCIAS

Barnes, C, Mercer, T., & Shakespeare, T. (2005). *Exploring disability: A sociological introduction,* (2nd Ed.), Cambridge, UK: Polity Press.

Barton, L. (1993). The struggle for the citizenship: the case of disabled people. *Disability and Society, 8(3*), 236-248. http://dx.doi.org/10.1080%2F02674649366780251

Briggs, S. R., & Cheek, J. M. (1986). The role of factor analysis in the development and evaluation of personality scales. *Journal of Personality, 54,* 106-148. http://dx.doi.org/10.1111%2Fj.1467-6494.1986.tb00391.x

Brown, M. (2006). Participation Objective, Participation Subjective. *The Center for Outcome Measurement in Brain Injury*. http://www.tbims.org/combi/pops (accessed December 27, 2012).

Bryman, A., & Cramer, D. (2003). *Análise de dados em ciências sociais. Introdução às técnicas utilizando o SPSS para windows* (3ª. Ed.). Oeiras, Portugal: Celta.

Byrne, B. M. (2006). *Structural equation modelling with EQS: Basic concepts, applications, and programming*. (2nd Ed.). Mahwah, NJ: Lawrence Erlbaum Associates.

Cohen, J. (1988). *Statistical power analysis for the behavioural sciences.* Hillsdale, NJ, Erlbaum.

Cummins, R. A. (1997). Self-rated quality of life scales for people with an intellectual disability: a review. *Journal of Applied Research in Intellectual Disabilities 10*, 119–216. http://dx.doi.org/10.1111%2Fj.1468-3148.1997.tb00017.x

Cummins, R. A. (2000). Objective and subjective quality of life: An interactive model. *Social Indicators Research, 52,* 55–72.

Cummins, R. A. (2001). Self-rated quality of life scales for people with an intellectual disability: a reply to Ager & Hatton. *Journal of Applied Research in Intellectual Disabilities 14*, 1–11. http://dx.doi.org/10.1046%2Fj.1360-2322.2001.00057.x

De Mayer, J., Vanderplasschen, W., & Broekaert, E. (2009). Exploratory Study on Drug Users' Perspectives on Quality of Life: More than Health-Related Quality of Life? *Social Indicators Research, 90*, 107–126. http://dx.doi.org/10.1007%2Fs11205-008-9315-7

Farquhar, M. (1995). Definitions of quality of life: a taxonomy. *Journal of Advanced Nursing, 22,* 502–508. http://dx.doi.org/10.1046%2Fj.1365-2648.1995.22030502.x

Felce, D. & Perry, J. (1996). Assessment of quality of life. In Schalock R.L. (Ed.), *Quality of Life: Volume I: Conceptualization and Measurement (pp. 63-73).* Washington, DC.: American Association on Mental Retardation.

Ferdinand, R. & Smith, M.A. (2003). *Nebraska Developmental Disabilities Provider Profiles.* Nebraska, Lincoln: The Arc of Nebraska.

Gardner, J. F. & Nudler, S. (1997). Beyond compliance to responsiveness: accreditation reconsidered. In Schalock, R.L. (Ed.), *Quality of Life: Volume II: Application to Persons with Disabilities (pp. 135-48).* Washington, DC.: American Association on Mental Retardation.

Garratt, A., Schmidt, L., Mackintosh, A., & Fitzpatrick, R. (2002). Quality of life measurement: bibliographic study of patient assessed health outcome measures. *BMJ, 324*, 1417–1419. http://dx.doi.org/10.1136%2Fbmj.324.7351.1417

Gettings, R. M. & Bradley, V. J. (1997). *Core Indicators Project.* Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

Gilson, S., & DePoy, E. (2002). Theoretical approaches to disability content in social work education. *Journal of Social Work Education, 38*, 153-165.

Hays, R. D., Hahn, H., & Marshall, G. (2002). Use of the SF-36 and other health-related quality of life measures to assess persons with disabilities. *Archives of Physical Medicine and Rehabilitation, 83*(12 Suppl 2), S4–9. http://dx.doi.org/10.1053%2Fapmr.2002.36837

Herrmann, P. (2005). Empowerment: the core of social quality. *European Journal of Social Quality, 5 (1/2)*, 289-299. http://dx.doi.org/10.3167%2F146179105780337558

Hu, L.-T., & Bentler, P. M. (1995). Evaluating model fit. In R. H. Hoyle (Ed.), *Structural equation modeling: Concepts, issues, and applications* (pp. 76-99). Thousand Oaks, CA, Sage.

Hughes, C., Hwang, B., Kim, J., Eisenman, L. T. & Killian, D. J. (1995). Quality of life in applied research: a review and analysis of empirical measures. *American Journal on Mental Retardation, 99*, 623-41.

Huppert, F., & Whittington, J. (2003). Evidence for the independence of positive and negative well-being: implications for quality of life assessment. *British Journal of Health Psychology, 8*, 107-122. http://dx.doi.org/10.1348%2F135910703762879246

Instituto de Emprego e Formação Profissional (2004). Valor acrescentado do Trabalhador com (d)eficiência. Lisboa, Portugal: Palmigráfica.

Joyce, C. R. B., McGee, H. M., & O'Boyle, C. A. (1999). *Individual Quality of Life: Approaches to Conceptualization and Assessment.* Australia, AU: Harwood.

Keith, K. D., & Schalock, R. L. (2000). *Cross-cultural Perspectives on Quality of Life.* Washington DC, American Association on Mental Retardation.

Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M.-C., Courbois, Y., Schalock, K., Verdugo, M. A., & Walsh, P. N. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research, 49,* 740–744. http://dx.doi.org/10.1111%2Fj.1365-2788.2005.00743.x

Little, T. D., Cunningham, W. A., Shahar, G., & Widaman, K. F. (2002). To parcel or not to parcel: Exploring the question, weighing the merits. *Structural Equation Modeling, 9*, 151-173. http://dx.doi.org/10.1207%2FS15328007SEM0902_1

Maroco, J. (2007). *Análise estatística – com utilização de SPSS.* Lisboa, Portugal: Edições Sílabo.

McCarthy, H. (2003). The disability rights movement: experiences and perspectives of selected leaders in the disability community. *Rehabilitation Counseling Bulletin, 46,* 209–223. http://dx.doi.org/10.1177%2F003435520304600402

Meekosha, H. (2004). Drifting down the Gulf Stream: navigating the cultures of disability studies. *Disability & Society, 19* (7), 721-733.http://dx.doi.org/10.1080%2F0968759042000284204

Mooney, A. (2006). Quality of life: Questionnaires and questions. *Journal of Health Communication, 11*, 327–341. http://dx.doi.org/10.1080%2F10810730600614094

Nata, G., & Menezes, I. (2007). Escala de Suporte dos Direitos das Minorias, In *Diferença Cultural e Democracia: identidade, cidadania e tolerância na relação entre maioria e minorias (*Dissertação de doutoramento). Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto, Portugal.

Nata, G., & Menezes, I. (2010). Ciclos de vida e atitudes perante a vida: satisfação com a vida, religiosidade e redes de relações sociais, In José Machado Pais & Vítor Sérgio Ferreira (Eds.), *Tempos e transições de vida: Portugal ao espelho da Europa* (pp.225-254). Lisboa, Portugal: Imprensa de Ciências Sociais.

Nelson, G., & Prilleltensky, I. (2005). *Community Psychology: in pursuit of liberation and well-being.* New York, NY: Pallgrave MacMillan.

Nelson, G., Lord, J., & Ochocka, J. (2001). *Shifting the paradigm in community mental health: towards empowerment and community.* Toronto, Canada: University of Toronto Press.

O'Brien, J., & Dempsey, I. (2004). Comparative Analysis of Employment Services for People with Disabilities in Australia, Finland, and Sweden. *Journal of Policy and Practice in Intellectual Disabilities, 1, 3/4,* 126–13. http://dx.doi.org/10.1111%2Fj.1741-1130.2004.04027.x

Oliver, M. (1990). *The politics of disablement.* Basingstoke, UK: McMillan.

Pallant, J. (2001). *SPSS survival manual- a step by step guide to data analysis using SPSS for Windows.* Buckingham, UK: Open University Press.

Pfeiffer, D. (2000). The devils are in the details: the ICIDH2 and the disability movement. *Disability & Society, 15* (7), 1079-1082. http://dx.doi.org/10.1080%2F713662020

Prilleltensky, I., Nelson, G., & Peirson, L. (2001). The role of power and control in children's lives: an ecological analysis of pathways towards wellness, resilience and problems. *Journal of Community and Applied Social Psychology, 11*, 143-158. http://dx.doi.org/10.1002%2Fcasp.616

Renwick, R., Brown, I. & Rafael, D. (2000). Person-centered quality of life: contributions from Canada to an international understanding. In K.D. Keith & R.L. Schalock (Eds), *Cross-cultural perspectives on Quality of Life* (pp. 5-22). Washington, D.C.: American Association on Mental Retardation.

Schalock R. L., & Keith K. D. (1993). *Quality of Life Questionnaire.* Worthington, OH: IDS Publishing Corporation.

Schalock, R. (2004). The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies, 14*(4), 204-215. http://dx.doi.org/10.1177%2F10442073040140040201

Schalock, R. L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R. L. Schalock (Ed.), *Quality of life: Volume I: Conceptualization and Measurement* (pp. 123-39). American Association on Mental Retardation, Washington, DC.

Schalock, R. L., & Verdugo, M. A. (2003). *Calidad de vida: manual para professionales de la educación, salud y servicios sociales.* Madrid, Spain: Alianza Editorial.

Sousa, J., Casanova, J.L., Pedroso, P., Moita, A., Gomes, A.T., Seiceira, F., Fabela, S. & Alves, T. (2007). *Mais qualidade de vida para as pessoas com deficiências e incapacidades – uma estratégia para Portugal.* Vila Nova de Gaia, Portugal: CRPG.

Stancliffe, R. J. (2001). Living with the support in the community: predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews, 7,* 91–98. http://dx.doi.org/10.1002%2Fmrdd.1013

Tate, D. G., Kalpakjian, C. Z., & Forchheimer, M. B. (2002). Quality of life issues in individuals with spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 83*(12 Suppl 2), S18–25. http://dx.doi.org/10.1053%2Fapmr.2002.36835

The World Health Organization Quality of Life Group (1995). The World Health Organization Quality of Life Assessment (WHOQOL): position paper from the World Health Organization. *Social Science Medicine, 41*, 1403-9.

Thompson, V.L., Noel, J.G., Campbell, J. (2004). Stigmatization, discrimination, and mental health: the impact of multiple identity status. *American Journal of Orthopsychiatry, 74*, 529-544. http://dx.doi.org/10.1037%2F0002-9432.74.4.529

Ubel, P., Loewenstein, G., & Jepson,C. (2003). Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. *Quality of Life Research 12*, 599–607.

Van Campen, C., & Iedema, J. (2007). Are persons with physical disabilities who participate in society healthier and happier? Structural equation modelling of objective participation and subjective well-being. *Quality of Life Research, 16*, 635–645. http://dx.doi.org/10.1007%2Fs11136-006-9147-3

Vash, C. (2004). Viewing disability through differing lenses: medical, political and psychological. *Rehabilitation Counselling Bulletin, 47(4*), 247-250. http://dx.doi.org/10.1177%2F00343552040470040601

Verdugo, M. A., Prieto, G., Caballo, C., & Peláez, A. (2005). Factorial Structure of the Quality of Life Questionnaire in a Spanish Sample of Visually Disabled Adults. *European Journal of Psychological Assessment, 21*(1), 44–55. http://dx.doi.org/10.1027%2F1015-5759.21.1.44

Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research, 49* (10), 707-717. http://dx.doi.org/10.1111%2Fj.1365-2788.2005.00739.x

Wagner, C., Armstrong, A., Frase, R., Vandergoot, D., & Thomas, D. (2006). Evidence-based employment practices in vocational rehabilitation. In Kristofer J. Hagglund & Allen W. Heinemann (Eds.), *Handbook of applied disability and rehabilitation research (pp.179-210).* New York, NY: Springer Publishing Company.

Ware, J. E., Kosinski, M., & Keller, S. D. (1996). A 12-item short-form health survey. *Medical Care, 34*(3), 220–233. http://dx.doi.org/10.1097%2F00005650-199603000-00003

Ware, J. E., Kosinski., & M. Keller, S.D. (2002). *How to score version 2 of SF-36 health survey.* Lincoln, RI: Quality Metric.

Wehmeyer, M. L., & Schalock, R. (2001). Self-determination and quality of life: Implications for special education services and supports. *Focus on exceptional children, 33*(8), 1-16.

Wehmeyer, M. L., & Schwartz, M. (1998). The relationship between self-determination, quality of life, and life satisfaction for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 33*, 3-12.

WHOQOL Group (1998). The World Health Organization Quality of Life assessment (WHOQOL): Development and general psychometric properties. *Social Science & Medicine, 46*, 1569-1585.

World Health Organisation (2001). *The International Classification of Functioning, Disability and Health*—icf. Geneve, Switzerland, WHO.

World Health Organisation (2004). *The World Health Organization Quality of Life (WHOQOL)-BREF* —icf. Geneve, Switzerland, WHO.

STUDY 2

Quality of life in disability: validation of the Schalock's multi-dimensional to the Portuguese context

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Quality of life in disability: validation of Schalock's multi-dimensional model to the Portuguese context

ABSTRACT. This paper aims to evaluate the validation of Schalock's quality of life multi-dimensional model (1996) in the Portuguese context. We also analyze the quality of life of disabled people by adding a political dimension (adapted from the *Minorities' Rights Support Scale* by Nata & Menezes, 2007) to this construct and seeking to understand the impact of discrimination. The sample is composed of 217 participants, most of whom have a physical disability, aged 16 to 81. Validation procedures of the *Quality of Life Questionnaire* (Schalock & Keith, 1993) and descriptive statistics and correlation analysis were conducted. Confirmatory Factor Analysis revealed good local and global fit indices, and the internal consistency of the scales was satisfactory. An adapted version of the instrument composed of five scales—satisfaction, competence, empowerment, equality of rights and positive discrimination—is proposed. The results reveals the importance of rights and empowerment for the quality of life of disabled people and indicate a strong critical consciousness concerning the experience of discrimination in different contexts. Taken together, the findings indicate the strong need for social and political changes in this domain.

Keywords: quality of life, disability, discrimination, sociopolitical model, rights.

Introduction

A medical/individual perspective has been prevalent in quality of life research in the field of disability. Within this rubric, individuals' quality of life with a disability has been placed in the field of pathology and deficit. Based on the assumption that the absence of a medical condition constitutes in itself a better quality of life (Cummings, 2001; Huppert & Whittington, 2003) and that there is a dichotomy between health and illness, disability fails to fulfill the criteria for 'normality' (De Mayer, Vanderplasschen, & Broekaert, 2008; Pfeiffer, 2000).

Moreover, the concept of 'health-related quality of life' has been widely used in disability research. This concept is assessed by evaluating the 'normality' of an individual's mental and physical health and their influence on the individual's functioning (e.g. Farquhar, 1995; WHO, 2001; Ware, Kosinski, & Keller, 2002; Cummins, 2000). This assessment has often been executed using the *Short Form Health Survey–36* (SF-36) and the *Short Form Health Survey–12* (SF-12) (Ware, Kosinski, & Keller, 1996; Garratt, Schmidt, Mackintosh & Fitzpatrick, 2002).With these instruments, the 'abnormality' of the disabled individuals' physical condition is tested (Tate, Kalpakjian, & Forchheimer, 2002; Hays, Hahn, & Marshall, 2002) based on their ability to accomplish two feats: move a table or climb stairs (Huppert & Whittington, 2003).

This emphasis on the 'normality' of physical and mental functionality neglects the possibility of an individual's well-being in the presence of his/her impairment. Similarly, the medicalization of disability and the consequent authority granted to health professionals has been a disabling factor in peoples' lives (Pfeiffer, 2000). Empirical evidence reinforces this finding: accounts of disabled people suggest that, according to others, a life with a disability is not worth living (McCarthy, 2003). Furthermore, empirical data reflect a gap in the way that disabled individuals' quality of life is perceived by themselves and by the general population (Ubel, Loewenstein, & Jepston, 2003). This underestimation of disabled individuals' quality of life as a result of medicalization influences political decisions, which are largely based on economic factors and medical decisions. Health professionals and patients thus interpret health situations or physical conditions through the filter of the medical model of disability (Ubel et al*.*, 2003).

However, this model of medical assessment, which has produced academic research that attributes a sense of inferiority to disabled individuals' quality of life, has been strongly opposed by various models that emerged several decades ago. The disability movement has given rise to other models of disability that have supported broader opportunities for disabled people to participate in society (Wehmeyer & Schalock, 2001; Wehmeyer & Schwartz, 1998). Sociopolitical, rights and environmental models interpret disability in the interaction between the individual (impairment) and the context. Moreover, these models aim to attain a similar level of the quality of life for disabled and non-disabled citizens (Keith & Schalock, 2000).

Within a sociopolitical paradigm, the assessment of individuals' quality of life takes into account the respondents' priorities instead of one relying on normative comparisons (Joyce, McGee, & O'Boyle, 1999). One's personal, familial; community and societal well-being go well beyond the technological, scientific and medical developments conveyed by the medical model. Furthermore, the empowerment model replaces the normalizing movement when it advocates for person-centered planning and self-determination (Verdugo, Prieto, Caballo & Peláez, 2005).

Within this paradigm, Schalock and Verdugo (2002) and Schalock (2004) have arrived at a consensus concerning the key domains of an individual's quality of life. Interestingly, these key domains are consonant with the well-being domains proposed by Community Psychology. Well-being is considered at an individual, relational, community and social level (Nelson, Lord, & Ochocka, 2001; Prillentensky, Nelson, & Peirson, 2001). We can identify corresponding key domains for individuals' quality of life as identified by Schalock and Verdugo (2003) and Schalock (2004) in several studies[6]. As shown in Table 1, the domains of quality of life, such as self-determination, personal development, physical and emotional well-being and civil rights, correspond to domains of individual well-being; interpersonal relationships, family, social inclusion and leisure are related to one's relational well-being; and environmental circumstances (living conditions), material well-being and safety represent the dimension of community and social well-being.

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[6] The review of the studies on quality of life included the studies of Hughes, Hwang, Kim, Eisenman & Killian, 1995; WHO, 1995; Felce & Perry, 1996; Schalock, 1996; Cummins, 1997; and Gardner & Nudler, 1997; Getting & Bradley, 1997; Renwick, Brown & Rafael, 2000; and Ferdinand & Smith, 2003.

Table 1 – Quality of life's key domains and the well-being domains of Community Psychology

Domains of well-being in Community Psychology (Nelson, Lord, Ochocka, 2001; Prilleltensky, Nelson & Peirson, 2001)	- Individual well-being: personal control, choice, self-esteem, competence, autonomy, positive identity, civil rights; - Relational well-being: participation in social, community and political life; - Community and social well-being: opportunities to acquire basic resources through work, income and education and living conditions.
Key domains of quality of life (Schalock & Verdugo, 2003; Schalock, 2004)	- Self-determination, personal development, physical and emotional well-being, and civil rights; - Interpersonal relations, family, social inclusion, and leisure; - Environment (living conditions), material well-being and safety.

Of the many definitions of quality of life in the literature, one of the most commonly used is the World Health Organization's (WHO) definition. WHO defines Quality of Life as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL GROUP, 1998). In contrast to the bio-psychosocial perspective defended by WHO, Schalock and Verdugo (2003) define quality of life as the promotion of equal opportunities between people, regardless of their physical condition, thus espousing a sociopolitical perspective. Schalock's model of quality of life (1996) used in this empirical research considers this construct to be multidimensional, comprising the following aspects: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights.

In Portugal, there is one study of the quality of life of disabled people that was conducted by Sousa et al., 2007 (CRPG/ISCTE), comprising a sample of 15.005 disabled people. The results of this study revealed the importance of a sociopolitical dimension of a person's quality of life with a disability. The findings indicate that Portuguese disabled people have negative levels of quality of life in self-determination, personal development, physical and material well-being, rights and social inclusion. Moreover, the findings suggest that the social inequalities that disabled individuals experience in their access to training, work and income reveal discrimination and prejudice in the Portuguese society. However, this discrimination is not felt as such by disabled people, suggesting that there is a sense of conformity toward their situation and a diminished social consciousness because they do not regard disability as a social condition (Sousa et al., 2007).

This empirical study assesses the quality of life of disabled people according to a sociopolitical perspective. It proposes the following aims:

- to evaluate the validation of the Schalock's multidimensional model of quality of life (1996) in the Portuguese context through confirmatory factor analysis;
- to assess the adequacy of two new subscales—the equality of rights and positive discrimination from the *Minorities' rights support scale* (Nata & Menezes, 2007)—for the quality of life scale through confirmatory factor analysis;
- to examine levels of quality of life in their various dimensions (satisfaction, competence, empowerment, equality of rights and positive discrimination) and their correlations; and
- to assess the impact of discrimination on people's lives by probing the values concerning the existence, motives and contexts of discriminatory experiences and the level of discomfort felt, as well as the relationship between discrimination and quality of life.

Method

Participants

As described in table 2, the sample is composed of 217 participants: 149 men (69,00%) and 67 women (31,00%) between the ages of 16 and 81 (M=35,86; SD=12,60). Single participants account for 148 (69,80%), 55 (25,90%) are married and 9 (4,20%) are widow(er)s or divorced. Participants' sources of income include work (N=81; 39,70%), pensions/allowances and subsidies (N=95; 46,60%) or other sources (N=28; 13,70%). Regarding education, 11 (5,10%) cannot read or write, 80 (37, 20%) had completed the 9th grade, 82 (38,10%) had completed high school or a technical course and 42 (19,50%) had completed a degree or post-graduate studies.

As to their professional situation, 95 (44,60%) are employed or working students, 41 (19,20%) are unemployed, 30 (14,10%) are not actively employed and 47 (22,10%) are students or trainees.

With reference to the type of impairment, 107 (49, 30%) have a physical impairment, 6 (2,80%) have an intellectual impairment, 49 (22,60%) have a sensory impairment and 40 (18,40%) have multiple impairments. As to the origin of impairment, 89 (44,30%) of the participants noted a congenital cause and 112 (55,70%) noted an acquired cause.

Most of the participants use assistive devices: 25 (15,50%) use crutches or prostheses, 70 (43,50%) use a manual wheelchair and 16 (9,90%) use a power wheelchair. With respect to autonomy in daily life activities (eating, getting dressed, bathing), 122 (56,20%) have total autonomy in their daily life activities, 23 (10,60%) have a medium level of autonomy and 23 (10,60%) have reduced autonomy.

Table 2. *Characteristics related to socio-demographics and to impairment, mobility and autonomy*

Variable	*N*	Category	Mean/Frequency (percentage)
Gender	216	Men Women	149 (69,00) 67 (31,00)
Age	209		Mean = 35,86 *SD* = 12,60 Minimum = 16 Maximum = 81
Civil status	212	Single Married Widow(er)/divorced	148 (69,80) 55 (25,90) 9 (4,20)
Education degree		Illiterate Mandatory education–9th grade College degree/ Post-graduation	11 (5,10) 80 (37,20) 42 (19,50)
Professional situation	213	Employed/ working student Student/trainee Unemployed Not actively employed	95 (44,60) 47 (22,10) 41 (19,20) 30 (14,10)
Source of income	204	Work Subsidy/allowance Others	81 (39,70) 95 (46,60) 28 (13,70)
Type of impairment	202	Physical Sensorial Intellectual Multiple	107 (49,30) 49 (22,60) 6 (2,80) 40 (18,40)

Origin of impairment	201	Congenital	89 (44,30)
		Acquired	112 (55,70)
Assistive device	161	No assistive device	50 (31,10)
		Crutches/prostheses	25 (15,50)
		Manual wheelchair	70 (43,50)
		Power wheelchair	16 (9,90)
		Not applicable	47 (21,70)
Mobility	206	Own car	87 (40,10)
		Family or friend's car	50 (23,00)
		Public transportation	43 (19,80)
General autonomy	212	Reduced	52 (24,50)
		Medium	65 (30,70)
		Total	95 (44,80)
Autonomy on daily activities	216	Reduced	23 (10,60)
		Medium	23 (10,60)
		Total	122 (56,20)
		Not applicable	48 (22,10)

Assessment Instruments

Questionário de Qualidade de Vida (Questionnaire of Quality of Life) (QQV). The QQV is an adapted version of four scales. Most of the items are adapted from the *Quality of Life Questionnaire (QoL.Q)* (Schalock & Keith, 1993). Other items have been adapted from the scales *The World Health Organization Quality of Life–BREF* (WHO, 2004) and the *Disability Assessment Schedule* (WHO, 2001), which have been added to three original dimensions of the *QoL.Q* (satisfaction, competence, empowerment) (cf. Table 3). Two additional dimensions have been added to the QQV—equality of rights and positive discrimination—which were adapted from the *Minorities' Rights Support Scale* (Nata & Menezes, 2007) (cf. Table 3).

In his literature review, Cummins (1997) has found that the *QoL.Q* is the most frequently used scale in quality of life research. This scale was originally developed for people with intellectual disabilities and has primarily been used with that population (e.g., Lachapelle et al., 2005); however, it has also been used with visually impaired people (Verdugo, Schalock et al., 2005). The original *QoL.Q* uses an ordinal scale with three categories.

The Portuguese version was adapted by the authors and includes 33 items using a five-point Likert scale (1 for 'totally disagree' and 5 for 'totally agree'; for some items, 1 for 'decided totally alone' and 5 for 'someone totally decided for me'). The questionnaire includes the following dimensions: satisfaction (11 items, α= .79) (ex.: Generally speaking, my life is as I want it to be), competence/productivity (10 items, α= .86) (ex.: My work or what I carry out daily is important for me and for others), empowerment/independence (6 items, α= .687) (ex.: I can leave the house or get in whenever I want), equality of rights (3 items, α= .74) (ex.: Disabled people should have the same opportunities as everyone else) and positive discrimination (3 items, mean inter-item correlation= .231) (ex.: Disabled people should have special rights because they are discriminated against).

Table 3. *Dimensions, number of items and new items for the QQV*

Dimension	Number of items	New items and original scale used
Satisfaction	11	I can move around well in my neighborhood. (Disability Assessment Schedule, OMS, 2001) I'm satisfied with my personal relationships. (WHOQOL-BREF, OMS, 2004) I'm satisfied with my physical appearance. (Quality of Life Index, Ferrans & Power, 1984) I'm satisfied with my sexual life. (WHOQOL-BREF, OMS, 2004) I'm satisfied with my access to health care (WHOQOL-BREF, OMS, 2004) I'm satisfied with my health. (WHOQOL-BREF, OMS, 2004)
Competence	10	I consider myself competent in work/training. My colleagues in work/training treat me well. I'm satisfied with the abilities and experiences I have been acquiring in work/training. (Authors of the study)
Empowerment	6	Who decides the leisure activities you participate in? (Authors of the study)
New dimensions		*Minorities' Rights Support Scale* (Nata & Menezes, 2007)
Equality of rights	3	Disabled people should have the same opportunities as everyone else. If a disabled person does the same job as someone else, that person should receive the same salary. Disabled people should have the same rights as everyone else.

Positive Discrimination	3	Disabled people should have special rights because they are discriminated against (treated in a negative way by other people or society) Disabled people should have representation in parliament, city halls, local councils, etc., because they are a minority. Disabled people should receive concessions (subsidies, for example) to lead an independent life.

Escala da experiência de discriminação (Discriminatory Experiences Scale); EED. The EED is a version of '*The experience of discrimination scale*' (Thompson, Noel & Campbell, 1996, cited in Thompson, Noel & Campbell, 2004) adapted by the authors. It includes four items referring to the existence of an experience of discrimination ('Have you ever felt discriminated against?'), the motive for the discrimination (impairment, race, gender, age, socioeconomic status, religion, sexual orientation or others—with an option to be more specific), the contexts where the discrimination occurred (school, work or other—with an option to be more specific) and the degree of discomfort felt due to the experience, using a scale ranging from 1-5 (1 for 'none at all' and 5 for 'much').

Escala de Autonomia (Autonomy scale) (EA). The EA is a version of the questionnaires *Disability Assessment Schedule* (WHO, 2001) and *Participation Objective, Participation Subjective* (Brown, 2006) by the authors. It includes 7 items, 3 of which refer to daily activities (eating, getting dressed and bathing) and 4 to other activities, such as domestic activities, purchasing groceries, preparing/cooking meals and being on one´s own for several days. For each item, the question is whether the participants can carry out the task on their own or if they require assistance (and, in that case, if the assistance is total or partial and whether it is available).

Design and Procedure

The snowball sampling method was used (Maroco, 2007) due to the difficulties in accessing this socially excluded population. Disability organizations were contacted, as well as personal contacts (one of the researchers is part of the disability community); they were encouraged to respond to the questionnaire and to spread the word about the study. Before administering the questionnaire, a discussion was carried out with four persons with physical disabilities who had different socio-demographic features. These individuals provided suggestions on how to improve the items' comprehensiveness.

The criterion for including participants in the study was the existence of impairment; in the case of an acquired impairment, it needed to have occurred at least one year prior. Participants were required to be at least 16 years old.

The questionnaire was administered both on-line and on paper[7] and it guaranteed anonymity. Information regarding the time required to fill out the questionnaire, its aim, its target population and the contact information of the research team was available. The administration of the questionnaire took place from August 2008 to February 2009.

Statistical analyses

Confirmatory factorial analysis using the EQS 1.6 program was conducted for validation purposes. First, an analysis of local fit for each of the quality of life dimensions (satisfaction, competence, empowerment, social integration, equality of rights and positive discrimination) was carried out. Second, a first- and second-order CFA global model fit was tested to determine which model revealed a better goodness-of-fit. Furthermore, Cronbach's alpha coefficient and mean inter-item correlation analyses were executed to test the instrument's internal consistency.

Descriptive and correlational analyses were carried out using the program SPSS 19. Analyses of means and standard deviations for the four quality of life dimensions

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[7] Of the entire sample, 27% completed the on-line questionnaire and 73% completed the paper version. Chi square analyses of different socio-demographic variables were conducted, and significant differences were revealed between the on-line/paper questionnaires, the participants' professional situation (x^2 (3) = 23,72, $p < .001$) and the type of transportation used (x^2(3) = 8,64, $p < .05$). The inactive participants used the on-line form of the questionnaire more frequently (27, 1%) than the paper form (9, 1%). The participants who used public transportation (25,4%) and owned a car (49,2%) used the on-line form more frequently (17,7%) than the paper form (36,7%). T-tests were also carried out, revealing significant differences between two dimensions: participants using the paper form scored higher on the satisfaction dimension (M = 3,60; SD = .64) than those using the on-line form (M = 3,17; SD = .58). In addition, differences were found in the competence in work/training dimension (paper form respondents: M = 3,99; SD = .82 and on-line respondents M = 3,62; SD = .81). The magnitude of the differences was moderate in the satisfaction score (*eta-squared* = .09) and low in the competence score (*eta-squared* = .04) (Cohen, 1988).

were conducted. The Kolmogorov-Sminorv Test was used to test the normal distribution of the sample, which revealed an abnormal distribution for all dimensions aside from the dimension of satisfaction. With this type of distribution, Spearman’s Rank Order Correlation was chosen to analyze correlations between the quality of life dimensions. The impact of discrimination on participants' lives was examined with descriptive analyses, including frequencies and percentages related to discrimination (experience, motive, context, and degree of discomfort). Spearman’s Rank Order Correlation was conducted to study the relationship between discrimination and quality of life.

Results

Confirmatory factor analysis (CFA)

The original version of the *QoL.Q* (Shalock & Keith, 1993) includes 40 items and has four dimensions: satisfaction, competence/productivity, empowerment/independence and social integration. Confirmatory Factor Analysis revealed good local fit indices for each of the dimensions except for social integration, which was removed from the scale due to its inadequate fit indices ($\chi^2_{(5)} = 72.06$, $p < .001$; CFI = .69; RMSEA = .26) (cf. Table 4). Of the six items that comprised this dimension, only three remained after depuration proceedings, and they were related to participation in associations/recreational activities.

It was thus necessary to carry out depuration proceedings, i.e., to remove items from all sub- scales. This removal was based on the factor loading of each item, redundancy and/or ambiguity. The criteria for removal were a low factor loading (under 0.35) and a consequent improvement of fit indexes once removed. Correlations between error variances of some items were performed using the criterion of semantic similarity between those items (Byrne, 2006). The robust version (Byrne, 2006) was chosen for all dimensions, as it was found to be more suitable due to the abnormality of distribution.

Table 4. *Results from CFA: fit indices and descriptions of modifications*

Scales	*$S\text{-}B_X^2$ (gl)*	*CFI*	*RMSEA*	*IC 90%*
Satisfaction	67,02 (43)**	.93	.05	[.03-.08]
Modifications: removal of items sat8, sat9 and saud14 and error variances correlation of items sat2 and sat6.				
Competence	35,44 (33)*	.98	.05	[.00-.14]
Modifications: removal of item trab15 and error variances correlation of items trab18 and trab24 and between trab20 and trab21.				
Social integration	72,06 (5)***	.69	.26	[.21-.31]
Modifications: removal of items soc33, soc34, soc35, soc37, soc38 and soc39.				
Empowerment	10,05 (9)*	.98	.03	[.00-.09]
Modifications: removal of items quot24_R, quot28 and quot29_R.				
Equality of rights	.1257 (1) ns	1	.00	[.00-.13]
Modifications: correlation between error variances of items dir40 and dir41.				
Positive Discrimination	1,64 (1) ns	.98	.06	[.00-.20]
Modifications: removal of item dir45.				

* $p < .05$; ** $p < .01$; *** $p < .001$; ns (not significant)

Afterwards, the first-order (global) model's fit was tested, and in some dimensions, items were randomly parceled (in 2 or 3 parcels, according to the number of items) to achieve a parsimonious and justified model (for further details on the advantages of using parceling, see Little, Cunningham, Shahar, & Widaman, 2002). The test of first-order global fit with factor analysis shows good fit indices ($\chi^2_{(17)} = 14.62$ ns; CFI = .93; RMSEA = .00) (cf. Table 5). This finding reveals that the model is multidimensional. The diagram regarding the first-order global fit is displayed in figure 1.

The goodness-of-fit of the second-order (global) model was also tested (cf. Table

5), and the AIC values (Akaike's Information Criterion) of both models were compared to determine which presented the lowest value, thus revealing the best-fitted model (Hu & Bentler, 1995). The value for the second-order global model (-40.26) is higher than the value of the first-order model (-10.84), which confirms the multidimensionality of the model.

Table 5. Results from CFA: first- and second-order model fit; fit indices and AIC scores

	X^2 *(df)*	*CFI*	*RMSEA*	*AIC*
First-order model fit	14,6163 (17) ns	.93	.00	-10,84
Second-order model fit	103,74 (72)**	.92	.06	-40,26

** p < .01; ns (not significant)

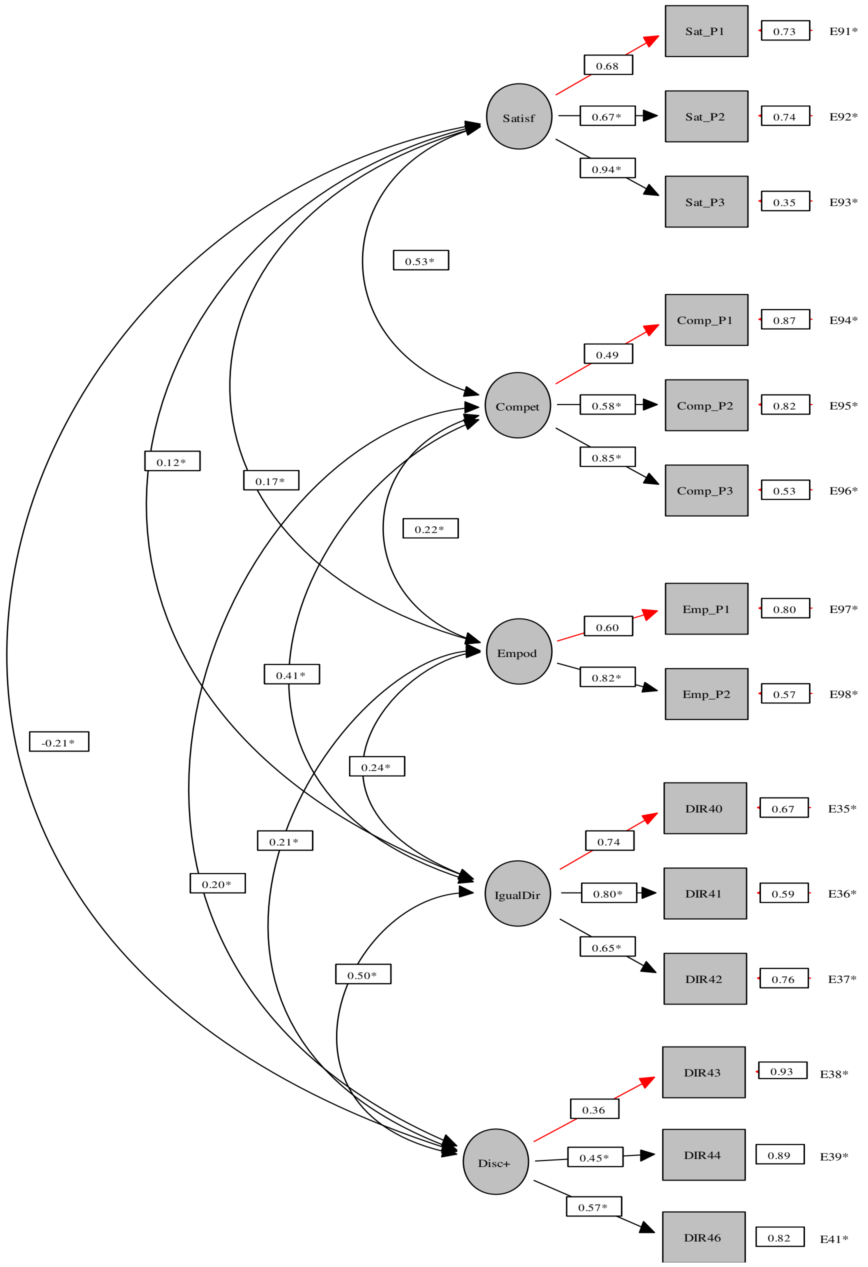

Figure 1 – First-order global model–5-dimension-structure and factor loadings.

Satisf = Satisfaction; Compet = Competence; Empod = Empowerment; IgualDir = Equality of rights; Disc+ = Positive discrimination.

Reliability analysis

The sub-scales of quality of life have good internal consistency with Cronbach's alpha coefficients reported between .859 and .687 (cf. Table 6). Moreover, positive discrimination has a good internal consistency with the mean inter-item correlation reported to be .231 (in the range of .2 - .4) (Briggs & Cheek, 1986) (cf. Table 6). We chose to use the mean inter-item correlation for positive discrimination because the Cronbach's alpha coefficient is more sensitive to the number of scale items; using the mean inter-item is therefore more adequate (Pallant, 2001).

Table 6. Values of internal consistency (Cronbach's alpha coefficient) and mean inter-item correlation, means and standard deviations of the dimensions

Dimensions	Number of items	*Cronbach's alpha coefficient/ Mean inter-item correlation*	*M*	*SD*	*n*
Satisfaction	11	$\alpha = .794$	3,49	.66	217
Competence	10	$\alpha = .859$	3,89	.83	211
Empowerment	6	$\alpha = .687$	4,20	.75	217
Equality of rights	3	$\alpha = .737$	4,67	.67	216
Positive discrimination	3	*Mean inter-item correlation =* .231	3,96	.88	215

Dimensions of quality of life

As displayed in Table 6, equality of rights (M = 4.67, SD = .67) and empowerment (M = 4.20, SD = .75) are the dimensions with the highest means, followed by positive discrimination (M = 3.96, SD = .88), competence (M = 3.89, SD = .83) and satisfaction (M = 3.49, SD = .66).

The relationships between dimensions of quality of life were investigated using Spearman's Rank Order Correlation. There is a moderate positive correlation ($r = .447$, $p < .001$) (Bryman & Cramer, 2003) between satisfaction and competence in work/training, and this correlation has the highest value (cf. Table 7), with high levels of satisfaction in life associated with high levels of competence in work/training. Additionally, there is a positive correlation (r = .183, p < .001) between competence in work/training with equality of rights (cf. Table 7).

Empowerment is significantly and positively correlated with satisfaction (r = .152, p < .01) and with equality of rights (r = .277, p < .001), with high levels of empowerment associated with high levels of satisfaction in life and equality of rights. Finally, equality of rights is correlated with positive discrimination (both are dimensions of rights), with high levels of equality of rights associated with high levels of positive discrimination (r = .159, p < .01) (cf. Table 7). This finding implies that the more people advocate equal rights, the more they also advocate positive discrimination. Except for the correlation between satisfaction and competence in work/training, all other correlations reveal low scores (Bryman & Cramer, 2003).

Table 7. Spearman's correlations between dimensions

	1	2	3	4	5
(1) Satisfaction	1				
(2) Competence	.447*** (n=211)	1			
(3) Empowerment	.152** (n=217)	.107 (n=211)	1		
(4) Equality of rights	.008 (n=216)	.183*** (n=210)	.277*** (n=216)	1	
(5) Positive discrimination	-.048 (n=215)	-.038 (n=209)	.119 (n=215)	.159** (n=215)	1

* p < .05; ** p < .01; *** p < .001

Impact of discrimination

The impact of discrimination was analyzed with the use of descriptive statistics regarding the existence, motive, contexts and discomfort level experienced (cf. Table 8). The relationship between the dimensions of quality of life and discrimination was investigated using Spearman's Rank Order Correlation (cf. Table 9).

Table 8. Frequencies and percentages of responses related to the existence, motive and contexts of discrimination; mean and standard deviation of the degree of discomfort with discrimination

	Frequency	%
Existence:		
Yes	145	67,40
No	70	32,60
Motive:		
Impairment	125	57,60
Race	1	.50
Age	1	.50
Gender	1	.50
Sexual orientation	1	.50
Economic status	5	2,30
Contexts:		
School	53	37,90
Work	46	33,10
Family	8	5,80
Friends	14	10,10
Health services	20	14,40
Degree of discomfort	Mean 3,78	Standard deviation 1,168

As displayed in table 8, 67.40% (n = 145) of the participants have been discriminated against by people or society. Impairment is the primary underlying motive for discrimination (57.80%, n = 125), as other motives have low levels of expression (n < 5). School (37.90%, n = 53) and work (33.10%, n = 46) are the main contexts of discrimination, followed by health services (14.40%, n = 20). Discrimination experienced in personal relationship with friends (10.10%, n = 14) and family (5.89, n = 8) is less frequent than the contexts mentioned above. The mean score of discomfort level is 3.78 (SD = 1.168).

Table 9. Spearman's correlations between discrimination with dimensions of quality of life

	Discrimination
Satisfaction	-.209** (n=215)
Competence	-.102 (n=209)
Empowerment	-.237** (n=215)
Equality of rights	-.092 (n=214)
Positive discrimination	-.041 (n=214)

p* < .05; ** *p* < .01; * *p* < .001

Spearman's correlation analysis between the quality of life dimensions and discrimination reveal a negative correlation with satisfaction (r = -.209, p < .005) and empowerment (r = -.237, p < .05), with high levels of discrimination associated with low levels of satisfaction and empowerment (cf. Table 9).

Discussion

This empirical research aimed to evaluate the validation of Schalock's multidimensional quality of life model in the Portuguese context. It also intended to analyze the quality of life of disabled people from a sociopolitical perspective, along with the impact of discrimination.

As to the first aim of the study, CFA analyses revealed adequate fit indices; therefore, the validation procedures of the *QoL.Q* for the Portuguese sample were satisfactory. The goodness-of-fit statistics obtained through the CFA procedure, as well as the internal consistency scores, indicate that the final model structure is stable and valid. Removing the sub-scale of social integration is a relevant aspect of this procedure worthy of further analysis.

Verdugo, Schalock et al (2005), in their study of a sample of blind Spaniards, conducted CFA and found that the four original dimension model lacked goodness-of-fit; additionally, the exploratory factor analysis revealed a three-dimensional model in which 'social integration' was excluded. This dimension was also removed in our study. Only the items related to participating in associations/leisure activities obtained acceptable factor loadings. However, we chose to remove this dimension because these items did not seem to accurately reflect social integration when considering the habits of the Portuguese population. Indeed, a comparative study of 23 EU countries concerning attitudes toward life (Nata & Menezes, 2010) concluded that Portugal is the country with the highest level of sociability; however, Portugal obtained a negative mean score in community involvement, a concept defined by participation in charity or volunteer organizations or in organized activities in the area of residence. As in Spain, Portugal has no established tradition of participation in civic organizations or associations, which may be related to its late democratic transition (Nata & Menezes, 2010). Therefore, due to cultural differences, the dimension of social integration revealed poor fit with respect to a Portuguese sample, whereas the remaining dimensions demonstrated an adequate local fit.

Two important conclusions can be stated concerning the validation of the instrument. The first is related to its multi-dimensional nature; the tested model, which includes 5 factors, has proven to be multi-dimensional, given the fact that when conducting a comparison of scores of AIC, the fit of the first-order global model displayed more adequate fit indices than the second-order global model (Byrne, 2006). The second conclusion relates to the fact that the dimensions of equality of rights and positive discrimination—as proposed by the authors—can be included in this model. Thus, a multi-dimensional model of quality of life composed of five dimensions—satisfaction, competence, empowerment, equality of rights and positive discrimination—fits the Portuguese population, demonstrating the importance of using two sub-scales of rights when measuring individuals' quality of life with a disability.

The second aim of this research was to analyze the quality of life of disabled people from a sociopolitical perspective, accounting for the impact of discrimination. A starting point for this analysis pertains to the dimensions related to participants' satisfaction in life. First, the correlation between satisfaction in life with competence in work/training proved to be the strongest and seems to reflect the importance of positive perceptions about competence in a professional domain. Work is one of the factors with a major impact on the social and material well-being of disabled people (Barnes, Mercer, & Shakespeare, 2005). Additionally, work presents a systematic advantage associated with a substantial reduction in expenses with subsidies/allowances and other services provided by the state (O'Brien & Dempsey, 2004). Understandably, disabled individuals' perception of competence in work/training is highly related to their satisfaction in life. This finding is similar to what Verdugo, Schalock et al. (2005) found with Spaniards with visual impairment, which led these authors to suggest that services for disabled people should focus on interventions promoting the perception of competence in the professional/training area. However, there are numerous obstacles to employment for disabled people, namely physical barriers in buildings, lack of knowledge and the existence of prejudice (Instituto de Emprego e Formação Profissional, 2004). In this study, the results reveal a significant positive correlation between equality of rights with the sense of competence in work/training and a high frequency of discriminatory experiences in the employment context. These findings suggest that an individual focus on promoting employability or perception of competence is insufficient; instead, a broad intervention is required to change the attitudes and practices of employers and the society as a whole. Moreover, employment and training services for disabled people should focus on the promotion and assurance of equality of rights in the workplace (Wagner, Armstrong, Frase, Vandergoot & Thomas, 2006).

In addition to its correlation with competence in work/training, empowerment is also associated with satisfaction in life. The correlation between self-determination (including 5 items of the original sub-scale of empowerment) with satisfaction found by Verdugo, Schalock et al. (2005) has also been proven to exist in our study. In addition, one might theorize about the influence that the type of impairment has upon the concepts that reflect the individual's reality. For example, in the study by Verdugo, Schalock et al. (2005) with a sample of blind Spaniards, the concept of self-determination was chosen instead of the construct of empowerment. In the present study, the dimension of empowerment is adequate for the sample and is associated with equal rights, which in turn are correlated with positive discrimination. These results suggest that power and being in control of one's life is associated with a political dimension, which, while referenced in Schalock's model (1996), had no concrete expression in the *QoL.Q*.

To fully address the impact of discrimination on the quality of life of disabled people, we must examine some findings more closely. First, the significant negative correlation between empowerment and discrimination prompts us to consider the relevance of a rights' dimension in promoting and assessing the empowerment of disabled people (due to the correlation mentioned above). In addition, a high frequency level of discrimination based on disability has been experienced by more than half of the sample in such important contexts as school and work while participants reveal a high mean score for empowerment. This finding might signify that the quality of life of Portuguese disabled people is determined by individual empowerment rather than by their access to and use of empowering social structures and social attitudes.

In fact, discrimination occurs so often in disabled people's everyday life (e.g., Gilson & De Poy, 2002; McCarthy, 2003) that it is regarded as a profound structural violence; it has a marked negative impact on the well-being of disabled people, their families and communities (Stancliffe, 2001). This research reveals both a significant negative correlation between discrimination and satisfaction as well as a high score mean in the discomfort felt in discriminating experiences. This finding seems to demonstrate the severe impact that discrimination has on people's lives. Considering this discriminatory framework, the high level of consensus concerning the importance of equality of rights is easily understandable and clearly addresses the need felt by disabled people to be recognized as equal to all other citizens.

In conclusion, this empirical study reveals that disabled individuals' quality of life is marked by the relationship between their satisfaction in life and their perception of competence in their work/training and their degree of empowerment. The results regarding empowerment suggest that disabled people only have an individual level of empowerment, as more than half of the participants report high levels of discrimination in contexts that are fundamental for social inclusion and that cause a significant psychological impact. The participants' high level of consensus on the subject of equal rights, as well as the association between this political dimension and empowerment, should cause us to reflect on the urgent need to promote a critical political consciousness on disabled individuals' quality of life and the discrimination to which they are exposed.

It is therefore critical to take into account the relevance of rights and empowerment in promoting disabled individuals' quality of life instead of focusing on personal tragedy (Oliver, 1990) and biological determinism (Barnes et al, 2005), which 'blam[e] the victim' (Nelson & Prillentensky, 2005) and perpetuate the oppression of disabled people through sociopolitical means (Meekosha, 2004). Power and being in control of one's life—which are important to every human being—should not be understood as imposing on someone else. Instead, power is a matter of mutual responsiveness that should exist in the various contexts of a person's life (Herrmann, 2005).

We thus question whether the medical model is able to promote the quality of life of disabled people (Vash, 2004; Van Campen & Iedema, 2007). By reassessing the medicalization of disability (Barton, 1993), this model engenders policies that build barriers by assuming that personal and misfortunate circumstances create obstacles (Barnes et al, 2005). Studies on disabled individuals' quality of life should take into account the barriers and discrimination that disabled people face throughout their lives. These studies should also include a political dimension to unveil the dimensions that influence satisfaction in life and not just the perceptions thereof.

Some limitations of the present study will now be discussed. First, the fact that we used an instrument that was originally developed for subjects with intellectual disabilities on a group of participants with various types of impairments (mainly physical) should be taken into consideration. Although the instrument has proven to be adequate, it is possible that the type of impairment plays an important role in an individual's quality of life. Therefore, future research focusing on physical disabilities is important for better understanding the quality of life of this population.

A limitation of this study may be the abnormal distribution of the sample and the bias it might reflect; it may not be representative of the disabled Portuguese population. This distribution was to be expected, as it reflects the social conditioning that disabled people face. Our sample was the one we managed to gain access to, thus representing a part of the disabled population that has achieved some degree of social inclusion. We tried to overcome one of the conditioning factors that society imposes on disabled people, such as physical inaccessibility, with an on-line questionnaire. Nevertheless, the fact remains that we have not reached a significant number of disabled people who are not integrated in society and who do not have access to it. Future studies should attempt to overcome this limitation.

Finally, this study reveals that disabled individuals' quality of life should be understood in a sociopolitical context, promoting equality (Schalock & Verdugo, 2003) and conceptualizing disability as resulting from the interaction between an individual and the society. This understanding implies that it is everyone's responsibility to promote a good quality of life and respect for the civil rights of disabled people.

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REFERENCES

Barnes, C, Mercer, T., & Shakespeare, T. (2005). *Exploring disability: A sociological introduction,* (2nd Ed.), Cambridge, UK: Polity Press.

Barton, L. (1993). The struggle for the citizenship: the case of disabled people. *Disability and Society, 8(3)*, 236-248. http://dx.doi.org/10.1080%2F02674649366780251

Briggs, S. R., & Cheek, J. M. (1986). The role of factor analysis in the development and evaluation of personality scales. *Journal of Personality, 54,* 106-148. http://dx.doi.org/10.1111%2Fj.1467-6494.1986.tb00391.x

Brown, M. (2006). Participation Objective, Participation Subjective. *The Center for Outcome Measurement in Brain Injury*. http://www.tbims.org/combi/pops (accessed December 27, 2012).

Bryman, A., & Cramer, D. (2003). *Análise de dados em ciências sociais. Introdução às técnicas utilizando o SPSS para windows* [Quantitative Data Analysis for Social Scientists:

introduction to the techniques using the SPSS for Windows] (3rd Ed.). Oeiras, Portugal: Celta.

Byrne, B. M. (2006). *Structural equation modelling with EQS: Basic concepts, applications, and programming.* (2nd Ed.). Mahwah, NJ: Lawrence Erlbaum Associates.

Cohen, J. (1988). *Statistical power analysis for the behavioural sciences.* Hillsdale, NJ, Erlbaum.

Cummins, R. A. (1997). Self-rated quality of life scales for people with an intellectual disability: a review. *Journal of Applied Research in Intellectual Disabilities 10*, 119–216. http://dx.doi.org/10.1111%2Fj.1468-3148.1997.tb00017.x

Cummins, R. A. (2000). Objective and subjective quality of life: An interactive model. *Social Indicators Research, 52,* 55–72.

Cummins, R. A. (2001). Self-rated quality of life scales for people with an intellectual disability: a reply to Ager & Hatton. *Journal of Applied Research in Intellectual Disabilities 14*, 1–11. http://dx.doi.org/10.1046%2Fj.1360-2322.2001.00057.x

De Mayer, J., Vanderplasschen, W., & Broekaert, E. (2009). Exploratory Study on Drug Users' Perspectives on Quality of Life: More than Health-Related Quality of Life? *Social Indicators Research, 90*, 107–126. http://dx.doi.org/10.1007%2Fs11205-008-9315-7

Farquhar, M. (1995). Definitions of quality of life: a taxonomy. *Journal of Advanced Nursing, 22,* 502–508. http://dx.doi.org/10.1046%2Fj.1365-2648.1995.22030502.x

Felce, D. & Perry, J. (1996). Assessment of quality of life. In Schalock R.L. (Ed.), *Quality of Life: Volume I: Conceptualization and Measurement (pp. 63-73).* Washington, DC.: American Association on Mental Retardation.

Ferdinand, R. & Smith, M.A. (2003). *Nebraska Developmental Disabilities Provider Profiles.* Nebraska, Lincoln: The Arc of Nebraska.

Gardner, J. F. & Nudler, S. (1997). Beyond compliance to responsiveness: accreditation reconsidered. In Schalock, R.L. (Ed.), *Quality of Life: Volume II: Application to Persons with Disabilities (pp. 135-48).* Washington, DC.: American Association on Mental Retardation.

Garratt, A., Schmidt, L., Mackintosh, A., & Fitzpatrick, R. (2002). Quality of life measurement: bibliographic study of patient assessed health outcome measures. *BMJ, 324*, 1417–1419. http://dx.doi.org/10.1136%2Fbmj.324.7351.1417

Gettings, R. M. & Bradley, V. J. (1997). *Core Indicators Project.* Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

Gilson, S., & DePoy, E. (2002). Theoretical approaches to disability content in social work education. *Journal of Social Work Education, 38*, 153-165.

Hays, R. D., Hahn, H., & Marshall, G. (2002). Use of the SF-36 and other health-related quality of life measures to assess persons with disabilities. *Archives of Physical Medicine and Rehabilitation, 83*(12 Suppl 2), S4–9. http://dx.doi.org/10.1053%2Fapmr.2002.36837

Herrmann, P. (2005). Empowerment: the core of social quality. *European Journal of Social Quality, 5 (1/2)*, 289-299. http://dx.doi.org/10.3167%2F146179105780337558

Hu, L.-T., & Bentler, P. M. (1995). Evaluating model fit. In R. H. Hoyle (Ed.), *Structural equation modeling: Concepts, issues, and applications* (pp. 76-99). Thousand Oaks, CA, Sage.

Hughes, C., Hwang, B., Kim, J., Eisenman, L. T. & Killian, D. J. (1995). Quality of life in applied research: a review and analysis of empirical measures. *American Journal on Mental Retardation, 99*, 623-41.

Huppert, F., & Whittington, J. (2003). Evidence for the independence of positive and negative well-being: implications for quality of life assessment. *British Journal of Health Psychology, 8*, 107-122. http://dx.doi.org/10.1348%2F135910703762879246

Instituto de Emprego e Formação Profissional (2004). Valor acrescentado do Trabalhador com (d)eficiência [Added value of the worker with (dis)abilities]. Lisboa, Portugal: Palmigráfica.

Joyce, C. R. B., McGee, H. M., & O'Boyle, C. A. (1999). *Individual Quality of Life: Approaches to Conceptualization and Assessment.* Australia, AU: Harwood.

Keith, K. D., & Schalock, R. L. (2000). *Cross-cultural Perspectives on Quality of Life.* Washington DC, American Association on Mental Retardation.

Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M.-C., Courbois, Y., Schalock, K., Verdugo, M. A., & Walsh, P. N. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research, 49,* 740–744. http://dx.doi.org/10.1111%2Fj.1365-2788.2005.00743.x

Little, T. D., Cunningham, W. A., Shahar, G., & Widaman, K. F. (2002). To parcel or not to parcel: Exploring the question, weighing the merits. *Structural Equation Modeling, 9*, 151-173. http://dx.doi.org/10.1207%2FS15328007SEM0902_1

Maroco, J. (2007). *Análise estatística – com utilização de SPSS* [Statistical analysis – using the SPSS]. Lisboa, Portugal: Edições Sílabo.

McCarthy, H. (2003). The disability rights movement: experiences and perspectives of selected leaders in the disability community. *Rehabilitation Counseling Bulletin, 46,* 209–223. http://dx.doi.org/10.1177%2F003435520304600402

Meekosha, H. (2004). Drifting down the Gulf Stream: navigating the cultures of disability studies. *Disability & Society, 19* (7), 721-733.http://dx.doi.org/10.1080%2F0968759042000284204

Mooney, A. (2006). Quality of life: Questionnaires and questions. *Journal of Health Communication, 11*, 327–341. http://dx.doi.org/10.1080%2F10810730600614094

Nata, G., & Menezes, I. (2007). Escala de Suporte dos Direitos das Minorias [Minorities' Rights Support Scale], In *Diferença Cultural e Democracia: identidade, cidadania e tolerância na relação entre maioria e minorias* [Cultural Difference and Democracy: identity, citizenship and tolerance between the majority and the minorities] (Doctoral dissertation). Faculty of Psychology and Educational Sciences of University of Porto, Porto, Portugal.

Nata, G., & Menezes, I. (2010). Ciclos de vida e atitudes perante a vida: satisfação com a vida, religiosidade e redes de relações sociais. [Life cycle and attitudes towards life: satisfaction with life, religiousness and social networks]. In José Machado Pais & Vítor Sérgio Ferreira (Eds.), *Tempos e transições de vida: Portugal ao espelho da Europa* [Times and life transitions: Portugal in the mirror of Europe] (pp.225-254). Lisboa, Portugal: Imprensa de Ciências Sociais.

Nelson, G., & Prilleltensky, I. (2005). *Community Psychology: in pursuit of liberation and well-being.* New York, NY: Pallgrave MacMillan.

Nelson, G., Lord, J., & Ochocka, J. (2001). *Shifting the paradigm in community mental health: towards empowerment and community.* Toronto, Canada: University of Toronto Press.

O'Brien, J., & Dempsey, I. (2004). Comparative Analysis of Employment Services for People with Disabilities in Australia, Finland, and Sweden. *Journal of Policy and*

Practice in Intellectual Disabilities, 1, 3/4, 126–13. http://dx.doi.org/10.1111%2Fj.1741-1130.2004.04027.x

Oliver, M. (1990). *The politics of disablement.* Basingstoke, UK: McMillan.

Pallant, J. (2001). *SPSS survival manual- a step by step guide to data analysis using SPSS for Windows.* Buckingham, UK: Open University Press.

Pfeiffer, D. (2000). The devils are in the details: the ICIDH2 and the disability movement. *Disability & Society, 15* (7), 1079-1082. http://dx.doi.org/10.1080%2F713662020

Prilleltensky, I., Nelson, G., & Peirson, L. (2001). The role of power and control in children's lives: an ecological analysis of pathways towards wellness, resilience and problems. *Journal of Community and Applied Social Psychology, 11*, 143-158. http://dx.doi.org/10.1002%2Fcasp.616

Renwick, R., Brown, I. & Rafael, D. (2000). Person-centered quality of life: contributions from Canada to an international understanding. In K.D. Keith & R.L. Schalock (Eds), *Cross-cultural perspectives on Quality of Life* (pp. 5-22). Washington, D.C.: American Association on Mental Retardation.

Schalock R. L., & Keith K. D. (1993). *Quality of Life Questionnaire.* Worthington, OH: IDS Publishing Corporation.

Schalock, R. (2004). The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies, 14*(4), 204-215. http://dx.doi.org/10.1177%2F10442073040140040201

Schalock, R. L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R. L. Schalock (Ed.), *Quality of life: Volume I: Conceptualization and Measurement* (pp. 123-39). American Association on Mental Retardation, Washington, DC.

Schalock, R. L., & Verdugo, M. A. (2003). *Calidad de vida: manual para professionales de la educación, salud y servicios sociales.* Madrid, Spain: Alianza Editorial.

Sousa, J., Casanova, J.L., Pedroso, P., Moita, A., Gomes, A.T., Seiceira, F., Fabela, S. & Alves, T. (2007). *Mais qualidade de vida para as pessoas com deficiências e incapacidades – uma estratégia para Portugal* [More quality of life for people with disabilities and impairment – a strategy for Portugal].Vila Nova de Gaia, Portugal: CRPG.

Stancliffe, R. J. (2001). Living with the support in the community: predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews, 7,* 91–98. http://dx.doi.org/10.1002%2Fmrdd.1013

Tate, D. G., Kalpakjian, C. Z., & Forchheimer, M. B. (2002). Quality of life issues in individuals with spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 83*(12 Suppl 2), S18–25. http://dx.doi.org/10.1053%2Fapmr.2002.36835

The World Health Organization Quality of Life Group (1995). The World Health Organization Quality of Life Assessment (WHOQOL): position paper from the World Health Organization. *Social Science Medicine, 41*, 1403-9.

Thompson, V.L., Noel, J.G., Campbell, J. (2004). Stigmatization, discrimination, and mental health: the impact of multiple identity status. *American Journal of Orthopsychiatry, 74*, 529-544. http://dx.doi.org/10.1037%2F0002-9432.74.4.529

Ubel, P., Loewenstein, G., & Jepson,C. (2003). Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. *Quality of Life Research 12*, 599–607.

Van Campen, C., & Iedema, J. (2007). Are persons with physical disabilities who participate in society healthier and happier? Structural equation modelling of objective participation and subjective well-being. *Quality of Life Research, 16*, 635–645. http://dx.doi.org/10.1007%2Fs11136-006-9147-3

Vash, C. (2004). Viewing disability through differing lenses: medical, political and psychological. *Rehabilitation Counselling Bulletin, 47(4*), 247-250. http://dx.doi.org/10.1177%2F00343552040470040601

Verdugo, M. A., Prieto, G., Caballo, C., & Peláez, A. (2005). Factorial Structure of the Quality of Life Questionnaire in a Spanish Sample of Visually Disabled Adults. *European Journal of Psychological Assessment, 21*(1), 44–55. http://dx.doi.org/10.1027%2F1015-5759.21.1.44

Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research, 49* (10), 707-717. http://dx.doi.org/10.1111%2Fj.1365-2788.2005.00739.x

Wagner, C., Armstrong, A., Frase, R., Vandergoot, D., & Thomas, D. (2006). Evidence-based employment practices in vocational rehabilitation. In Kristofer J.

Hagglund & Allen W. Heinemann (Eds.), *Handbook of applied disability and rehabilitation research (pp.179-210).* New York, NY: Springer Publishing Company.

Ware, J. E., Kosinski, M., & Keller, S. D. (1996). A 12-item short-form health survey. *Medical Care, 34*(3), 220–233. http://dx.doi.org/10.1097%2F00005650-199603000-00003

Ware, J. E., Kosinski., & M. Keller, S.D. (2002). *How to score version 2 of SF-36 health survey*. Lincoln, RI: Quality Metric.

Wehmeyer, M. L., & Schalock, R. (2001). Self-determination and quality of life: Implications for special education services and supports. *Focus on exceptional children, 33*(8), 1-16.

Wehmeyer, M. L., & Schwartz, M. (1998). The relationship between self-determination, quality of life, and life satisfaction for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 33*, 3-12.

WHOQOL Group (1998). The World Health Organization Quality of Life assessment (WHOQOL): Development and general psychometric properties. *Social Science & Medicine, 46*, 1569-1585.

World Health Organisation (2001). *The International Classification of Functioning, Disability and Health*—icf. Geneve, Switzerland, WHO.

World Health Organisation (2004). *The World Health Organization Quality of Life (WHOQOL)-BREF* —icf. Geneve, Switzerland, WHO.

STUDY 3

Disability, embodiment and ableism: stories of resistance

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Disability, embodiment and ableism: stories of resistance

ABSTRACT. Non-disabled responses to visible impairment embody either social invisibility or over-attentiveness. The subjective and inter-subjective experiences of impaired bodies and intersubjective encounters within society are important aspects of disablement and the construction of a disabled identity. Impairment is read by and influences the social structure of ableism.

This paper attempts to understand how ableist discourses about impaired bodies have impacted on and been resisted by disabled people and how embodiment is related to identity. In pursuit of these aims, a qualitative study was conducted with seven people who have visible physical impairments. The results indicate that disabled embodiment is produced and experienced within an ableist context that mobilizes the charitable gaze and the medical model to signify impaired bodies at the expense of the recognition of disabled identity. In order to deconstruct ableism and recognize and respect the value of the disabled identity, a politics of recognition is required.

Keywords. Ableism, body politics, embodiment, identity, impaired bodies, recognition.

Introduction

'What counts as a legitimate body' (Shilling 1993:145) is a question that has been at the core of disability discourse. Disabled people have struggled with a corporeal identity that is predominately defined by a medical model that reduces it to abnormality (Zitzelsberger 2005) stressing the need for correction or normalization (Edwards and Imrie 2003). The medical gaze plays a crucial role in invalidating bodies that do not conform to the norm. Impaired bodies are regarded as abnormal, deviant, inferior and even sub-human (Campbell 2008). Furthermore, the prominence of bio-medical ideas in the public discourse on disability 'monopolizes not only physical capital but also political, symbolic and social capital, loosely corresponding to and operationalised on different social fields' (Gottfried 1998:459). Subjects are produced and placed 'within a hierarchy of bodily traits that determines the distribution of privilege, status, and power' (Garland Thomson 1997: 6). As Braidotti (1996 cit in Meekosha 1999) states, some bodies 'matter more than others: some are, quite frankly, disposable'. Disabled bodies epitomise the latter.

The social model of disability makes a clear distinction between impairment and disability. It rejects medical categories focusing on the elimination of prejudice and discrimination and defends self-determination, social integration and the civil rights of disabled people. The body is the site of physical disability (Stoer, Magalhães and Rodrigues 2005), but a number of academics have argued that the social model of disability has excluded it from disability discourse (Morris 1991; Hughes 2000; Patterson and Hughes 2000). In fact, the social model considers 'the impaired body untouched, unchallenged: a taken-for-granted fixed corporeality' (Meekosha 1998:175) and ' . . . within disability studies the term 'body' tends to be used without much sense of bodiliness as if the body were little more than flesh and bones' (Paterson and Hughes 1999:600).

However, debate about the body and impairment is re-emerging within the disability movement (e.g. Shakespeare 1992; French 1993). The movement has been recovering this lost corporeal space, and as Hughes and Paterson (2006:101) emphasize 'disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning'.

To bring ‘bodies back in’ (Zola 1991:1) or to recognize how corporeal practices ‘produce and give a body its place in everyday life’ (Turner 2001: 259) are questions fundamental to the disability project. In order to validate the impaired body within disability studies, Campbell (2001:44) has defined ableism as: ‘a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human.’ Ableism imposes a corporeal standard, the falling away from which represents the pathway to disability (Campbell 2009), which for disabled people produces two consequences: the distancing of disabled people from each other and the emulation by disabled people of ableist norms (Campbell 2008).

The body politics of Critical Disability Studies that ableism envisages, offers valuable ways to theorize disability and challenge disability oppression (e.g. Corker 1999; Hughes 1999). Furthermore, the politics of difference can be an important lens for destabilizing ableism because it legitimates not sameness but human variation (Jones 2006). As Taylor (1994) says, the politics of difference is about recognizing ‘the equal value of different ways of being’, and moving to a tradition concerned with rights to secure positive recognition, albeit symbolically, for minority identities (Galeotti 2002). The social struggle of disabled people understood as a struggle for ‘recognition’ (Honneth 1995a, b), embodies the deconstruction of ableism and the celebration of difference.

This paper intends to understand how ableism has been imposed, incorporated, negotiated and resisted by disabled people and how embodiment is related to identity in an able-bodied (or ableist) culture.

Methods

The study was conducted in Portugal. We note that, in recent years, there have been some changes in social attitudes to disability in Portugal. Nevertheless, most disabled people live in a social context in which a paradigm of personal tragedy dominates social relations between disabled and non-disabled persons, disempowering the former. Furthermore, a remediation model of disability dominates the forms of welfare provision that are extended to disabled people (Loja, Costa and Menezes 2011).

Participants included four men and three women and they were selected using a 'purposive sample' (Portney and Watkins 1993), with criteria which included: visibility of impairment, sex, socio-economic status, origin of impairment (acquired or congenital), causes of acquired impairment (accident, war), and length of disability (in the case of acquired disability). Two key informants from the disabled community (one disabled person and a non-disabled ally) helped in the selection and recruitment of participants. All of the participant's names are fictitious and some of their life facts were changed in order to preserve their anonymity.

Mary is 36, married and a mother of one child. She has a university degree and works. She has been paraplegic since she was 21 years old, the result of a traffic accident. She uses a manual wheelchair. Helen is 39, single and works. She has had a progressive neuromuscular condition since she was a baby and she started to use a manual wheelchair, permanently, 4 years ago. Helen, a Paralympics medalist for more than a decade, has been a top-level athlete. Kate is 19 and she is a university student. She has cerebral palsy and uses a powerchair. John is 43, single and works. He has had quadriplegia since he was 20 years old; it was the result of a traffic accident. He uses a manual wheelchair and is committed to sports. David is 22. He dropped-out of university after a traffic accident 3 years ago that caused quadriplegia. He uses a manual wheelchair. Bob is married, 65 years old and has 2 children. He is now retired from a job that he had prior to a leg amputation, which was the outcome of an injury during the Portuguese colonial war in Africa at the beginning of the 70s. He has been an activist since after the end of the war and the democratic revolution of 1974. He uses prosthetics and crutches. Finally, Peter is 20, single and a university student. He has been a Paralympian for some years. He has cerebral palsy and uses a powerchair.

Exploratory (semi-structured) interviews were conducted in order to ascertain participants' views on the psychosocial experience of disability, experience(s) of disabled embodiment, identity and its relation to embodiment, the politics of disability and empowerment and social change.

As a part of a PhD project, this research has followed the ethical procedures demanded by the Portuguese Foundation of Science and Technology and the Faculty of Psychology and Education of Universidade do Porto. All participants were given and completed an informed consent form.

The interviews took place during May - September 2010 and varied in duration between 31 minutes to 2 hours and 20 minutes. A content analysis of the verbatim transcripts of the audiotaped interviews was conducted. We categorized the data by using codification (Glaser 1978) with semantic criteria (Bardin 1977). The themes that emerged included: ableism and disabled embodiment; disabled identity; disabled life stories and the impact of social change on disability. This paper develops only the first two themes.

The interviewer is the first author; a wheelchair user with a sudden, acquired physical impairment dating from early adulthood. The research plan and interview processes were influenced by the interviewer's experiences of impairment, disabled embodiment and ableism as well as by her commitment to disability politics.

The non-disabled gaze

Impairment structures intercorporeal encounters (Hughes and Paterson 2006). In the shared space of 'intercorporeality' (Merleau-Ponty 1962), the privileged non-disabled gaze marks out the contours of ableism.

The non-disabled gaze invalidates impaired bodies. Its mode of perception is derived from the carnal point of view of non-disablement, recognizing 'truth' and 'perfection' only in normality (Hughes 1999). The gaze is invested with affects that shape the intercorporeal relations between disabled and non-disabled people.

Disabled respondents in this study noted that the non-disabled gaze included pity, curiosity as well as 'heroic' and positive views. Pity shapes intercorporeal emotions in abled-disabled encounters. It arises from what Oliver (1990) calls 'personal tragedy theory' and is institutionalized in the charitable disposition that constitutes disabled people as 'objects' of benefaction. One respondent described the demeaning power of pity.

> "I was shopping and a lady approached me and gave me a coin and said 'Take it. It's the only money I have' and I looked to her and replied 'Lady, excuse me but I am not begging. Do I look like I am starving?' She just stood there and I gave her the coin back and went away. I felt so outraged! (…) And I thought that it was a humiliation. It was like diminishing me to the bottom. Ok, she could have good intentions. But still, it's not because I am in a wheelchair that I am begging. I was really shocked with that situation; I didn't have time to react besides saying that. She was an elderly lady and it made me controlled a bit." (Kate)

Impairment is a part of the domain of history, culture and meaning (Hughes and Paterson 2006). The charitable disposition is part of the historical legacy of disability and Kate's words remind us of how disabled people were treated in the past when begging was one of the only means of survival (Stiker 1997). Kate tells a story of oppression in everyday life of the demeaning consequences of unconscious assumptions and reactions of well-meaning people in ordinary interactions (Young 1990). The charitable inclination turns Kate into public property and she is expected to have a public persona that is not always welcome or positive (Read 2000).

In the non-disabled imaginary pity may be aligned with the attribution to disabled people of the quality of heroism. Paralympians may find themselves in this 'dual position' feted for their athletic achievements which, however commendable, are recognized largely because of their impairments. Disability is the master identity that transcends other identities (Shakespeare 1996), transforming achievements into something realized in spite of impairment. The gaze is double edged.

> "(…) I am proud of the medals I won. It's a merit. And then the 'poor cripple' is substituted by 'There's the champion!'. But still there are those people who say 'Poor cripple, he can do so many things'. It still happens. So there's a mix of attitudes". (Peter)

The non-disabled gaze or ableist point of view is also driven by curiosity perceived as a ‘right’ to intrude, inquire, appropriate impairment as a public spectacle. To stare is to ‘enfreak’ (Garland-Thompson 1997) and to assert power over. ‘Curiosity’ is an invasion of personal space and may manifest itself in direct personal questions, unthinkable in ‘normal’ discourse. Yet disabled people can and do tolerate these ableist interjections.

> “Imagine what it is like that someone is staring at you, to the point of bothering you, and then you greet the person, and the person crosses the street and approaches you. This is spectacular (laughing)! This happened to me in the country. And then the person asks you: ‘what happened to you? Whose son are you?’ I have to say that I don’t see meanness in that, it’s curiosity in its pure sense.” (John)

Change in social attitudes towards disability in Portugal (see Loja, Costa and Menezes 2011) manifests themselves in more positive forms of intersubjectivity. The emergence of a gaze that embodies recognition is related to contemporary practices of equality and to enhanced sensitivity to accessibility issues.

> “Discrimination? No, to be honest, I don’t feel it. Before there was a kind of bitterness when I asked for example if a place was accessible, and the other person would reply to me: ‘no, we don’t have that’. A bitter answer, you see? Today, there’s a difference, if the place isn’t accessible, they answer ‘sorry, but we don’t have access’. There’s a difference.” (Bob)

The non-disabled gaze for disabled people is an experience of power relations playing out on the surface of the body (Hughes 1999). The gaze is the medium through which ableism invalidates the impaired body and at the same time sustains its own authenticity.

Ableism and (physical) capital

Tyrannies of perfection (Glassner 1992) and normalcy (Davis 1995) are particularly relevant to a politics of disablement (Hughes and Paterson 2006). Hahn (1985b) suggests that discrimination results from perceptions of disability that are impregnated with assumptions which equate impairment with biological inferiority. This suggests that disabled people do not 'belong' and do not deserve the same treatment as able-bodied people (Morris 1991). Disabled people's bodily signals expose something unusual, imperfect and negative about their moral status. The stigma of bodily difference is interpreted as a moral deficit (Goffman 1963).

Ableist thoughts and practices undermine the physical capital of disabled people; it is annihilated by architectural and attitudinal barriers. Bourdieu (1990) argues that the body is a form of physical capital, a site of power and status that can accumulate various resources and convert them into economic, cultural, emotional or social capital. Disabled people, however, struggle to recognize themselves in this articulation of the values and uses of the body.

> "Sometimes the physical barriers make you feel vulnerable. There were times that I went to my parent's home and my mother was not there yet. So I had to stay inside my car because I can't get out without help. And then I felt: 'Here I am, at the door of the house, there are two steps and I can't get over it'. I had to stay there. (…)" (Mary)

Besides the impact of architectural barriers on physical capital, such barriers also undermine comfort in social space. Inaccessible public spaces curtail social relationships and therefore the possibility of converting physical capital into social capital is significantly constrained.

> "When I go to parties that are accessible, there's no problem, but baptisms, weddings or communions... in those social events I feel as an obstacle. I kept thinking that the others were thinking 'if this guy wasn't here, it would be much easier'. E: But did you feel

> that in the past or now? e: Now I might have one situation or other, but it's rare. I felt more in the past because.... Well, to be honest I avoid going to baptisms." (Peter)

The pervasiveness of physical barriers not only constrains social relationships but also work performance, undermining the professional competence and the economic capital of disabled people.

> "One time I went to a trial and I didn't have access to the lawyer balcony. I had to stay next to the formal suspect. The judge kept looking at the lawyer balcony to look at me and then he remembered I wasn't there, but I was next to the suspect. And I didn't even have a desk to put my papers on so I had to put it on my lap. So, I felt... I didn't feel discriminated but those difficulties end up interfering with our credibility in our work. People look at us with those difficulties and our performance is put aside. And that does create difficulties in our lives." (Mary)

Mary raised the issue of the struggle for 'credibility' and how the ableist organization of everyday public affairs weakens her physical, social and economic standing, spoiling her performance and her identity. The lawyer is continually converted into the cripple and capital accumulation is thwarted. And there is a psycho-emotional price to pay (Thomas 1999; Reeve 2006).

> "E: So even with the movement that you have, you still feel inhibited when you are around people? e: Sometimes. I never felt like that with disabled people. But with non-disabled I end up feeling a bit.... E: And why does it happen? e: I don't know, maybe there are things that I didn't get over. It depends if I trust in those who are with me. If they are people from my day-to-day life, I don't feel it. But if I am going out to dinner and I am with

> people that I never met, then I would feel a bit lost but then I can put myself together." (Helen)

The difficulties in accumulating capital and sustaining credibility, that respondents refer to above, impact negatively on disabled people's desire to venture into public space. It is not just architectural barriers that are a form of confinement but recognition of the inhospitability of public space.

In public, disabled people are regarded as 'unable', not able to be 'active doers'. In the ableist or non-disabled imaginary disabled people are a dilemma of negotiation, reorganizing and reconfiguring social relations (Papadimitriou 2008a). As a consequence disabled people are often uncomfortable in public spaces. They occupy an unexpected place in the field (Blackmore 2007).

> "I avoid going to public places. E: May I ask why? e: Maybe I haven't adjusted well yet. I am better now because until now I've been running from those places because of the gazes. (...) E: If there weren't the gazes, would it be easier for you to go out? e: Yes, if we were simply ignored and only seen as normal people. I would go out much more." (David)

For disabled women, public space maybe be doubly inhibiting because they must also deal with the masculine gaze as well as the ideals of beauty (e.g. Thompson and Stice 2001) that construct aesthetics hierarchies in which disabled people are dis-figured.

> "In my first years after the accident, I didn't go out. I mean I didn't go out during the day. I only went out at night. During the daytime, people looked a lot at me; especially the elderly people and that bothered me a lot. They said that phrase: 'Oh, it's a pity because you're so pretty'. So if I was ugly, that wouldn't be a problem!" (Mary)

Feminine body-beauty ideals not only create distance between disabled and non-disabled women but may also drive a wedge between disabled people which may be explained by fear of being discredited through association (Titchkosky 2006).

> "Even though I met many people who are in the same condition as I am, at the hospitals that I went through, I don't have any friend who is in a wheelchair. And maybe that's because I don't want to see my image reflected in front of me constantly." (Mary)

The invalidation of impaired bodies and the constant struggle to establish 'credibility', has a profound effect on intimate relationships, undermining how disabled people feel about their attractiveness and desirability and their possibilities for intimate partnerships. Fear of rejection is not unusual:

> "I've been through some difficult situations (with boyfriends). And in those cases, it's a fear situation. Fear of not being accepted, that the other person won't like you for what you are. (…)" (Helen)

> "When I meet someone (in international tournaments) who have many more physical limitations than me but still have a family and even children, I feel stupid in a good sense because I think 'he can't do half of what I can and he has a family'. E: And why do you think it happens outside the country but not here? e: I don't know. Here mentalities are still very weak. People are afraid." (Peter)

> "E: Why didn't you want to marry in the past? e: Well it had to do with my past and with the wheelchair. Does anyone want to be with a cripple? I say cripple now but I would even call me worse names. I devalued myself." (Peter)

The capital required to establish credibility as a lover or parent requires the kind of physical 'authenticity' denied to disabled people by ableist norms and practices, assumptions about the kind of 'clean and proper' body (Kristeva 1982) that is a pre-requisite for friendship, parenting and love and even everyday forms of social interaction.

Ableism invalidates the physical capital of disabled people in a complex and multifaceted way, including the construction of architectural barriers and the lack of tolerance of bodily difference. It also constrains opportunities for capital accumulation in the social and economic fields and is gendered in its forms of invalidation. But the non-disabled gaze is contested and refused. The humiliating, ableist eye of power (Hughes 1999) can be and is resisted.

Ableism: Negotiation and resistance

Beyond the production of embodied selves by discursive processes, individuals are agents productive in conforming to, reiterating and contesting normative standards of 'acceptable' bodies (Csordas 1994; Sullivan 2001). The body is embroiled in social processes and consequently can be a 'site of economic, political, sexual and intellectual contestation' (Grosz 1994:19). In this section of this paper, the focus is on how ableist constructions of impairment can be negotiated and resisted how participants are able to confront physical and attitudinal barriers, standard body image and prescribed notions of romantic (un)attractiveness. Structure and agency, the economic, the cultural and the intimate gel together in patterns of negotiation and resistance (Thomas 1999). And that there is always a need to resist (Thomas 1999).

In a physical world replete with architectural barriers to wheelchair users and people with mobility impairments, one of the participants reveals his way of coping:

> "I've always tried to adjust myself. I've never fought against physical barriers. I have always taken the curve on this issue. That's my way of being. But I always do what I want but in another way. (...) And I am focused on that: this is the goal and I have to accomplish it. Of course I am aware that the entire

> environment should be more prepared and thought for disabled people. That's obvious!" (John)

Attitudinal barriers invested in the ableist imaginary manifest in pity and tragedy, particularly in Portugal's catholic dominated community, may descend into verbal and physical harassment. One participant fights back with verbal attacks.

> "There are people who start hugging me with a crucifix. E: But those people know you? e: No, no, they don't know me. They are people who see me in the street and hug me with a crucifix and start crying and this really bothers me, I mean, it's such a belittlement! 'Oh poor girl…' So I am rude to them and if I could I would stand up and get out of my wheelchair…!" (Kate)

Helen copes with the tyrannies of perfection (Glassner 1992) and normalcy (Davis 1995) by celebrating her difference. She isolates the significant attributes that constitute her difference and 'wears' them in a way that suits her. She has a nuanced attitude incorporating ambivalence towards her body (Shakespeare 1996), and lives her identity as she sees it.

> "Today if I have to wear a skirt or shorts, I do it without any problem. If someone is looking or doesn't like it, I don't care. I am like this and people have to like me as I am. I see things differently now because I know I can't change. A fat person, for example, might lose weight by doing diet and exercise. That person can do something if he/she has the strength to do it. But I, as stronger as I might be, I can never change and that's the difference. So we just have to accept who we are." (Helen)

The ambition to exercise the right to have a romantic partner or to develop the inner confidence that was built on past romantic relationships were strategies developed by two participants. They reject social judgements regarding their capacity to love and have replaced them with an internally based body image (Shakespeare, Gillespie-Sells and Davies 1996) that is positive and competent.

> "I know that at this moment I can have a life like anyone else. I want someone with me. And I am not ashamed of that, if that person loves me and I love her back." (Peter)

> "When I say I don't care about what people think it has to do with my inner confidence. I've already had someone loving me. So if that has already happened, it can happen again. And if the other person doesn't like me, it's because we are incompatible and that's fine." (John)

Disabled people in contemporary society resist the accumulated history of disability oppression and ableism. They confront physical and attitudinal barriers and stereotypes about their capacity for intimacy and configure themselves in ways that challenge centuries of oppression, refusing to internalize ableism, demanding recognition for who they are and what they want to become. The evidence suggests that many people are prepared to challenge ableism by adopting disability as a positive identity.

Ableism and disabled identity

The evidence suggests that disability has been stigmatized as a negative identity (Goffman 1963). The concept of normality, embedded in the medical model, has been at the core of the othering process that has shaped the understanding of disability as a physical, moral, emotional, mental and spiritual deficit. As Tregaskis (2004:93) claims: 'perhaps 'identity' is most important when you belong to a minority whose selfhood is constantly challenged by the presence and actions of a majority'.

Identity is fundamentally embodied for disabled people (Huang and Brittain 2006). As Shain (2002 cit in Campbell, 2008:159) states 'my impairment CANNOT be separated from who I am. I cannot overcome my own body'. Yet the story is more complex.

Bodily differences have different implications for the construction of a disabled identity. For some participants, it seems that the focus is, self-consciously, on the body itself and the significant impact of ableism, particularly in the context of uncontrollable body movements.

> "I don't know if I'd eliminated the part of my body that doesn't help me, if I would be more human… E: More human? In opposition to what, so I can understand? e: For example, if I am in a line, I am always holding my arm, otherwise I would hit someone. If my arm would disappear, I could be like this (not holding the arm). And maybe my impairment is more noticed because my hand is always folded. So, if my arm would disappear, Ok, I would miss an arm but how can I explain? People would know someone more controlled. I don't say that I am uncontrolled but without a defect, even though I would have a defect because I would miss an arm." (Peter)

Another respondent noted the considerable influence of the wheelchair, as symbol and prosthesis, on her sense of identity.

> "E: Do you think your impairment is in your identity? e: Yes, it is. I think that even though some people say 'I even forget you are in a wheelchair', I think the wheelchair is always present. E: But in the others or in you? e: In me, in me and in the others. It's always, always, always there. Sometimes I say that there are people who have more limitations than me but you can't see it. But mine, there's no way to escape from it. E: It is too visible? e: There's no way to escape from it." (Mary)

Within a culture that maintains perfectionist ideals of bodily beauty, gender and impairment intersect to complexify identity. In this context it can be difficult to acquire positive self-identity since the ideals of the ableist body appear to be so distant (Guthrie 1999).

> "E: What's the influence of your body on the person that you are? e: I think it has to do with the feminine vanity. I miss that part… The heels and the dresses… (laughing). Of the power, of having more freedom of choice. Imagine, I am going out with a group of girlfriends and they are all dressed up, with their heels and dresses and of course I feel different there. I wished I could be different. Not as much as in the past when I really got upset." (Mary)

Two participants with acquired impairments make a comparison between 'before and after'. They conclude that their self-characteristics can be separated from their impairments. The respondent with the more recent impairment attests to changes in his perspective on accessibility and on the penetrating nature of the non-disabled gaze but contends that his inner self has been uninterrupted by the changes to his body.

> "(…) we learn to see life in a different way due to our limitations that we didn't have before. For example, giving value to accessibility or being on the other side of the 'poor guy' look or the curiosity 'what's wrong with him?'. Now I understand that side and also the side where I am now and that might change our personality a bit. E: So it has changed in our values but as a person, did it change you? e: No, my inner self is basically the same. Only those values became more relevant." (David)

John who has an acquired impairment that has been part of his life for a long time is comfortable in distinguishing between impairment and self-identity emphasizing the continuity of the latter.

> "I think my characteristic would be the same. (Pause) Ok, I wouldn't have to fight so much. But my fighting is in a good way. (…) But there's a huge difference between now and before the accident. But in my inner self, I don't know if it influenced me because, by the end, it's just a physical change. We, as we are inside, everything are the same. If the physique contributes to change… I don't think so." (John)

For those with acquired impairments a stable sense of self-identity has been sustained. Yet this may indicate an understandable reluctance to focus on that aspect of their identity that is most negatively stigmatized (Hahn 1985b). It could also however, represent a strategy of resistance to ableist invalidation (Hahn 1985a). Maintaining an identity of equal value and worth 'before and after' the acquisition of impairment can be read as an egalitarian gesture.

For Bob who is a disability activist, it seems that 'communal attachment', identification with the 'disabled minority' (Hahn 1994), has a strong influence on his identity. Bob takes the view that, whatever his body can or cannot do, he is the equal of anyone. He links his citizen identity to his long experience of activism. Indeed, the evidence suggests that positive self-identification is more likely to be asserted in a collective context (Shakespeare 1996).

> "There was a short time that I fell out of bed because I forgot that I didn't have my legs. Then the awareness came up and sometimes I feel my feet hurting, but that's rare. But that says nothing to me, it's normal. (….) This is my feeling: I don't feel less than anyone, I feel perfectly equal to anyone." (Bob)

The results make it clear that identity is an embodied construction and is influenced by subjective bodily experience as well as social and intercorporeal encounters. In addition, gender, nature, severity of impairment and ideological perspective are among a host of factors that shape and modify identity. Ableism may dominate the social and cultural landscape but it is not the wellspring of disabled identity. Disabled people contest ableism by struggling for recognition in terms that they themselves set and seek to control, responding actively to their individual and collective experiences and their multiple identities (Tregaskis 2004). As Jones (2006:29) claims: 'the imperative for recognition is grounded not in the value that that identity has for those who do not share it, but in the value it has for those whose identity it is'.

Conclusions

Ableism is a concept that is useful in explaining disabled people's experience of oppression and constructions of disabled identity because it focuses on the contours of the non-disabled perspective. The non-disabled gaze invalidates impaired bodies undermining the physical capital of disabled people, which in turn, compromises their opportunities to convert it into economic, cultural, social and emotional capital.

However the stories of disabled people are marked by strategies of resistance that embody individual and collective struggles for recognition. The everyday challenge to ableism is a carnal style 'of being in the world that embodies resistance' (Hughes and Paterson 2006) to the multiple tyrannies that constitute the ableist imaginary. In order to deconstruct the exclusionary and demeaning aspects of ableism and respect the value of disabled identity, an embodied politics of recognition is required.

Affirming the diversity of bodies as a plus in a pluralist and inclusive society is the task of this kind of politics. In the current economic climate the politics of redistribution must be central to disability strategy but there is no doubt that the struggle for recognition (which is the struggle against ableism) is important in keeping on the agenda disabled people's demands for respect and esteem.

The participants in this study were relatively privileged disabled people with capital resources who had opportunities to participate in non-disabled social settings such as mainstream schools. Less privileged disabled people, who have experienced more exclusion and segregation, are more readily habituated to the dominant practices of ableism (Blackmore 2007). Opportunities, therefore, for the majority of disabled people in Portugal to acquire cultural, social and economic capital are severely constrained by the limited fields in which they have the chance to operate. Further empirical research needs to explore the impact of ableism and capital accumulation as they impact variably across class, structuring disabled lives differently and influencing the types of agency and resistance that emerge out of the struggle against the non-disabled imaginary.

REFERENCES

Bardin, L. 1977. Análise de conteúdo *[Content Analysis]*. Lisboa: Edições 70.

Barnes, C, T. Mercer, and T. Shakespeare. 2005. *Exploring disability: A sociological introduction,* 2nd edition. Cambridge: Polity Press.

Bourdieu, P. 1990. *The Logic of Practice*. Cambridge: Polity.

Campbell, F. 2008. Exploring internalized ableism using critical race theory. *Disability & Society,* 23(2): 151–162.

Campbell, F. 2001. Inciting legal fictions: Disability's date with ontology and the ableist body of the law. *Griffith Law Review 10*: 42–62.

Campbell, F. 2009. *Contours of ableism: the production of disability and abledness*. London and New York: Palgrave Macmillan.

Corker, M. 1999. Differences, conflations and foundations: the limits to 'accurate theoretical representation of disabled people's experiences? *Disability & Society, 14*(5): 627–642.

Corker, M. and French, S. 1999. *Disability discourse.* Philadelphia, PA: Open University Press.

Csordas, T. J. 1994. Introduction: the body as representation and being-in-the-world, In *Embodiment and experience: the existential ground of culture and self,* ed. T. J. Csordas, 1–24. Cambridge: Cambridge University Press.

Davis, L. 1995. *Enforcing Normalcy: Disability, Deafness and the Body*. New York: Verso.

Edwards, C. and Imrie, R. 2003. Disability and bodies as bearers of value. *Sociology, 37*(2): 239-256.

French, S. 1993. Disability, impairment or something in between, In *Disabling Barriers—Enabling Environments,* ed. J. Swain, V. Finkelstein, S. French and M. Oliver, 17-24. London: Sage.

Galeotti, A.E. 2002. *Toleration as Recognition.* Cambridge: Cambridge University Press.

Garland Thomson, R. 1997. *Extraordinary bodies: figuring physical disability in American culture and literature.* New York: Columbia University Press.

Glaser, B. G. 1978. *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory.* Mill Valley-California: The Sociology Press.

Glassner, B. 1992. *Bodies: the tyranny of perfection.* Los Angeles: Lowell House.

Goffman, E. 1963. *Stigma: Notes on the management of spoiled identity.* Engelwood Cliffs, NJ: Prentice-Hall.

Gottfried, H. 1998. 'Beyond Patriarchy? Theorising Gender and Class'. *Sociology, 32*: 451–68.

Grosz, E. 1994. *Volatile Bodies: Towards a Corporeal Feminism*. Bloomington: Indiana University Press.

Guthrie, S.R. 1999. Managing imperfection in a perfectionist culture: Physical activity and disability management among women with disabilities. *Quest, 51*: 369-381.

Hahn, H. 1985a. Disability policy and the problem of discrimination. *The American Behavioral Scientist, 28*: 293–318.

Hahn, H. 1985b. Introduction: disability police and the problem of discrimination. *American Behavioural Scientist* 28: 293- 318.

Hahn, H. 1994. The minority group model of disability: Implications for medical sociology. *Research in the Sociology of Health Care, 11*:3–24.

Hahn, H. 1997. An agenda for citizens with disabilities: Pursuing identity and empowerment. *Journal of Vocational Rehabilitation, 9*:31–37.

Hall, E. 1999. Workspaces: Refiguring the Disability-employment Debate, In *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*, ed. R. Butler and H. Parr, 138–54. London: Routledge.

Honneth, A. 1995a. *The Struggle for Recognition: the Moral Grammar of Social Conflicts.*

Cambridge: Polity Press.

Honneth, A. 1995b. *The Fragmented World of the Social: Essays in Social and Political Philosophy.* Albany, NY: State University of New York Press.

Huang, C. and Brittain, I. 2006. Negotiating identities through disability sport. *Sociology of Sport Journal, 23*: 352-37.

Hughes, B. 1999. The constitution of impairment: modernity and the aesthetic of oppression. *Disability & Society, 14*(2): 155–172.

Hughes, B. 2000. Medicine and the aesthetic invalidation of disabled people. *Disability and Society, 15*(4), 555-568.

Hughes, B. and Paterson, K. 2006. The social model of disability and the disappearing body: towards a sociology of impairment, In *Overcoming disabling barriers*, ed. Len Barton, 91-107. Oxon: Routledge.

Kristeva, J. 1982. *Powers of horror: an essay on abjection,* (Translated by L. Roudiez). New York: Columbia University Press.

Loja, E., Costa, E. and Menezes, I. 2011. Views of disability in Portugal: 'fado' or citizenship? *Disability & Society*, 26(5): 567-581.

Marks, D. 1999. Dimensions of oppression: theorizing the embodied subject. *Disability & Society,* 14(5): 611–626.

Meekosha, H. 1999. Body battles: bodies, gender and disability, In *The disability reader*, ed. T. Shakespeare, 163-180. London: Cassell.

Merleau-Ponty, M. 1962. *Phenomenology of Perception*, Translated by Colin Smith. London: Routledge.

Morris, J. 1991. *Pride against prejudice*. London: Women's Press.

Oliver, M. 1990. *The politics of disablement.* Basingstoke: McMillan.

Papadimitriou, C. 2008a. 'It was hard but you did it': the co-production of 'work' in a clinical setting among spinal cord injured adults and their physical therapists. *Disability and Rehabilitation,* 30(5): 365 – 374.

Papadimitriou, C. 2008b. The 'I' of the beholder: Phenomenological seeing in the context of disability. *Sports, Ethics, and Philosophy*, 2 (2): 216 – 233.

Paterson, K. and Hughes, B. 1999. Disability studies and phenomenology: The carnal politics of everyday life. *Disability & Society, 14*(5): 597-610.

Patterson, K. and Hughes, B. 2000. Disabled bodies, In *The body, culture and society*, ed. P. Hancock, B. Hughes, E. Jagger, K. Patterson, R. Russell, E. Tulle-Winton and M. Tyler, 29-44. Buckingham: Open University Press.

Portney, L. and M. Watkins. 1993. *Foundations of clinical research: Application to practice.* Stamford, CT: Appleton & Lange.

Read, J. 2000. *Disability, the Family and Society: Listening to Mothers.* Buckingham, Open University Press.

Reeve, D. 2006. Towards a psychology of disability: the emotional effects of living in a disabling society, In *Disability and Psychology: Critical Introductions and Reflections, ed.* D. Goodley and R. Lawthom, 94-107. London: Palgrave.

Shakespeare, T. 1992. A response to Liz Crow. *Coalition*, September: 40–42.

Shakespeare, T. 1996. Disability, identity and difference, In *Exploring the Divide*, ed. C. Barnes and G. Mercer, 94-113. Leeds, UK: The Disability Press.

Shakespeare, T., Gillespie-Sells, K. and Davies, D. 1996. *The Sexual Politics of Disability: Untold Desires.* Cassell: London.

Shilling, C. 1993. *The Body and Social Theory*. London: Sage.

Stiker, Henry-Jacques. 1997. *A History of Disability.* Ann Arbor: University of Michigan Press.

Stoer, S., Magalhães, A. and Rodrigues, D. 2005. *A diferença somos nós. A gestão da mudança social e as políticas educativas e sociais [The difference is on us. The management of the social change and the educative and social policies].* Porto: Afrontamento.

Sullivan, S. 2001. *Living across and through skins. Transactional bodies, pragmatism, and feminism.* Bloomington, IN: Indiana University Press.

Taylor, C. 1994. The politics of recognition, In *Multiculturalism: Examining the Politics of Recognition*, ed. A. Gutmann, 25–73. Princeton, NJ: Princeton University Press.

Thomas, C. 1999. *Female forms: experiencing and understanding disability.* Buckingham: Open University Press.

Thompson, J. K. and Stice, E. 2001. Thin-ideal internalisation: Mounting evidence for a new risk factor for body image disturbance and eating pathology. *Current Directions in Psychological Science*, 10: 181–183.

Titchkosky, T. 2006. *Disability, Self and Society.* Toronto: University of Toronto Press.

Tregaskis, C. 2004. *Constructions of disability: researching the interface between disabled and non-disabled people*. London: Routledge.

Turner, B. 2001. Disability and the Sociology of the Body, In *Handbook of Disability Studies*, ed. G. Albrecht, K. Seelman and M. Bury, 252–66. London: Sage.

Young, I.M. 1990. *Justice & the Politics of Difference.* Princeton, NJ: Princeton University Press.

Zitzelsberger, H. 2005. (In)visibility: accounts of embodiment of women with physical disabilities and differences. *Disability & Society,* 20(4): 389-403.

Zola, I. 1991. Bringing our Bodies Back in: Reflections on a Past, Present, and Future Medical Sociology. *Journal of Health and Social Behaviour,* 32(1): 1–16.

DISCUSSION

In this section, findings from the three studies will be discussed by recurring to three themes: '*fado*', citizenship and the embodied self. Finally, a proposal for change in regard to disability in Portugal will be presented.

'Fado'

Fado is a distinctive form of song in Portuguese culture, in which nostalgia, melancholy, loss and resignation are expressed. It literally means fate or destiny, one that we cannot escape from. Not worth resisting.

In Portuguese history we found that disability has been mainly lived like a *fado*. The history told by the leaders of associations indicates that before the restoration of democracy in the 1974 Revolution, charity and family assistance were the only devices for disabled people. The moral/religious model was the major way to interpret disability. Disabled people lived excluded from society, with their families, experiencing an embarrassing and guilty atmosphere. Even nowadays, the majority of disabled people are not integrated in society. A tragic vicious cycle paradigm, where disabled people get trapped, is prevalent in Portugal. This is a system-induced disempowerment, which extends to families, society, policies and politicians, and consists of architectural and attitudinal barriers, unemployment issues, compensatory measures that provoke dependency, isolation from the disabled community and internalized oppression.

Results from the first and the third studies revealed that architectural barriers stipulate a material organization of a physical space where disabled people are banned from accessibility and mobility. This is established by an ableist society for whom bodily difference is intolerable and should be kept at a distance. Dis/abl(e)ism is thus predominant with the high influence of the religious model in dominant social constructions on disability combined with weak politicization from the disability movement itself.

On a superficial level, the first study showed that the existence of architectural barriers in all the national territory generates huge accessibility and mobility issues. Because disabled people fail to attain the mobility, sensory or communications skills to master the existing environment, society turns them into being recipients of disability benefits (Hahn, 1988). When accessibility and mobility are denied, unemployment issues emerge and consequently, disabled people have to depend on subsidies or allowances. For non-disabled people, external goods, benefits, and advantages are simple entitlements, while disabled people have to gain access to what they are denied (Shildrick, 2009). Because these allowances are not enough to allow an independent way of life – as revealed by the disability leaders and which reflects the inexistence of independent living measures in Portugal - disabled people have to depend financially and instrumentally on their families. Rather than contributing towards the transition to independent living and consequently to cost saving for the State, compensatory measures (subsidies/allowances) have the opposite effect: disabled people remain dependent on them. Contradictions in Portuguese legislation and policies put disabled people in a paradox: for example, while they are supposed to be integrated in society – as conceived by employment and training policies -, they lose the 3rd person subsidy if they are employed (Law n. º 28/84, August 14th) which forces them to be dependent on their families on an instrumental level. Teixeira (2012), in his comparative analysis of disability policy typologies between UE countries (based on OECD[8], 2010 and ECOTEC[9], 2009) found that in Portugal a definition of disability that includes a number of social approaches coexists with a compensation orientation in dealing with disability. He found similarities with the European welfare typology by Gosta Esping-Anderson (1990) as compensation orientation seems to be prevalent in South European countries where there's a tradition of family based responsibility approach in regard to social issues.

Also in the first study, we found that besides the contradictions, legislation regarding accessibility and mobility is not fulfilled, and as a result, many disabled

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[8] Organisation for Economic Co-Operation and Development

[9] ECOTEC: Study on the Situation of Women with Disabilities in Light of the UN Convention for the Rights of People with Disabilities

people are confined to their homes. In public spaces disabled people are hardly seen due to an environment filled with physical barriers – inaccessible public space, public and private buildings, public transport, etc. Consequently, besides the financial dependency on families, disabled people are forced to get help from their social support system to overcome physical barriers.

Ineffectiveness of legislation combined with discrimination and violation of human rights' principles are predominant in disabled people's lives (Pinto & Teixeira, 2012). The final report of '*Disability Rights Promotion International - Portugal*' (Pinto & Teixeira, 2012) reveals that these extend to multiple life domains, particularly in social participation (with severe constraints in accessibility and mobility) and in access to support services, and access and participation in the job market.

On a deeper level, findings from the third study demonstrated that beyond the accessibility and mobility issues, when disabled people try to use the public space they are subjected to pity and curiosity gazes that sustain the social inhospitality of this space to bodily difference, generating psycho-emotional effects that often influence patterns of community use (Milner & Kelly, 2009). People 'know' how much disabled people are miserable, yet they cannot predict the amount of tragedy or happiness in life for anyone else (French & Swain, 2004). Indeed, there's a psychological and sometimes a physical risk when disabled people venture into mainstream contexts because their spatial inclusion includes the 'normality' of discrimination, abuse, intolerance and more subtle forms of personal exclusion (Clement, 2006; Hall, 2004; Reid & Bray, 1998). The non-disabled gaze does this job.

We found in the third study that pity and curiosity gazes are the most disturbing and frequent experiences reported by participants. These constitute violent expressions of the dominant models of disability: pity arises from the religious/charitable gaze, whereas curiosity arises from the medical gaze that leads to the 'right' to intrude with ableist interjections. Even though the 'heroic' view hasn't got such a violent connotation as the latter, still its interpretation of impairment and disability has some negative effects. This can be related to its link with the rehabilitative model, in which paralympic athletes are caught in a paradox where their achievements are only recognized in spite of their impairments; being a top-athlete is not their master identity but they are seen as disabled with 'special' features, thus overcoming disability.

To sum up, results from the third study revealed that the extreme pervasiveness of physical and attitudinal barriers is a reflection of an ableist society that undermines the physical capital of disabled people and its conversion into economic, social and emotional capital. In the first study we found that disabled people become resigned to compensatory measures provided by the State and are isolated from a community that could provide them alternative models of disability as well as a sense of belonging and identity. Internalized oppression emerges with feelings of inadequacy, self-doubt, worthlessness and inferiority (Barnes et al., 2005; Thomas, 1999). As Burstow (2003, p. 1296) states: 'the point is oppressed people are routinely worn down by the insidious trauma involved in living day after day in a sexist, racist, classist, homophobic, and ableist society'.

As their bodies are invalidated as being deficient, inferior and unable by the non-disabled gaze, disabled people are thus seen as second-class citizens (Hughes, 2004as). Because they are impaired, they are seen as naturally disadvantaged - this is the ideology that justifies and perpetuates the inferior position of disabled people (Abberley, 1987). As mentioned above, the reduction of disability to an essentialist phenomenon medically or morally defined has harmful implications by forming the basis for social arrangements that exclude people with impairments from equal participation in society and by producing negative meanings that undermine the subjective experiences of their well-being (Smith, 2009). As a result, segregation is allegedly required by the 'nature of things' (Hahn, 1996). And for some academics this segregation continues to benefit society at large (e.g. Abberley, 1998; Hahn, 1996; Shildrick, 2009). Hahn (1996, p. 14) asks:

> *"Is it possible that the segregation and discrimination inflicted on people with visible or labelled impairments may reflect an underlying proclivity by the dominant majority to seek to associate with persons who are viewed as similar and to avoid or resist contact with those who are regarded as deviant or different?"*

Patronizing attitudes, taking responsibility for another, even claiming empathy, often hide feelings of avoidance or an unwillingness to engage person to person (Shildrick, 2009; Hahn, 1996). Attitudes towards disabled people manifest 'not simply a reluctance to enter into full relationship, but a positive turning away and silencing of the unaccepted other' (Shildrick, 2009, p. 1). Goffman (1963, p. 146) writes about the 'good adjustment':

> *"It (good adjustment) means that the unfairness and pain of having to carry a stigma will never be presented to them; it means that normal will not have to admit to themselves how limited their tactfulness and tolerance is; and it means that normal can remain uncontaminated by intimate contact with the stigmatized, relatively unthreatned in their identity beliefs."*

With the above, the tragic vicious cycle paradigm often inhibits the emergence of a political dialogue or discourse about disability (Hahn, 1996) – as revealed by the disability leaders -, and therefore this perpetuation is sustained.

Citizenship

According to the disability leaders, a group of ex-soldiers who had been wounded in the colonial war began to oppose the tragedy paradigm by joining an associative movement in the post-1974 Revolution and began to use a sociopolitical approach. The sheer numbers (25 thousand war-impaired people) together with their willingness to fight for better conditions for themselves brought a new social awareness of the situation of disabled people in Portugal. They demanded constitutional recognition for the specific condition of disabled people; the responsibility of the State in the creation of policies to promote social integration of disabled people; and treatment as a citizen instead of charitable aid. Associations *of* disabled people were created with political and advocacy purposes, as well as with consumerist and self-help projects that would fill the gap of state provision of services. Disabled activists realized that disability meant exclusion from a citizenship that they used to enjoy when they were non-impaired. They fought for social inclusion as a way to break down social injustice and to remove barriers so that disabled people could participate in society.

Portugal then became a member of the European Union in 1986 and since then the European Social Fund has been a financial resource for policies about equality of rights and employment and training opportunities for disabled people. Also the country was strongly influenced to adopt specific legislation and policies for disabled people. As a result, in the last decades, we have witnessed some attitudinal changes in society regarding disability and some improvements in disabled people's lives. The positive views experienced by participants of the third study, where they find expressions of equality and sensitivity to accessibility issues, are products of the social model.

A citizenship approach would ideally bring together disabled people's relationship to 'conventional' political institutions and processes and the emergence of a 'politics of disability' (Barnes et al., 2005). Within it, equality of rights for disabled people is the basis to consider them citizens instead of these being subjected to pity and charity- this was expressed by the disability leaders when they tell about the beginning of the disability movement in Portugal. Within this perspective, inclusion means that disabled people should have equal access to all aspects of society and further that society has an obligation to accept and accommodate every one of its members (Brown & Brown, 2003). Acceptance, personal control, equal civil rights, access to opportunities, and equal provision of services and public supports are concepts related to inclusion (Brown & Brown, 2003). These are the main causes of the disability movement.

'Equal access' is thus considered a fundamental principle and its achievement must be secured as a matter of right, irrespective of cost (Hahn, 1996). It's understood as a manifestation of a fundamental belief in human equality rather than as a special concession indicating paternalistic sympathy for the plight of the less fortunate (Burkhauser & Haveman, 1982). Economic reasons are often invoked in order to explain the lack of implementation of equal access measures, demonstrating a tendency to confuse civil rights issues with cost-benefit calculations (Hahn, 1985b).

Yet, 'equal access' outweighs the benefits that a reduction in equality conveys (Burkhauser & Haveman, 1982).

In Portugal, equality of rights or equal access is far from reality, where barriers, discrimination, exclusion and segregation still prevail. Results from the first study revealed that politicians lack interest in disability issues, demonstrating incapacity to imagine an environment adapted to the needs of everyone by making assumptions that are self-evident (Hahn, 1996) based on the 'natural'/tragedy paradigm. Additionally, professionals are the ones who are most consulted, replacing the opinion of disabled people's representatives; furthermore, legislation and policies are approved merely to satisfy European directives but are never in fact carried out or supervised.

Even though Portuguese associations try to secure citizenship rights, due to the failure of conventional politics and policy-makers, they lack power of influence due to their inability to reach the majority of disabled people and the civil society. The non-fulfillment of legislation, the lack of dialogue with politicians, the non-representativeness of disabled people in the government, the financial dependency of associations on the State, the overload of services that are not provided by the State (taking time and energy to advocacy), are among the factors that explain the lack of political influence of associations. Attitudes of politicians, who should be accountable for disability matters, confirm the omnipresence of the tragic vicious cycle paradigm.

Indeed, associations seem to be more efficient at developing self-help strategies that can be purely practical rather than explicitly political (Oliver & Zerb, 1997). As Barnes, Mercer and Shakespeare (2005) claim achievements from organizations rest more on its capacity to transform its own organization and analysis of disability than to overturn the social oppression of disabled people. To explain this, environmental barriers and perennial lack of resources are some of the factors that prevent the disability movement from reaching the disabled population as a whole (Barnes et al., 2005). Also, the powerful effect of the tragic cycle paradigm helps to isolate disabled people and originates a reluctance to adopt a disability identity. Self-identification issues – as associated with a social stigma – are probably still the principal obstacle to the emergence of a powerful political constituency of disabled citizens (Hahn, 1996). When people only have access to a tragedy paradigm to signify their experience, either they assume the 'poor position' or reject it when they can 'pass'.

Anyway, as revealed in the first study, the main problem is that disabled people don't see their situation as a social one and are not aware of other paradigms that might suit them better. Indeed, politicization of a disabled identity is a powerful catalyst for meaningful social (Barnes et al., 2005) and individual change. A conscientization (Freire, 1972) through disability rights analysis can change a person's self-conception (Shakespeare, 2006).

Nonetheless, collectively or individually, a minority group of disabled people in Portugal manages to resist the pervasiveness of the tragedy paradigm. These are the ones who can escape from the 'tragic fate'/*fado* by making their own path regardless of the great barriers that still exist. Findings of the quality of life and discrimination study informed us that satisfaction in life is highly related to a sense of competence in job/training and empowerment; participants are highly aware of their rights and therefore manifest a great consensus regarding equality of rights; they experience high levels of discrimination in important areas of social inclusion (such as job and school), yet they hold a great sense of empowerment; and obviously, their level of satisfaction in life and sense of empowerment is highly disturbed when they are discriminated against. Barriers, discrimination, disempowering structures and environments are daily presences in disabled people's lives. These findings suggest that those who are integrated in society find in their individual empowerment the strength to keep themselves afloat in regard to social integration.

In fact, findings from the first and second studies seem to suggest that a triad of factors is important for an independent way of life. First, financial resources provided by education and job attainment allow an escape from a subsidy/allowance dependency and enable the acquisition of material resources such as a vehicle or proper technical aids. Secondly, emotional and instrumental support from the social support system, namely family and friends, and associations (in case of collective involvement). And finally, personal resources such as motivation, attitudes, individual empowerment, which are highly influenced by rights awareness developed by the other factors. However, State measures for developing and securing the rights of disabled people have only a very slight impact.

To end, barriers and discrimination are daily presences in disabled people's lives in Portugal and politization has not been (totally) effective in this struggle. Even though a citizenship perspective on disability is or can be a big step towards the improvement of disabled people's lives, results from empirical studies (e.g. Schall, 1998) corroborate the fact that, despite progress in passing disability rights legislation, patterns of discrimination against disabled people persist (McCarthy, 2003). The links between civil rights and cultural representations, between images of difference and social justice must thus be analysed (Meekosha & Jakubowicz, 1996).

The embodied self

As a form of oppression widely perpetuated in western societies, disability poses important questions about the 'nature of those societies, both in terms of their overt organisation and their social imaginaries' (Shildrick, 2009, p. 15).

The rights' perspective and the sociopolitical model have been challenging the normative political, juridical, and social structures of societies that practice categorical exclusion. Even though this struggle has been productive, it is lacking in the analysis and deconstruction of the structures that maintain those damaging normativities - postmodernist alternatives are more effective (Shildrick, 2009). Legal and social rights that overtly challenge discrimination against disabled people are not enough to address the persistent unease occasioned by corporeal difference and the impact of ableism on disabled people's lives, identity and subjective experience – this is revealed by the findings of the third study. While material changes in the social organization of disability have some effects on discrimination and devaluation of disabled people, the challenge by 'postconventional perspectives to the organizing binaries' and the damaging normativities, 'impel a far more complex approach that takes account equally of psychic, socio-cultural, and political domains' (Shildrick, 2009, p. 171).

In fact, the business-as-usual forms of ableism that disabled people confront on a daily basis and which account (for example) for internalized oppression, are not

challenged by our rules or laws, with the result that only the more extreme forms of injustice can be remedied (Campbell, 2008a). As Shildrick (2009, p. 13) claims: 'everyday law can never resolve the problematic of disability, and that what is at stake is no longer the place of normativity and governmentality, but the sphere of an impossible justice.'
Regarding psychic and sociocultural domains, cultural constructions and subjective experience of disability and impairment are played out within and through the body, in the dynamic interplay of self and the social world (Hughes & Paterson, 1997; Hughes, 1999, 2000; Paterson & Hughes, 1999). Corporeality is thus present in the self-other relation where impairment, as disruption of the putative neutrality of the normative, is signified 'as potentially compromised, as less than self-complete, and not to be counted as a full subject' (Shildrick, 2009, p. 20).

Findings of the third study suggest that disabled people live in an ableist society where a charitable and medical gaze invalidate their bodies and undermine their physical capital at the expense of the recognition of a disability identity. In everyday life, participants see their physical capital being deeply undermined by ableism. It is annihilated by architectural and attitudinal barriers, in which there's a lack of tolerance of bodily difference. The possibility to convert physical capital into social, economic and emotional capital is thus severely affected.

Impaired bodies are privileged objects of gaze where the abnormal is viewed from a safe distance (Shildrick, 2002). The visible vulnerability of these bodies – as signified by non-disabled people – is captured by a non-disabled gaze that contests the uncommon vulnerability of self-becoming (Shildrick, 2002) and, because of that, invalidates them. This invalidation is converted into an undermining of their physical capital thru physical and attitudinal barriers – disabled people are not allowed to disrupt the normative order where ablebodiedness hides an imperfect security (Shildrick, 2009). Findings from the third study indicated that the physical capital of disabled people is weakened in physical performance and aesthetic value. Physical barriers interfere significantly with mastering the physical environment, causing feelings of inadequacy in public space and dependence on others, which in turn undermine social capital. Additionally, these barriers also interfere with work performance and acquisition of a professional role, which compromises economic capital as well. In regard to attitudinal barriers, we found an imposition of aesthetic hierarchy and invalidation of disabled people in the role of romantic partners and parents. Prescriptive standards for body image and notions of (un)attractiveness are thus part of the ableistic normativities.

Nevertheless, participants negotiate and resist ableist barriers. Using the physical space in a creative way without the experience of emotional burn-out is how one participant deals with physical barriers. Verbal fighting against expressions of pity is how another participant removes herself out of the tragedy and religious trap. Tyrannies of perfection and normalcy are deconstructed with acceptance of bodily difference. And the right to have a partner or the inner confidence from past experiences releases two participants from the prescribed ideas of romantic (un)attractiveness.

Recognition is further tested in relation to these everyday encounters. Gender, nature and severity of impairment and ideological perspective influence the impact of ableism on the construction of disability identity. Some participants are self-conscious about the body itself when they have uncontrollable movements or when the wheelchair and the normative standard of female beauty have a great influence on body image. In regard to gender, besides the ableist gaze, disabled women are also subjected to the masculine gaze where tyrannies of perfection and feminine beauty are combined. Concerning the nature of impairment, those with acquired conditions are more protected from having a damaged identity due to the fact that they resist putting their selves at mercy of ableism by recurring to 'before and after' scenarios. Indeed, congenital conditions are more prone to negative comparison to a putative model of normality (Shildrick, 2002) as if 'they' were never part of 'normal' humanity. Additionally, severity (and nature) of impairment relates to hierarchies of impairments. Those with more incontrollable bodies constitute the highest threat to the ableistic notion of invulnerability. And finally, an ideological perspective established within a collective involvement permits the construction of a political identity. These findings suggest that disability identity is not uniform: some people might be self-conscious about the body itself due to a high influence of the medical and charitable gaze; some others maintain their 'self' intact by retrieving it from this influence; and others might adopt a political identity, especially if they are involved in the politics of disability.

Thus, participants manifest embodied forms of resistance as they create and engage in embodiments that go against hegemonic understandings of bodies by embracing alternative narratives and identities that recognize diversity and contest normality. With that, they rearticulate symbolic legitimacy of disavowed bodies (Butler, 1993). Indeed, signification takes over (Goodley, 2011) when disability uses its inherent 'prestige' of the possibility to disrupt (Michalko, 2002).

Impaired bodies are reminders of everyone's vulnerability and precariousness (Shildrick, 2009), yet as a source of fascination and rejection they reveal the precariousness of the cultural ideal of autonomy and wholeness (Goodley, 2011). In fact, impairment is an *unexceptional* condition of all corporeality (Shildrick, 2009). By analyzing impaired bodies through embodiment theory, we are allowed to reach signification and experience of bodies. As Shildrick (2009, p. 36) puts it:

> *"Those who undergo changes to their sensory apparatus, or to their mobility, are undoubtedly changed at a very fundamental level, but they are not thereby in deficit. Within the terms of phenomenology, the embodied self incorporates difference and modification not as a pre-given subject adjusting to evolving constraints and possibilities, but in aligning or realigning one's whole being to whatever perceptual schema is available."*

Ableism is thus an important concept because it allows understanding about the struggles of disabled people against the non-disabled imaginary. These struggles are embodied manifestations where carnal pride may become a site of unexpected possibility.

Proposal for change

In this part we'll focus on a proposal for change regarding disability in Portugal that consists of measures mentioned by interviewees from the first and the third studies. The first paper has already included in the part 'for the future' measures proposed by disability leaders. Nevertheless these will be included in this section in order to contribute to a complete picture of this proposal for change.

Participants have proposed measures regarding State action and the roles of civil society, disability associations and disabled people on this matter. The promotion of a wider critical political consciousness regarding disability issues is emphasized. Yet, at a deeper level, we also find reflections about the nature of the social imaginary, which alert us to the fact that, besides disablism, fighting against ableism is equally in play.

According to participants, State action must be based on an ideology of autonomy rather than an ideology of remediation where voluntarism seems to be the main response to resolve disability-related issues. Legislation and social policies regarding disability must be fulfilled and these must promote autonomy, independency and empowerment instead of dependent protection. Appropriate social compensation should be adopted, although not in a purely exclusive way. Furthermore, the State should have a more effective response to ensure equality of rights.

> *"The State should support more disabled people with appropriate compensation, and create mechanisms that allow them to live with dignity and overcome economic barriers. I mean mechanisms that are not subsidy or allowance, but ones that would compensate but made people do more than that. "ADFA*

State action seems to be highly influenced by the tragedy paradigm. Even though we find a socio-political perspective in the content of legislation and policies, its nonfulfillment reveals that there's not a real internalization of this perspective. The reliance of the State on voluntary work to tackle disability-related issues is a proof of that, leading to the perpetuation of the pity paradigm.

> *"The State has to stop the solidarity. That's b.s.! Or the volunteer work. You can be a volunteer, I can be a volunteer, but that's not how we get there because this sustains the pity. As long as there is volunteer work, there's pity. I am not saying that it should end completely but it shouldn't be the main response (…). Everything is solidarity. It can't be! Solidarity is for those children who die of starvation in Africa. That's solidarity! Equality of rights is another thing."* Peter

Accessibility and mobility are among the rights that are mostly claimed by disabled people. Fully accessible environments are absolutely essential so that disabled people have the chance to move around freely and consequently get equal opportunities to participate in society. For this, execution of legislation is decisive and perhaps disabled associations might need to carry out wide-ranging political action and mobilization, rather than relying on legislative shifts (Barnes et al., 2005).

> *"We believe that we all belong to the same world. So, friendly environments are extremely important for all of us. Social policies have to be alerted to this fact (...)."* LPDM

Feelings and experiences of 'belonging to the same world' are often denied to disabled people. Because accessibility and mobility are closely related to autonomy, we find that for Mary they are also linked to personhood. The focus is not on people's limitations anymore when disabled people are allowed to use their full physical capital without restrictions. They are allowed to enter 'humans' world' by confronting personal and institutionalized presumptions about the meaning of impairment and disability and about the lives and aspirations of disabled people (Swain & French, 2008).

> *"It (accessibility/mobility) is fundamental because as much as a person feels free and as much as the society has the perception of autonomy, then they will give us more value as persons and will not focus on our limitations."* Mary

Concerning civil society, education and involvement in disability issues are part of their role.

> *"(…) we have a society that is not prepared to accept a disabled person, who should be accepted as equal. (...) it has to start from elementary school, with education."* ADFA

Contact and respect are keywords in the dynamic relation between society and disabled people. When carried out properly, contact is one of the most effective ways to overcome/challenge prejudice and discrimination because it deconstructs the social imaginary which is loaded with the charitable and medical gaze.

> *"School inclusion will make a difference because those who grew up with someone disabled will develop other attitudes and information of what is a person in a wheelchair. When they become adults, they will have a different perception than those who never saw a disabled person in the street."* Helen

> *"When we talk to people, they start to see us differently and the gazes stop. The nosy ones kill their curiosity and those who feel pity start realizing that we are not 'poor people' and that life for us is not that bad and that we can even be normal persons or even better."* David

Both civil society and disabled people have specific roles in changing this ableistic relation. For Mary, society is not able to do this task on its own as they lack knowledge regarding disability. For David, society must be more aware of and facilitate accessibility so that disabled people have the chance to change their mentalities. Elimination of physical barriers by society is thus crucial to promote contact with disabled people.

> *"Our role is to start getting out, start facing them so we can turn this into a normal thing. And society's role is to be more aware to facilitate access and all that."* David

> *"We have to do that pathway; we have to change the way society look at us. (..) Because when people have contact with the difference, they start looking at it in a different way and they don't shut us down. At least in our society, they don't shut us down. (...) And society by itself can't do it because they don't know, so only if we go out and contact with them is that mentalities can be changed."* Mary

In this breeding ground, respect is key for the inclusion of disabled people in society according to Bob. For him, respect secures the conditions to include disabled people in the job market for example.

> *"E: What should happen to have more social inclusion of disabled people? e: Respect. That's it. Just respect. If there's respect, you can do everything. With the exception of few situations, everybody can work, you see? But you must give conditions; well you have to give conditions to everyone. Conditions of work, respect for the person who works, respect for the work, respect for life, you see?"* Bob

A wider critical political consciousness regarding oppressive social conditions and a full-rights citizenship perspective on disability must thus be promoted. And if civil society is more attentive to disability, maybe the political powers will become more interested in this field. Also, this can increase the opportunities for judges and policymakers to gain the knowledge necessary to make informed judgements about incidents of alleged discrimination (Hahn, 1996), which might have an impact on an effective fulfilment and accomplishment of legislation.

Disability groups are extremely important when it comes to exerting power of influence in civil society and in political life. Indeed, the disabled associative movement should influence the thinking and practices of the population at large, and not only of disabled people (Barnes et al., 2005). According to participants, a new model of associativism must be considered in Portugal. Proper organisation of disabled persons groups (Oliver & Zarb, 1997) is crucial in order to promote sociopolitical awareness of the unjust psychological and sociopolitical conditions that oppress disabled people.

> *"I am very critical about the associative movement of disabled people in Portugal, because I think they claim too much, and sometimes in the worst way, and are less active in creating answers. (…) I see claiming strategies that are linked to other interests."* ADFA

> *"We have to create a new model of associativism for disabled people. I see also (for year 2020) associativism with more quality."* ADFA

With respect to disabled people, they should be exposed to alternative models beyond the dominant individual one. Disability has to be considered by disabled people as a matter of social relations and not an individual defect in order to have the chance of getting into an empowering process (Barnes et al., 2005) that would allow them a feeling of control, a proactive approach to life and a critical understanding of the socio-political environment (Zimmerman & Warschausky, 1998). For that, development of a positive affirmative/political disabled identity is crucial.

> *"It's possible to find ways that are not about diminishing yourself. The person can analyze his/her own situation and circumstances and find a solution and should be guided by someone who is more experienced."* ACA-M

Rather than absorbing the mainstream representation of impaired people as victims of personal tragedy (Cameron, 2009), rather than assuming one's situation as personal failures, it is crucial that disabled people start recognizing their condition as a social one based on discrimination, prejudice and oppression (Shakespeare, 1996). Disabled people's self-organization is a primary source of a strong disability identity (Barnes et al., 2005) because it is an expression of group identity (French & Swain, 2004), but disability identity is also an individual process. What is at stake is to challenge the tyranny of the personal tragedy model (French & Swain, 2004) and the dominant stereotypes of powerlessness and objectification (Shakespeare, 2006), by adopting an affirmative disability identity (Swain & French, 2000) and by focusing attention on empowering disabled people and on the possibilities for changing society (Shakespeare, 1996).

On a deeper level, changing the social imaginary constituted by ableism, as well as the tragedy paradigm, is a crucial step in tackling exclusion, discrimination and oppression of disabled people if we want everyone to feel that 'they belong to the same world'. The importance of fighting against ableism is thus manifested by participants who referred to the breaking down of frontiers between disabled- non-disabled people and the imperfection of all human bodies.

> *"The change can occur if we sensitize the civil community, (…) when we will be able to make people think that we are all equal, and today I am in a wheelchair and tomorrow you might also be. This has to be more present in their lives."* CNOD

> *"People have to be educated and they have to understand that this is our world. Accidents happen. For me it was in the war but for others it is on the roads or at work. So everything has to be adapted, I mean everything has to suit everyone. If we see clearly, with the exception of myself who's perfect (kidding), there are not many people who has everything in the right place. Believe me. Either they need a hearing device, or glasses, or something for their teeth, there's something in humans that doesn't allow them to be perfect, you see?"* Bob

To summarize, a proposal of change regarding disability for Portugal includes the following measures:

- Adoption of an ideology of autonomy by the State that breaks down the system-induced disempowerment. The paradox produced by nonfulfillment of advanced legislation and policies towards social inclusion of disabled people must be resolved by a real internalization of a sociopolitical approach with respect to the State's interpretation of and action towards disability issues.

- Fulfillment of legislation and policies that ensure accessibility, mobility and effective inclusion of disabled people. Portuguese policies and legislation must have a real impact on social inclusion of disabled people.

- Improvement of the model of associativism practiced by disability associations so they would exert an effective influence on civil society in order to promote a wider sociopolitical awareness regarding disability issues, which in turn can turn disability as a public issue to which politicians are accountable.

- Development of education, involvement, contact and respect in order to improve the dynamic relation between society and disabled people and deconstruct the social imaginary loaded by the individual models (religious and medical).

- Dissemination of alternative models regarding disability into society and disabled people so that the latter can develop a positive disability identity and find new and positive interpretations to their experiences.

- And finally, more than extending the formal framework in which people who experience disabilities can maximise their own potentials, the dissolution of frontiers between disabled and non-disabled and the realization of imperfection in all human bodies opens the possibility of understanding and fighting the nature of the social imaginary that undermines everybody's relation with impairment and disability.

CONCLUSIONS

Rather than considering disability a simple question, this dissertation has tried to reveal its multiple layers of significance and meaning: through using the metaphor of *fado* to understand the tragedy paradigm, the concept of citizenship to understand the sociopolitical approach, and finally the concept of ableism and the theory of embodiment to understand the social imaginary that permeates everyone's relationship with disability. With that, we tried to enable us to scrutinize what, as Titchkosky (2007, p. 17) writes, 'we *are doing* to make disability'.

Findings of the three studies suggest that disability in Portugal is mainly lived within a tragic vicious cycle paradigm with origins from a moral/religious and medical model, which by the 'nature of things' legitimates the individualization of the 'problem' and disclaims society and politicians from the responsibility of including all of their members. The pervasiveness of a system-induced disempowerment leads to the social exclusion of the majority of disabled people, as it extends to families, society, policies and politicians. This system is responsible for inadequate provision of services and infrastructures for disabled people and also leads to serious psychological consequences, with profound damages to self and identity. This is manifested in the architectural and attitudinal barriers, unemployment issues, compensatory measures that provoke dependency, isolation from the disabled community and internalized oppression. The associative movement has not been able to reach the majority of disabled people or to influence civil society and the political power to overturn this system. The paradox produced by the nonfulfillment of policies and legislation leads a small group of disabled people - those who can achieve some degree of social inclusion - to support themselves on a rights awareness-based triad of factors, composed by financial and personal resources and social support system. Ultimately, disabled people manifest embodied forms of resistance that contradict the ableist normativities which undermine their physical capital - and its subsequent conversion into social, economic and emotional capital - and which impact on the recognition of a disability identity.

Further to the understanding of the disability experience, this thesis concludes with a proposal for change regarding disability in Portugal that contains measures suggested by participants of the research. On this proposal we find that a social model must be developed in Portugal so that the State, politicians and civil society recognize, in formal terms, the rights of disabled people and, in symbolic terms, their disability identity/ies. A wider sociopolitical awareness regarding disability issues should be spread into civil society and disabled people. Moreover, ableistic thoughts and practices need to be addressed through the process of education and involvement of all people.

As conveyed by critical disability studies, dis/abl(e)ism has materialized in all institutions: schools, hospitals, workplaces, universities, community groups, rehabilitation centers and families (Goodley, 2011), where disability discourse is generated (Corker & French, 1998). The premise of normality and reduction of difference (Robertson, 2001,) operates on welfare, education and other systems, which consequently always leave people out. Within this perspective, 'norming' (Davis, 1995) their bodies is the only chance for disabled people to be included, to which we have to ask if this suits society better than themselves.

Indeed, norming goes against celebrating difference. Norming requires that disabled people can be or act 'normal', that they want to be 'normal', and ultimately it would demand a 'normal' body to become a 'normal' person. That being said, we do have to think differently about impairment and disability in order to serve disabled people better. For that, the concept of ableism is particularly useful as it includes everyone.

Whether impaired or not, people see their embodiments being deeply influenced by ableism and the social imaginary attached. However, all the *extra*-ordinary bodies that produce ontological uncertainty, such as pregnant women (Shildrick, 2002), fat people, etc. would prove the *naturalness* of all bodies in their different forms. In fact, disabled bodies are variable modes of *becoming* when we consider vulnerability as a human existential state in which contingency and incompletion prevails (Shildrick, 2002). Disabled bodies are variable modes of *being* when we listen to lived bodies with impairment, in which, even faced by past extreme bodily disruption, 'different forms of perceptual awareness and interrelationship may become a site of unexpected possibility', when a 'new phenomenology of embodiment becomes familiar' (Shildrick, 2009, p. 36).

Due to everyone's implication in the nature of the sociocultural imaginary, the discourse of disability is a shared responsibility in which all the vulnerability that has been thrown to others must be a condition of becoming shared by all (Shildrick, 2009). We hope to open in the future the prospect of transforming this social imaginary. For now, beyond the contestation regarding the material organization of society, overturning the normative paradigms that determine who shall be valued and who not and 'opening up the discourse to the very instability that disability embodies' (Shildrick, 2009, p. 18) can be concerns of disability politics. Losing individual and socio-political certainty and moving beyond existing categories (Shildrick, 2009) where disabled people deconstruct dominant modes of cultural production from their 'valued position of one's own diversity, on one's own terms, reclaims the research agenda' (Goodley, 2011, p. 163). Plus, as Campbell (2008a, p. 159) affirms, 'for scholars there is an ethical imperative to interrogate the violence of ableism' by speaking of its consequences on practical domains and, especially, on the psychic life with the production of internalized ableism.

Disabled people are *the* ultimate intersectional subject through whom we can understand exclusion, resistance (Davis, 2006, p. xviii), diversity and interdependence (Longmore, 1987). Disability sits at the intersection of biology and society and of agency and structure; it is so complex, so variable, so contingent, so situated; it cannot be reduced to a singular identity (Shakespeare & Watson, 2001a). But beyond a personal identity, we must question ourselves if this/these identity/ies has/have more to say about humanity. As Margrit Shildrick (2002, p. 121) claims: 'as existent and potential bodies are increasingly complicated, the question becomes what is at stake not just for personal identity, but for the category of humanity itself'.

In regard to the limitations of this research, specific limitations of the second and the third studies are included on the papers. Nevertheless, some general limitations and directions for future research will be discussed below.

Participants that had participated in this research are the ones who could be reached. The majority of disabled people who are not included in society are not reachable and because of that we miss their perspective. Even though we interviewed disability experts who gave their insights about the community of disabled people in Portugal and we used an on-line format when we administered the questionnaire as a way to include those with mobility issues, the fact is that those who are also technologically excluded were also excluded from the study. Similarly, participants of the third study are relatively privileged people in regard to capital resources. Therefore, we may have only the perspective of those who had the chance to find a way to be integrated in society. Future research should try to resolve this limitation by finding innovative ways to reach those who are still 'invisible' in scholarly work.

Furthermore, the cultural values that reflect the social imaginary that constitutes ableism should be addressed in future research, where non-disabled people should be included. With that, we might have a better understanding of the nature of ableism in order to find strategies to achieve attitude change, particularly aesthetic anxiety that is less susceptible to influence by cognitive appeals that is existential anxiety (Hahn, 1986).

Future research should also include more studies within a phenomenology or embodiment perspective that would capture either, on a subjective level, the kinaesthetic, sensory and cognitive experiences of people with an array of impairments (Goodley, 2011) as well as extend the study on intersubjective experiences of disabled people. The pervasion of the deficit model has negatively standardized the bodily subjective experiences of disabled people and because of that, as Linton (1998a, p. 530) says: '[w]e are missing the constructs and theoretical material needed to articulate the ways in which impairment shapes disabled people's version of the world'.

With that, we find that it is important to have studies that combine the analysis of disablism as well as ableism in order to capture a full understanding of the experience of disabled people. Plus, when ableism is better understood, the transference of this knowledge to other people who are not impaired but still don't meet bodily normativities can enrich the positive development of everybody's embodiment.

And finally, scholars from different backgrounds should participate in disability studies as their perspectives are crucial to understand the broad system (Meekosha, 2004). In regard to Portugal, academics from different backgrounds could have an important role in the constitution of a disability studies discipline in academia that would be relevant for the development of scientific knowledge on disability in order to improve Portuguese disabled people's lives.

Beyond the limitations and directions for future research, this research sets out some implications that will be presented below.

By using a sociopolitical perspective to look at disability in Portugal, this study has revealed an understanding of disability in a social and political interface, which is relatively scarce in this context where studies within individuals' models predominate. With that, it highlights the Portuguese specificities that must be acknowledged and identified; namely, the social and political climate that confronts disabled people.

The triangulation of studies enriches this understanding where qualitative and quantitative methodologies were combined. Furthermore, we chose to have the participation of disability experts and disabled people, who both brought an insider perspective on the subject.

With the quality of life study, a scale to measure the quality of life for disabled people that uses a sociopolitical perspective was adapted and validated to the Portuguese context. With that, the study has contributed to beginning to plug the gap in measures based on a comprehensive type of quality of life that have a strong potential for being meaningful, relevant and applicable to disabled people's lives.

Empirical research on ableism and disabled embodiment is relatively scarce in disability studies, even more in the Portuguese context. By linking the theory of ableism and embodiment, this study sheds light on contemporary forms of disability experience in everyday life. It explored issues of physical capital, identity and resistance by drawing on disabled people narratives about being disabled in an ableist world, where they seek recognition through resistance in their everyday encounters with non-disabled people.

Beyond the contribution for the understanding of disability in Portuguese context, this research has included a proposal for change consisting of measures indicated by participants. This proposal tries to develop measures for enriching disabled people's lives by promoting a sociopolitical approach that tackles dis/abl(e)ism by including notions such as empowerment, human rights, dignity, equality, positive identity, positive embodiment and so forth.

Dis/abl(e)ism has a profound and wide impact on disabled people, in their quality of life, embodiment and identity. A tragic vicious cycle paradigm grounded on ableist thoughts and practices is contested by disabled people with the use of a rights' awareness approach and embodied forms of resistance.

In the end, the complexity of disability can be understood in its essence: it is about a mode of corporeality that exists in an excluding normativity. Consequently, it's everybody's responsibility to reflect on disability and position it somewhere among a multiplicity of embodied possibilities.

REFERENCES

Abberley, P. (1987). The concept of oppression and the development of a social theory of disability. *Disability, Handicap & Society, 2*(1), 5-19.

Abberley, P. (1998). The spectre at the feast: Disabled people and social theory. In T. Shakespeare (Ed.), *The disability Reader: Social science perspectives* (pp. 79-93). London: Cassell.

Albrecht, G. L. (1992). *The disability business: Rehabilitation in America*. Newbury Park, CA: Sage.

Albrecht, G. L. (2006). *Encyclopedia of disability* (Vol. 5). Thousand Oaks: Sage.

Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science and Medicine, 48*, 977-988.

Albrecht, G., Seelman, K. D., & Bury, M. (Eds.). (2001). *Handbook of disability studies.* London: Sage.

Barnes, C. (1990). *The cabbage syndrome: The social construction of dependence*. London: Falmer Press.

Barnes, C. (1991). *Disabled people in Britain and discrimination: A case for anti-discrimination legislation*. London: Hurst & Company.

Barnes, C. (1997). A legacy of oppression: A history of disability in western culture. In L. Barton & M. Oliver (Eds.), *Disability studies: Past, present and future* (pp. 3-24). Leeds: The Disability Press.

Barnes, C. (1998). The social model of disability: A sociological phenomenon ignored by sociologists. In T. Shakespeare (Ed.), *The disability reader: Social science perspectives* (pp. 65-78). London: Continuum.

Barnes, C. (2004a). Disability, disability studies and the academy. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers: Enabling environment* (pp. 28-33). London: Sage.

Barnes, C., & Mercer, G. (2005). *The social model of disability: Europe and the majority world.* Leeds: The Disability Press.

Barnes, C., Mercer, T., & Shakespeare, T. (2005). *Exploring disability: A sociological introduction* (2nd ed.) Cambridge: Polity Press.

Barton L. (Ed.). (1996). *Disability and society: Emerging issues and insights*. London: Longman.

Barton, L. (2004b). The disability movement: Some observations. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers: Enabling environments* (pp. 285-290). London: Sage.

Barton, L. (Ed.). (2001). *Disability, politics and the struggle for change*. London: David Fulton.

Bickenbach, J. E. (1993). *Physical disability and social policy*. Toronto: University of Toronto.

Birke, L. (2002). Unusual fingers: Scientific studies of sexual orientation. In D. Richardon & S. Seidman (Eds.), *Handbook of lesbian & gay studies* (pp. 55-71). London: Sage.

Blackmore, T. (2007). *"Half of my friends don't even see me as disabled": What can field, capital and habitus reveal about disability and inclusion?* (Doctoral dissertation). University of Exeter, U.K.

Blumenfeld, W. J. (Ed.). (1992). *Homophobia: How we all pay the price*. Boston: Beacon.

Borsay, A. (2005). *Disability and social policy in Britain since 1750: A history of exclusion*. Basingstoke: Palgrave Macmillan.

Bourdieu, P. (1990). *The logic of practice*. Cambridge: Polity.

Braddock, D., & Parish, S. L. (2001). An institutional history of disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 11-68). Thousand Oaks, CA: Sage.

Braidotti, R. (1994). *Nomadic subjects: Embodiment and sexual difference in contemporary feminist theory*. New York: Columbia University Press.

Brandon, T., & Elliott, A. (2008). The art of affirming identity. In J. Swain & S. French (Eds.), *Disability on equal terms* (pp. 90-103). London: Sage.

Brown, I., & Brown, R. I. (2003). *Quality of life and disability an approach for community practitioners*. London: Jessica Kingsley Publishers.

Brown, L., & Strega, S. (2005). Introduction: Trangressive possibilities. In L. Brown, & S. Strega (Eds.), *Research as resistance: Critical, indigenous, and anti-oppressive approaches* (pp. 1-18). Toronto: Canadian Scholars' Press.

Burkhauser, R. V., & Haveman, R. H. (1982). *Disability and work: The economics of American policy*. Baltimore: The John Hopkins University press.

Burstow, B. (2003). Toward a radical understanding of trauma and trauma work. *Violence Against Women, 9*(11), 1293-1317.

Bury, M. (2000). A comment on the ICIDH2. *Disability & Society, 15*, 1073-1077.

Butler, J. (1993). *Bodies that matter: On the discursive limits of sex*. London: Routledge.

Calhoun, C. (1990). *Social theory and the politics of identity*. Cambridge: Blackwell.

Cameron, C. (2009). Tragic but brave or just crips with chips?: Songs and their lyrics in the Disability Arts Movement in Britain. *Popular Music, 28*(3), 381-396.

Campbell, F. K. (2001). Inciting legal fictions: Disability's date with ontology and the ableist body of the law. *Griffith Law Review, 10*, 42-62.

Campbell, F. K. (2008a). Exploring internalized ableism using critical race theory. *Disability & Society, 23*(2), 151-162.

Campbell, F. K. (2008b). Refusing able(ness): A preliminary conversation about ableism. *M/C: Media and Culture, 11*(3), 1-15.

Campbell, F. K. (2009). *Contours of ableism: Territories, objects, disability and desire*. London: Palgrave Macmillan.

Campbell, F. K. (2009). Having a career in disability studies without even becoming disabled!: The strains of the disabled teaching body. *International Journal of Inclusive Education*, *13*(7), 713-725.

Campbell, F. K. (2009). Medical education and disability studies. *J Med Humanit*, *30*, 221-235.

Carneiro, N. (2009). Homossexualidades: uma psicologia entre ser, pertencer e participar [Homossexualities: a psychology between being, belonging and participating]. Porto: Livpsic.

Charlton, J. (1998). *Nothing about us without us: Disability, oppression and empowerment*. Berkeley, CA, University of California Press.

Christensen, C. (1996). Disabled, handicapped or disordered: What's in a name?. In C. Christensen & F. Rizvi (Eds.), *Disability and the dilemmas of education and justice* (pp. 63-78). Buckingham: Open University Press.

Clement, T. (2006). What's the vision?. In C. Bigby, C. Fyffe, & J. Mansell (Eds.), *From ideology to reality: Current issues in implementation of intellectual disability policy.*

Proceedings of the roundtable on intellectual disability policy (pp. 13-23). Bundoora: La Trobe University.

Coleridge, P. (1993). *Disability, liberation and development*. Oxford: Oxfam.

Corker, M. (1998). *Deaf and disabled or deafness disabled*. Buckingham: Open University Press.

Corker, M., & French, S. (Eds.). (1999). *Disability discourse*. Buckingham: Open University Press.

Corker, M., & Shakespeare, T. (Eds.). (2002). *Disability/postmodernity: Embodying disability theory*. London: Continuum.

Crow, L. (1996). Including all our lives: Renewing the social model of disability. In C. Barnes & G. Mercer (Eds.), *Exploring the divide: Illness and disability* (pp. 55-72). Leeds: The Disability Press.

Darke, P. (2004). The changing face of representation of disability in the media. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers: Enabling environments* (2nd ed., pp. 100-105). London: Sage.

Davies, D. (1997). Homophobia and heterosexism. In D. Davies & C. Neal (Eds.), *Pink therapy: A guide for counselors and therapists working with, lesbians, gay and bisexual clients* (pp. 24-40). Buckingham: Open University Press.

Davis, L. (2001). Identity politics, disability, and culture. In G. Albrecht, K. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 535-545). Thousand Oaks, CA: Sage.

Davis, L. J. (1995). *Enforcing normalcy: Disability, deafness, and the body*. New York: Verso.

Davis, L. J. (2006). Preface to the second edition. In L. J. Davis (Ed.), *The disability studies reader* (2nd ed., pp. viii–xv). New York: Routledge.

Derrida, J. (1970). Structure, sign and play in the discourse of the human sciences. In R. Macksey & E. Donato (Eds.), *The structuralist controversy* (pp. 247-272). Baltimore: Johns Hopkins University Press.

Edwards, S. D. (2005). *Disability: Definitions, value and identity*. Abingdon: Radcliffe.

Edwards, S. D. (2009). Definitions of disability: Ethical and other values. In K. Kristiansen, S. Vehmas, & T. Shakespeare, *Arguing about disability: Philosophical perspectives* (pp. 30-41). London: Routledge.

Eldar, R., & Jelić, M. (2003). The association of rehabilitation and war. *Disability & Rehabilitation, 25*(18), 1019-1023.

Erikson, E. H. (1976). *Identidade, juventude e crise* [Identity, youth and crisis] (A. Cabral, Trans.). Rio de Janeiro: Zahar editores.

Erikson, Erik H. (1968). *Identity: Youth and crisis.* New York: W.W. Norton & Company.

Erikson, Erik H. (1980). *Identity and the life cycle.* New York: International Universities Press. (Original work published 1959)

Esping-Anderson, G. (1990). *The three worlds of welfare capitalism.* Cambridge: Polity Press & Princeton: Princeton University Press.

Fanon, F. (1984). *Black skin, white masks.* London: Pluto Press. (Original work published in 1954)

Finkelstein, V. (1980). *Attitudes and disabled people: Issues for discussion.* New York: World Rehabilitation Fund.

Finkelstein, V. (1981a). To deny or not to deny disabilities. In A. Brechin, P. Liddiard, & J. Swain (Eds.), *Handicap in a social world* (pp. 31-38). London: Hodder & Stoughton.

Finkelstein, V. (1981b). Disability and the helper/helped relationship: An historical view. In A. Brechin, P. Liddiard, & J. Swain (Eds.), *Handicap in a social world* (pp. 12-22). London: Hodder & Stoughton.

Finkelstein, V. (1996). Outside 'inside out'. *Coalition*, April, 30–36.

Finkelstein, V. (2001). A personal journey into disability politics. Paper presented at the Leeds University Centre for Disability Studies, England.

Fox, D., Prilleltensky, I. & Austin, S. (2009). *Critical psychology: an introduction* (2nd edition). London: SAGE.

Fox-Genovese, E. (1991). *Feminism without illusions: A critique of individualism.* Chapel Hill: University of North Carolina Press.

Fraser, N. (1995). From redistribution to recognition. *New Left Review, 212*, 68-92.

Freire, P. (1972). *The pedagogy of the oppressed.* Harmondsworth: Penguin.

French, S. (1993). Disability, impairment or something in between. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers: Enabling environments* (pp. 17-24). London: Sage.

French, S. (1994). The disabled role. In S. French (Ed.), *On equal terms: Working with disabled people* (pp. 47-60). Oxford: Butterworth-Heinemann.

French, S., & Swain, J. (2004). Whose tragedy? Towards a personal non-tragedy view of disability. In J. Swain, S. French, C Barnes, & C Thomas (Eds.), *Disabling barriers: Enabling environments* (2nd ed., pp. 34-40). London: Sage.

French, S., & Swain, J. (2008). There but for fortune. In J. Swain & S. French (Eds.), *Disability on equal terms* (pp. 7-20). London: Sage.

Friedman, L. J. (1999). *Identity's architect: A biography of Erik H. Erikson*. New York: Scribner.

Galeotti, A. E. (2002). *Toleration as recognition*. Cambridge: Cambridge University Press.

Garland, R. (1995). *The eye of the beholder: Deformity and disability in the Graeco Roman world*. London: Duckworth.

Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *NWSA Journal*, *14*(3), 1-32.

Garland-Thomson, R. (2005). Feminist disability studies. *Signs: Journal of Women in Culture and Society*, *30*(2), 1557-1587.

Ghai, A. (2006). *(Dis)embodied form: Issues of disabled women*. Delhi: Shakti Books.

Gilligan, C. (1982). *In a different voice: Psychological theory and women's development.* Cambridge, MA: Harvard University Press.

Gilson, S. F., & DePoy, E. (2002). Theoretical approaches to disability content in social work education. *Journal of Social Work Education*, *38*, 153-165.

Glassner, B. (1992). *Bodies: The tyranny of perfection.* Los Angeles: Lowell House.

Gleeson, B. (1999). *Geographies of disability.* London: Routledge.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* Engelwood Cliffs, NJ: Prentice-Hall.

Goodley, D, & Lawthom, R. (Eds.). (2005b). *Disability and psychology: Critical introductions and reflections*. London: Palgrave.

Goodley, D. (2011). *Disability studies: An interdisciplinary introduction*. London: Sage.

Goodley, D., & Lawthom, R. (2005a). Epistemological journeys in participatory action research: Alliances between community psychology and disability studies. *Disability & Society*, *20*(2), 135-151.

Gray, D.B., & Hahn, H. (1997). Achieving occupational goals: The social effects of stigma. In C. Christiansen & C. Baum (Eds.), *Occupational therapy: Enabling function and well-being* (pp. 394-409). Thorofare, NJ: Slack.

Grey-Thompson, T. (2005). *Tactile paving (and other bad inventions).* Retrieved from http://www.bbc.co.uk/ouch/opinion/tactile_paving_and_other_bad_inventions.shtml

Gross, B. H., & Hahn, H. (2004). Developing issues in the classification of mental and physical disabilities. *Journal of Disability Policy Studies, 15*(3), 130-134.

Grosz, E. (1993). Bodies and knowledges: Feminism and the crisis of reason. In L. Alcoff & E. Poer (Eds.), *Feminist epistemologies* (pp. 187-215). New York: Routledge.

Gustavsson, A., Sandvin, J., Traustadóttir, R., & Tøssebro, J. (2005). *Resistance, reflection and change: Nordic disability research*. Lund: Studentlitteratur.

Hahn, H. (1985a). Introduction: Disability policy and the problem of discrimination. *American Behavioral Scientist, 28*, 293-318.

Hahn, H. (1985b). Toward a politics of disability: Definitions, disciplines, and policies. *Social Science Journal, 22*, 87-105.

Hahn, H. (1986). Public support for rehabilitation programmes: The analysis of U.S. disability policy. *Disability, Handicap & Society, 1*(2), 121-37.

Hahn, H. (1988). The politics of physical differences: Disability and discrimination. *Journal of Social Issues, 44*, 39-47.

Hahn, H. (1996). Antidiscrimination laws and social research on disability: The minority group perspectives. *Behavioral Sciences and the Law*, *14*, 41-59.

Hahn, H. (1997). Advertising the acceptable employment image: Disability and capitalism. In L. J. Davis (Ed.), *The disability studies reader* (pp. 172–186). New York: Routledge.

Hahn, H. (1997). An agenda for citizens with disabilities: Pursuing identity and empowerment. *Journal of Vocational Rehabilitation, 9*, 31-37.

Hahn, H. D., & Belt, T. L. (2004). Disability identity and attitudes toward cure in a sample of disabled activists. *Journal of Health and Social Behavior, 45*, 453-464.

Hall, E. (2004). Social geographies of learning disability: Narratives of exclusion and inclusion. *Area 36, 3*, 298-306.

Haraway, D. (1990). A manifesto for cyborgs: Science, technology and socialist feminism in the 1980s. In L. Nicholson (Ed.), *Feminism/Postmodernism* (pp. 190-233). London: Routledge.

Haraway, D. (1991). *Simians, cyborgs and women: The reinvention of nature*. London: Free Association Books.

Hargreaves, J. (2000). *Heroines of sport: The politics of difference and identity*. London: Routledge.

herising, F. (2005). Interrupting positions: Critical thresholds and queer pro/positions. L. Brown, & S. Strega (Eds.), *Research as resistance: Critical, indigenous, andanti-oppressive approaches* (pp. 127-152). Toronto: Canadian Scholars' Press.

Hochschild, A. R. (1983). *The managed heart: Commercialisation of human feeling*. Berkeley, CA: University of California Press.

Honneth, A. (1995a). *The struggle for recognition: The moral grammar of social conflicts*. Cambridge: Polity Press.

Honneth, A. (1995b). *The fragmented world of the social: Essays in social and political philosophy*. Albany, NY: State University of New York Press.

Huang, C.-J., & Brittain, I. (2006). Negotiating identities through disability sport. *Sociology of Sport Journal, 23*, 352-375.

Hughes, B. (1999). The constitution of impairment: Modernity and the aesthetic of oppression. *Disability & Society, 14*(2), 155-172.

Hughes, B. (2000). Medicine and the aesthetic invalidation of disabled people. *Disability & Society, 15*(3), 555-568.

Hughes, B. (2002a). Disability and the body. In C. Barnes, L. Barton, & M. Oliver (Eds.), *Disability studies today* (pp. 58-76). Cambridge: Polity Press.

Hughes, B. (2002b). Invalidated strangers: Impairment and the cultures of modernity and postmodernity. *Disability & Society, 17*(5), 571-584.

Hughes, B. (2004). Disability and the body. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers, enabling environments* (2nd ed., pp. 63-68). London: Sage.

Hughes, B. (2009). Disability activisms: Social model stalwarts and biological citizens. *Disability & Society, 24*(6), 677-688.

Hughes, B. (2012). Elias: Disability, modernity and cultures of exclusion. In D. Goodley, B. Hughes, & L. Davis (Eds.), *Social theories of disability: New developments*. Basingstoke: Palgrave.

Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of 'impairment'. *Disability & Society, 12*(3), 325-340.

Hughes, B., & Paterson, K. (2000). Disabled bodies. In P. Hancock, B. Hughes, E. Jagger, K. Paterson, R. Russell, E. Tulle-Winton, & M. Tyler (Eds), *The body, culture and society: An introduction* (pp. 29-44). Buckingham: Open University Press.

Hughes, B., & Paterson, K. (2006). The social model of disability and the disappearing body: Towards a sociology of impairment. In L. Barton (Ed.), *Overcoming disabling barriers* (pp. 91-107). Oxon: Routledge.

Ikäheimo, H. (2009). Personhood and the social inclusion of people with disabilities: A recognition-theoretical approach. In K. Kristiansen, S. Vehmas, & T. Shakespeare, *Arguing about disability: Philosophical perspectives* (pp. 77-92). London: Routledge.

Ingstad, B., & Reynolds Whyte, S. (Eds.). (1995). *Disability and culture*. Los Angeles: University of California Press.

Jenkins, R. (1996). *Social identity*. London: Routledge.

Jones, P. (2006). Equality, recognition and difference. *Critical Review of International Social and Political Philosophy, 9*(1), 23-46.

Kagan C., Burton M, Duckett P, Lawthom R, Siddiquee A. (2011). *Critical Community Psychology*. Wiley- Blackwell, Oxford.

Kiesler, D. J. (1999). *Beyond the disease model of mental disorders*. Westport. CT: Praeger.

Kleinfield, S. (1979). *The hidden minority: A profile of handicapped Americans*. Boston: Atlantic Monthly Press.

Kristeva, J. (1982) *The powers of horror: An essay on abjection*. New York: Columbia University Press.

Kristiansen, K., Vehmas, S., & Shakespeare, T. (2009). Introduction: The unavoidable alliance of disability studies and philosophy. In K. Kristiansen,

S. Vehmas, & T. Shakespeare, *Arguing about disability: Philosophical perspectives* (pp. 1-11). London: Routledge.

Lather, P. (1991). *Getting smart: Feminist research and pedagogy with/in the postmodern.* New York: Routledge.

Leder, D. (1990). *The absent body*. Chicago: University of Chicago Press.

Letherby, G. (2003). *Feminist research in theory and practice*. Buckingham: Open University Press.

Liachowitz, C. H. (1988). *Disability as a social construct: Legislative roots*. Philadelphia: University of Pennsylvania Press.

Linton, S. (1998a). Disability studies/not disability studies. *Disability & Society, 13*(4), 525–539.

Linton, S. (1998b). *Claiming disability: Knowledge and identity*. New York: New York University Press.

Livneh, H. (1982). On the origins of negative attitudes toward people with disabilities. *Rehabilitation Literatura*, *43*, 338-347.

Locker, D. (1983). *Disability and disadvantage*. London: Tavistock.

Longmore, P. K. (1987). Screening stereotypes, images of disabled people in television and motion pictures. In A. Gartner & T. Joe (Eds.), *Images of the Disabled, Disabling Images* (pp. 65-78). New York: Praeger.

Longmore, P. K., & Umansky, L. (Eds.). (2001). *The new disability history*. New York: New York University Press.

Lyotard, J.-F. (1979). *The postmodern condition: A report on knowledge*. Manchester: Manchester University Press.

Mackenzie, C., & Scully, J. L. (2007). Moral imagination, disability and embodiment. *Journal of Applied Philosophy, 24*(4), 335-355.

Marks, D. (1999a). *Disability: Controversial debates and psychosocial perspectives*. London: Routledge.

Marks, D. (1999b). Dimensions of oppression: Theorizing the embodied subject. *Disability & Society, 14*(5), 611–626.

Masefield, P. (2006). *Strength: Broadsides from disability on the art.* Trentham: Stoke-on-Trent.

McCarthy, H. (2003). The disability rights movement: Experiences and perspectives of selected leaders in the disability community. *Rehabilitation Counseling Bulletin*, *46*, 209-223.

McRuer, R. (2002). Critical investments: AIDS, Christopher Reeve, and queer/disability studies. *Journal of Medical Humanities, 23*(3/4), 221-237.

McRuer, R. (2006). *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press.

McRuer, R., & Wilkerson, A. L. (2003) Introduction, desiring disability: Queer theory meets disability studies. *GLQ: A Journal of Lesbian & Gay Studies*, *9*(1/2), 1-23.

Meekosha, H. (1998a). Superchicks, clones, cyborgs, and cripples: Cinema and messages of bodily transformations. *Social Alternatives, 18*(1), 24-28.

Meekosha, H. (1998b). Body battles: Bodies, gender and disability. In T. Shakespeare (Ed.), *The disability reader* (pp. 163-180). London: Continuum.

Meekosha, H. (2004). Drifting down the Gulf Stream: Navigating the cultures of disability studies. *Disability & Society, 19*(7), 721-733.

Meekosha, H., & Jakubowicz, A. (1996). Disability, participation, and representation in social justice. In C. Christensen & F. Rizvi (Eds.), *Disability and the dilemmas of education and justice* (pp. 79-95). Buckingham: Open University Press.

Merleau-Ponty, M. (1962). *Phenomenology of perception* (C. Smith, Trans). London: Routledge.

Merleau-Ponty, M. (1968). *The visible and the invisible.* Evanston, IL: Northwestern University Press.

Michalko, R. (2002). *The difference that disability makes.* Philadelphia, PA: Temple University Press.

Michalko, R. (2009). The excessive appearance of disability. *International Journal of Qualitative Studies in Education, 22*(1), 65-74.

Mills, C.W. (1959). *The sociological imagination*. London: Penguin.

Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, *24*(1), 47-62.

Mitchell, D., & Snyder, S. (2006). Narrative prosthesis and the materiality of metaphor. In L. Davis (Ed.), *The disability studies reader* (2nd ed., pp. 205-216). New York: Routledge.

Morgan, K., & Nerison, R. (1993). Homosexuality and psychopolitics: An historical overview. *Psychotherapy*, *30*(1), 133-140.

Morris, J. (1991). *Pride against prejudice: Transforming Attitudes to Disability*. London: Women's Press.

Morris, J. (1993). *Independent lives: Community care and disabled people.* London: Macmillan.

Morris, J. (Ed.). (1996). *Encounters with strangers: Feminism and disability*. London: The Women's Press.

Nata, G. & Menezes, I. (2007). Escala de Suporte dos Direitos das Minorias [Minorities' Rights Support Scale], In *Diferença Cultural e Democracia: identidade, cidadania e tolerância na relação entre maioria e minorias* [Cultural Difference and Democracy: identity, citizenship and tolerance between the majority and the minorities] (Doctoral dissertation). Faculty of Psychology and Educational Sciences of University of Porto, Porto, Portugal.

Oliver, M. (1983). *Social work with disabled people*. Basingstoke: Macmillan.

Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan.

Oliver, M. (1996). *Understanding disability: From theory to practice.* Basingstoke: Macmillan.

Oliver, M., & Barnes, C. (1996). *Disabled people and social policy: From exclusion to inclusion.* London: Longman.

Oliver, M., & Zarb, J. (1997). The politics of disability: A new approach. In L. Barton & M. Oliver (Eds.), *Disability studies: Past, present and future* (pp. 195-216). Leeds: The Disability Press.

Olkin, R. (2002). Could you hold the door for me?: Including disability in diversity. *Cultural Diversity and Ethnic Minority Psychology*, *8*(2), 130-137.

Olkin, R. (2003). Women with physical disabilities who want to leave their partners: A feminist and disability-affirmative perspective. *Women and Therapy, 26*(3/4), 237-246.

Olkin, R. (2009). *Women with physical disabilities who want to leave their partners: A feminist and disability-affirmative perspective.* Berkeley, CA: California School of Professional Psychology/Through the Looking Glass, Co.

Olkin, R., & Pledger, C. (2003). Can disability studies and psychology join hands?. *American Psychologist, 58*(4), 296-304.

Overboe, J. (2007). Disability and genetics: Affirming the bare life (the state of exception). Genes and Society: Looking Back on the Future [Special Issue]. *Canadian Review of Sociology, 44*(2), 219-235.

Parsons, T. (1951). Illness and the role of the physician: A Sociological perspective. *American Journal of Orthopsychiatry, 21*, 452-460.

Paterson, K., & Hughes, B. (1999). Disability studies and phenomenology: The carnal politics of everyday life. *Disability & Society, 14*(5), 597-610.

Pfeiffer, D. (1998). The ICIDH and the need for its revision. *Disability & Society, 13*(4), 503-523.

Pfeiffer, D. (2000). The devils are in the details: The ICIDH2 and the disability movement. *Disability & Society, 15*(7), 1079-1082.

Phillips, A. (1993). *Democracy and difference.* Cambridge: Polity.

Phillips, A. (1995). *The politics of presence.* Oxford: Clarendon Press.

Pinto, P. C., & Teixeira, D. (2012). *DRPI-Portugal: Relatório final.* Lisboa: Disability Rights Promotion International Portugal.

Price, J., & Shildrick, M. (1998). Uncertain thoughts on the dis/abled body. In M. Shildrick & J. Price (Eds.), *Vital signs: Feminist reconstructions of the biological body* (pp. 224-249). Edinburgh: University Press.

Priestley, M. (2003). *Disability: A life course approach.* Cambridge: Polity.

Prilleltensky, I. & Nelson, G. (2002). *Doing psychology critically: making a difference in diverse settings.* New York: Pallgrave McMillan.

Promis, D., Erevelles, N., & Matthews, J. (2001). Reconceptualizing inclusion: The politics of university sports and recreation programs for students with mobility impairments. *Sociology of Sport Journal, 18*, 37-50.

Putnam, M. (2005). Conceptualizing disability: Developing a framework for political disability identity. *Journal of Disability Policy Studies, 16*(3), 188-198.

Reeve, D. (2002). Negotiating psycho-emotional dimensions of disability and their influence on identity constructions. *Disability & Society, 17*(5), 493-508.

Reeve, D. (2007). *Homo sacer and zones of exception: Metaphors for the contemporary experience of disablism?.* Paper presented at the Nordic Network of Disability Research Conference, Stockholm.

Reeve, D. (forthcoming). Psycho-emotional disablism: The missing link?. In N. Watson, A. Roulstone and C. Thomas (Eds), *Routledge Companion to Disability Studies*, London: Routledge.

Reid, P., & Bray, A. (1998). Real jobs: The perspectives of workers with learning disabilities. *Disability & Society*, *13*, 229-39.

Robertson, C. (2001). Autonomy and identity: The need for new dialogues in education and welfare. *Support for Learning, 16*(3), 122-127.

Rosenwasser, P. (2000). *Tool for transformation: Co-operative inquiry as a process for healing from internalized oppression*. Paper presented at the Adult Education Research Conference (AERC), British Columbia.

Saxton, M. (2000). Why members of the disability community oppose prenatal diagnosis and selective abortion. In E. Parens & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 147-164). Washington, DC: Georgetown University Press.

Schall, C. M. (1998). The American disabilities act: Are we keeping our promise? An analysis of the effect of the ADA on the employment of people with disabilities. *Journal of Vocational Rehabilitation*, *10*, 191-203.

Schalock R. L., & Keith K. D. (1993). *Quality of Life Questionnaire.* Worthington, OH: IDS Publishing Corporation.

Schalock, R. L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R. L. Schalock (Ed.), *Quality of life: Volume I: Conceptualization and measurement* (pp. 123-39). Washington, DC: American Association on Mental Retardation.

Schalock, R. L., & Verdugo, M. A. (2003). *Calidad de vida: Manual para professionales de la educación, salud y servicios sociales.* Madrid: Alianza Editorial.

Scott-Hill, M. (2004). Impairment, difference and 'identity'. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers: Enabling environments* (pp. 87-93). London: Sage.

Scully, J. L. (2003). Drawing lines, crossing lines: Ethics and the challenge of disabled embodiment. *Feminist Theology, 11*(3), 265-280.

Shakespeare, T. (1996). Disability, identity and difference. In C. Barnes & G. Mercer (Eds.), *Exploring the divide* (pp. 94-113). Leeds: The Disability Press.

Shakespeare, T. (1997). Rules of engagement: Changing disability research. In L. Barton & M. Oliver (Eds.), *Disability studies: Past present and future* (pp. 248-253). Leeds: The Disability Press.

Shakespeare, T. (2000). *Help*. Birmingham: Venture Press.

Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

Shakespeare, **T**. (2007). Debating disability. *Journal of Medical Ethics, 34*, 11-14.

Shakespeare, T. W., & Watson, N. (1997). Defending the social model. *Disability & Society, 12*(2) 293-300.

Shakespeare, T., & Watson, N. (2001a) The social model of disability: An outdated ideology?. In S. Barnarrt & B. M. Altman (Eds.), *Exploring theories and expanding methodologies: Where are we and where do we need to go?* (Vol. 2, pp. 9-28). Amsterdam: JAI.

Shakespeare, T., & Watson, N. (2001b). Making the difference: Disability, politics and recognition. In G. Albrecht, K. D. Seelman, & M. Bury (Eds.), *The Handbook of disability studies* (pp. 546-564). Thousand Oaks, CA: Sage.

Shapiro, J. P. (1993). *No pity: People with disabilities forging a new civil rights movement.* New York: time books.

Sherry, M. (2006). *If I only had a brain: Deconstructing brain injury*. London: Routledge.

Shildrick, M. (2002). *Embodying the monster: Encounters with the vulnerable self.* London: Sage.

Shildrick, M. (2009). *Dangerous discourses of disability, subjectivity and sexuality*. Hampshire, UK: Palgrave Macmillan.

Shildrick, M., & Price, J. (1999a). Openings on the body: A critical Introduction. In J. Price and M. Shildrick (Eds.), *Feminist theory and the body* (pp. 1–14). Edinburgh: Edinburgh University Press.

Shildrick, M., & Price, J. (1999b). Breaking the boundaries of the broken body. In J. Price & M. Shildrick (Eds.), *Feminist theory and the body* (2nd ed., pp. 432-444). Edinburgh: Edinburgh University Press.

Shilling, C. (1993). *The body and social theory*. London: Sage.

Shilling, C. (2005). *The body in culture, technology and society*. London: Sage.

Silvers, A. (1998a). Disability rights. In R. Chadwick, D. Callahan, & P. E. Singer (Eds.), *Encyclopedia of applied ethics* (pp. 781-796). San Diego, CA: Academic Press.

Silvers, A. (1998b). Formal justice. In A. Silvers, D. Wasserman, & M. B. Mahowald (Eds.), *Disability, difference, discrimination: Perspectives on justice in bioethics and public policy* (pp. 13-146). Lanham, MD: Rowman and Littlefield.

Sink, J. M., Field, T. F., & Gannaway, T. (1978). History and scope of adjustment services in rehabilitation. *Journal of Rehabilitation*, *44*(1), 14-19.

Sloan, T. (2000). *Critical psychology: voices for change.* London: McMillan Press.

Smart, J. F. (2001). *Disability, society and the individual.* Austin, TX: Pro-Ed.

Smart, J. F. (2004). Models of disability: The juxtaposition of biology and social construction. In T. F. Riggar & D. R. Maki (Eds.), *Handbook of rehabilitation counseling* (pp. 25-49). New York: Springer.

Smart, J. F. (2005). The promise of the International Classification of Functioning, Disability, and Health (ICF). In A.E. Dell Orto, & P.W. Power, *The psychological and social impact of illness and disability (5th ed.).* (pp. 582-595). New York: Springer Publishing Co.

Smart, J. F., & Smart, D. W. (2006). Models of disability: Implications for the counseling profession. *Journal of Counseling & Development*, *84*, 29-40.

Smith, S. R. (2009). Social justice and disability: Competing interpretations of the medical and social models. In K. Kristiansen, S. Vehmas, & T. Shakespeare, *Arguing about disability: Philosophical perspectives* (pp. 15-29). London: Routledge.

Stiker, H. (1997). *A history of disability*. Ann Arbor: University of Michigan Press.

Stone, E. (1999). Disability and development in the majority world. In E. Stone (Ed.), *Disability and development: Learning from action and research on disability in the majority world* (pp. 1-18). Leeds: The Disability Press.

Stromstad, M. (2004). Accounting for the ideology and politics in the development of inclusive practice in Norway. In L. Ware (Ed.), *Ideology and the politics of (in)exclusion* (pp. 146–165). New York: Peter Lang.

Sutherland, A. (1981). *Disabled we stand.* London: Souvenir Press.

Swain, J., & Cameron, C. (1999). Unless otherwise stated: Discourses of labelling and identity in coming out. In M. Corker & S. French (Eds.), *Disability discourse* (pp.68-78). Buckingham, UK: Open University Press.

Swain, J., & French, S. (2000). Towards an affirmative model of disability. *Disability and Society, 15*(4), 569-582.

Swain, J., & French, S. (2004). Researching together: A participatory approach. In S. French & J. Sim (Eds.), *Physiotherapy: A psychosocial approach* (pp. 317-332). Oxford: Butterworth-Heinemann.

Swain, J., & French, S. (2008). Affirming identity. In J. Swain & S. French (Eds.), *Disability on equal terms* (pp. 65-78). London: Sage.

Swain, J., French, S., & Cameron, C. (2003). *Controversial issues in a disabling society.* Buckingham: Open University Press.

Takala, T. (2009). Gender, disability and personal identity: Moral and political problems in community thinking. In K. Kristiansen, S. Vehmas, & T. Shakespeare, *Arguing about disability: Philosophical perspectives* (pp. 124-133). London: Routledge.

Taylor, C. (1992). *The ethics of authenticity.* Cambridge, MA: Harvard University Press.

Taylor, C. (1994). The politics of recognition. In A. Gutmann (Ed.), *Multiculturalism: Examining the politics of recognition* (pp. 25-73). Princeton, NJ: Princeton University Press.

Teixeira, P. (2012). *Dispositivos de intervenção no domínio da Reabilitação: a promoção do empoderamento e da cidadania de pessoas incapacitadas em Portugal* [Intervention devices in the rehabilitation field: the promotion of empowerment and citizenship of disabled people in Portugal] (Doctoral dissertation). Faculty of Psychology and Educational Sciences of University of Porto, Porto, Portugal.

Thomas, C. (1999). *Female forms: Experiencing and understanding disability.* Buckingham: Open University Press.

Thomas, C. (2001). Feminism and disability: The theoretical and political significance of the personal and the experiential. In L. Barton (Ed.), *Disability, politics and the struggle for change* (pp. 48-58). London: David Fulton.

Thomas, C. (2004a). Disability and impairment. In In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers: Enabling environments* (2nd ed., pp. 21-27). London: Sage.

Thomas, C. (2004b). Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research, 6*(1), 22-36.

Thomas, C. (2004c). How is disability understood? An examination of sociological approaches. *Disability & Society, 19*(6), 569-583.

Thomas, C. (2004d) Developing the social relational in the social model of disability: a theoretical agenda, in: C. Barnes & G. Mercer (Eds) *Implementing the social model of disability: theory and research* (Leeds, The Disability Press).

Thomas, C. (2007). *Sociologies of disability, 'impairment', and chronic illness: Ideas in disability studies and medical sociology*. London: Palgrave.

Titchkosky, T. (2003). *Disability, self and society*. Toronto: University of Toronto Press.

Titchkosky, T. (2007). *Reading & writing disability different: The textured life of embodiment.* Toronto: University of Toronto Press.

Tøssebro, J. (2004). Understanding disability. *Scandinavian Journal of Disability Research, 6*(1), 3-7.

Tregaskis, C. (2003). *Constructions of disability: Researching the interface between disabled and non-disabled people*. London: Routledge.

Tremain, S. (2000). Queering disability studies. *Sexuality and Disability, 18*(4), 291-299.

Tremain, S. (2002). On the subject of impairment. In M. Corker & T. Shakespeare (Eds.), *Disability/Postmodernity: Embodying disability theory* (pp. 32–47). London: Continuum.

Tremain, S. (2006). On the government of disability: Foucault, power and the subject of impairment. In K. Davis (Ed.), *The disability studies reader* (2nd ed., pp. 185–196). New York: Routledge.

Turner, B. (2008). *The body and society* (3rd ed.). London: Sage.

Turner, B. S. (1992). *Regulating bodies: Essays in medical sociology*. London: Routledge.

Vehmas, S. (2004). Ethical analysis of the concept of disability. *Mental Retardation*, *42*, 209-222.

Vehmas, S. (2008). Philosophy and science: The axes of evil in disability studies? *Journal of Medical Ethics*, *43*, 21-23.

Vernon, A. (1999). The dialectics of multiple identities and the disabled people's movement. *Disability & Society*, *14*, 385-398.

Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability. *Disability & Society*, *17*(5), 509-527.

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability.* London: Routledge.

Williams, C. (2003). Sky service: The demands on emotional labor in the airline industry. *Gender, Work and Organisation, 10*(5), 513-551.

Young, I. M. (1990). *Justice and the politics of difference.* Princeton, NJ: Princeton University Press.

Young, I. M. (1997). Asymmetrical reciprocity: On moral respect, wonder, and enlarged thought. *Constellations, 3*(3), 340-363.

Zarb, G. (1992). On the road to damascus: First steps towards changing the relations of disability research production. *Disability, Handicap & Society*, *7*(2), 125-138.

Zimmerman, M. A., & Warschausky, S. (1998). Empowerment theory for rehabilitation research: Conceptual and methodological issues. *Rehabilitation Psychology, 43*(1), 3-16.

APPENDIX

Faculdade de Psicologia e de Ciências da Educação
Universidade do Porto

Este estudo insere-se no âmbito de uma investigação de doutoramento em curso na Universidade do Porto acerca do impacto dos discursos sociais e políticos na vivência da incapacidade física em Portugal, cujo objectivo é perceber a qualidade de vida das pessoas com incapacidade física e a forma como as barreiras físicas e sociais interferem nas suas vidas. Destina-se assim a pessoas com incapacidade física congénita ou adquirida, sendo que, no caso de ser adquirida, esta deverá ter, pelo menos, 1 ano de existência. O seu contributo é muito valioso para nós e por isso pedimos-lhe que colabore connosco, respondendo às questões seguintes da forma mais sincera possível. A informação que dará é anónima e os dados serão apenas usados para fins de investigação.

No caso de querer mais informações sobre este estudo poderá usar o seguinte e-mail incapacidadefisica@fpce.up.pt para contactar a equipa de investigação.

Agradecemos desde já a sua disponibilidade e colaboração!

Ema Loja
Isabel Menezes
Maria Emília Costa

Nas páginas seguintes irá encontrar uma série de afirmações para as quais lhe pedimos que avalie segundo uma escala de 1-5, sendo que **1** corresponde a “**Discordo totalmente**” e **5** corresponde a “**Concordo totalmente**”.

Leia atentamente cada uma das frases e assinale a resposta que melhor descreve a forma como **habitualmente se sente ou pensa.** Não pense demasiado no significado de cada questão. A resposta mais espontânea é a mais valiosa.

Satisfação	Discordo totalmente — Concordo totalmente
1. De uma forma geral, a minha vida é como eu quero que seja.	1 2 3 4 5
2. Ao comparar-me com os outros, eu estou melhor que eles.	1 2 3 4 5
3. A maioria das coisas que me ocorrem na vida são gratificantes.	1 2 3 4 5
4. Estou satisfeito/a com as condições do sítio onde vivo.	1 2 3 4 5
5. Consigo movimentar-me bem no meio onde vivo.	1 2 3 4 5
6. Tenho menos problemas que as outras pessoas.	1 2 3 4 5
7. Estou satisfeito/a com as minhas relações pessoais.	1 2 3 4 5
8. Estou satisfeito/a com a minha aparência física.	1 2 3 4 5
9. Estou satisfeito/a com a minha vida sexual.	1 2 3 4 5
10. Estou satisfeito/a com o acesso aos cuidados de saúde.	1 2 3 4 5
11. Estou satisfeito/a com a minha saúde.	1 2 3 4 5
Estudo e trabalho	
12. O meu trabalho ou o que faço diariamente é importante para mim e para os outros.	1 2 3 4 5

Se estiver desempregado/a ou não trabalha, passe para a pergunta 23.

Se não estiver a estudar ou a fazer formação, passe para a pergunta 26.

13. Considero que sou bom/boa no meu trabalho.	1 2 3 4 5
14. Os meus colegas de trabalho tratam-me bem.	1 2 3 4 5
15. Estou satisfeito/a com as capacidades e experiência que tenho adquirido no trabalho.	1 2 3 4 5
16. Acho que recebo um salário justo pelo meu trabalho.	1 2 3 4 5
17. O meu trabalho proporciona-me o dinheiro suficiente para comprar as coisas que preciso.	1 2 3 4 5
18. Estou satisfeito/a com os benefícios que tenho no meu trabalho.	1 2 3 4 5

Se não está a estudar ou a fazer formação passe para a pergunta 26.

19. No meu curso/ formação considero que sou bom/boa.	1 2 3 4 5
20. Os meus colegas de curso/formação tratam-me bem.	1 2 3 4 5
21. Estou satisfeito/a com as capacidades e experiência que tenho adquirido no meu curso/formação.	1 2 3 4 5

Quotidiano	Discordo totalmente — Concordo totalmente
22. Os meus amigos podem visitar-me em minha casa quando querem.	1 2 3 4 5
23. Posso sair e entrar em casa quando quero.	1 2 3 4 5

Direitos	
24. As pessoas com incapacidade física devem ter as mesmas oportunidades que qualquer pessoa.	1 2 3 4 5
25. Se uma pessoa com incapacidade física fizer um trabalho igual ao de outra pessoa, deverá receber o mesmo salário.	1 2 3 4 5
26. As pessoas com incapacidade física devem ter os mesmos direitos que qualquer outra pessoa.	1 2 3 4 5
27. As pessoas com incapacidade física devem ter direitos especiais porque são discriminadas (tratadas de forma negativa pelas pessoas e pela sociedade).	1 2 3 4 5
28. As pessoas com incapacidade física deviam ter um representante (um lugar) nos órgãos de poder (Assembleia da República, Câmaras, Juntas de Freguesia,…) porque são uma minoria.	1 2 3 4 5
29. As pessoas com incapacidade física devem ter condições (subsídios por ex.) para ter uma vida independente.	1 2 3 4 5

Nas próximas questões, deverá responder considerando que 1 corresponde “Decidi completamente sozinho” e 5 corresponde “Alguém decidiu completamente por mim”.	Decidi completamente sozinho — Alguém decidiu completamente por mim
30. Quem decidiu o trabalho ou as actividades que faz diariamente?	1 2 3 4 5
31. Quem decide como gasta o seu dinheiro?	1 2 3 4 5
32. Quem decide sobre as coisas que faz diariamente, como ir para a cama, comer?	1 2 3 4 5
33. Quem decide as actividades que faz por lazer?	1 2 3 4 5

(QOL.Q, Schalock & Keith, 1993a; WHOQOL-BREF, OMS, 2004; Quality of Life Index, Ferrans & Power, 1984; Disability Assessment Schedule, OMS, 2001; EDM, Nata & Menezes, 2007)

As questões seguintes visam perceber em que medida já viveu uma experiência em que se sentiu discriminado/a por outras pessoas ou instituições.

34. Alguma vez se sentiu discriminado/a (tratado/a de forma negativa pelas pessoas e pela sociedade)?	Sim ☐ Não ☐
35. Se sim, considera que foi discriminado/a por causa de: (pode escolher mais que uma opção se tiver sido o caso)	Deficiência ☐ Raça ☐ Idade ☐ Religião ☐ Sexo ☐ Orientação sexual ☐ Estatuto económico ☐ Outro(s)☐ Qual(is)?______________________
36. Se sim, em que contexto(s) isso ocorreu?	Escola ☐ Emprego ☐ Família ☐ Amigos ☐ Serviços de Saúde ☐ Outros ☐ Qual(is)?________________________________ ____ ____
37. Se sim, em que medida isso o/a deixou desconfortável?	Nada Muito 1 2 3 4 5

(EDS, Sanders, 1996)

1. Sexo: Masculino ☐ Feminino ☐

2. Data de nascimento _____________

3. Estado Civil: ___________________

4. Tem filhos? Não ☐ Sim ☐

5. Grau de escolaridade

Não sabe ler nem escrever, ou não frequentou a escola ☐

1º. ciclo do ensino básico (1º.-4º.anos) ☐

2º. ciclo do ensino básico (5º.-6º. anos) ☐

3º. ciclo do ensino básico (7º.-9º. anos) ☐

Ensino secundário (10º.-12º. anos) ☐

Curso técnico ☐ Qual?__________________________

Curso superior ☐ Qual? __________________________

Pós-graduação (mestrado, doutoramento) ☐

6. Quantos livros tem em casa?

Até 10 livros ☐

De 11 a 50 (uma prateleira) ☐

De 51 a 150 (várias prateleiras) ☐

Mais de 151 (uma ou mais estantes) ☐

7. Qual é a sua situação profissional?

Empregado(a) ☐ Profissão:_____________________________

Desempregado(a) ☐

Não trabalha/Reformado(a) ☐

Estudante ☐

Em formação ☐

Trabalhador(a)-estudante ☐

8. Qual é a sua fonte de rendimentos?

Emprego ☐

Subsídio ou pensão ☐ Qual?____

Outro(s) ☐ Qual(is)?____

9. Especifique a deficiência que tem:____

10. Tem alguma deficiência a nível cognitivo? Não ☐ Sim ☐

11. Tem alguma deficiência a nível sensorial (visual ou auditiva)?

Não ☐ Sim ☐

12. Origem da deficiência: Congénita ☐ Adquirida ☐ Há quanto tempo? _________

13. Como é que se move?

Sem ajuda técnica ☐ Com ajuda técnica como canadianas, próteses (por ex.) ☐

Cadeira de rodas: Manual ☐ Eléctrica ☐

14. Como se desloca normalmente?

Viatura própria (conduz) ☐

Viatura de familiares/amigos ☐

Transporte público (autocarro, metro, camioneta) ☐

Táxi ☐

Outros ☐ Qual?_____________________________________

15. Tem dificuldades em falar e/ou em ser compreendido/a? Sim ☐ Não ☐

16. Para as seguintes tarefas, por favor diga se necessita ou não de ajuda, e no caso de necessitar, diga se tem ajuda disponível ou não e ainda se a ajuda é total ou parcial. Ponha uma cruz na resposta que é mais adequada para si.

	Consegue fazer sozinho	Necessita de ajuda			
		Ajuda disponível	Ajuda não disponível	Ajuda total	Ajuda parcial
Tomar banho					
Vestir-se					
Comer					
Realizar atividades domésticas					
Fazer compras no supermercado					
Preparar refeições, cozinhar					
Estar sozinho/a por uns dias					

(Disability Assessment Schedule, OMS, 2001; POPS, Brown, 2006)

17. Gostaria de acrescentar alguma informação/comentário ao questionário?

Por favor verifique se preencheu todo o questionário.

Muito obrigada pela sua colaboração!