Social Relationships and Social Participation of Women with Disability

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To my family

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PREFACE

This book explores the social relationships and participation of women with disabilities, as well as the barriers they are facing within their physical and social environments. The book is based on the doctoral research I conducted in 2017–18. Qualitative social research methods were applied for this work, and in particular, interviews I conducted with thirty women (aged 22–44) with three different types of disability (mental, physical, and sensory), living in Milan, Italy. According to the current literature relevant to this topic, many of the findings of this research appear to concern not only women with disabilities living in Italy, but also persons with disabilities widely. The idea for this research derived from years of my professional and academic experience on topics related to disabilities and the sociology of health. It has also been my passion and personal interest to gain a better understanding of how our disabling society can finally embrace and treat all people as equal, and applaud differences and variety in our social world, against "normalisation." Moreover, after reviewing the current scientific literature on this subject, it appeared that there is a lack of up-to-date research, and thus information, on social relationships and social participation-related aspects focusing simultaneously on more than one type of disability, and women in particular.

Various key aspects of social relationships have been explored in the present book, for example: social network characteristics and trustworthiness (constituting components of social capital); social support; employment and leisure activities; political participation; coping mechanisms; loneliness; and barriers to social participation and autonomous living, along with suggestions to overcome these barriers.

Disability has been conceptualised in this study following the biopsychosocial model of functioning and disability of the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF). Accordingly, disability is perceived not as an intrinsic characteristic or deficit of a person due to their health condition, but as a multifaceted deficit of the surrounding contextual factors, which, in conjunction with body structures and functions, fail to facilitate the full integration of the person with a health condition in all aspects of social life.

Furthermore, barriers to and facilitators for the social participation and inclusion of persons with disabilities, through patterns of their reported experiences, in terms of their social relationships and social participation, have been identified. This book is intended for not only academics, health professionals, researchers, and other experts in the field, but also persons with disabilities who are interested in exploring how they could overcome the barriers to social participation they are facing based on suggestions from other persons with disabilities and the current scientific literature. The points made in this book can contribute to the discussion around the full integration of persons with disabilities through the removal of the barriers to their social participation and autonomy, together with the strengthening of their social relationships and received support.

Nowadays, the pure biomedical model of health and disability has been largely considered as outdated and it is suggested that it should no longer be adopted in policies and everyday healthcare practice, without consideration of the social determinants of health and their impact. Additionally, although numerous studies highlight the fact that the social and physical environment of a person has an enormous impact on their health and wellbeing, physicians often do not focus on the social experiences of their patients at all, and only on the biomedical treatment. However, medicalised remedies are not the only way to help people improve their health and disability experiences. Concerning the mentality dominating the medical profession of “fixing” the person with a disability, it is time to replace this with exploring how their everyday lives could be improved through enhancing the facilitating contextual factors surrounding the person. It is not the person with a disability that is unable to integrate, but the inability of the physical and social environment that hinders full integration for everyone equally. It is clear from this study that women with disabilities experience numerous and multi-faceted barriers related to their personal and social development, having an impact on their physical and mental health, as well as overall wellbeing. The biopsychosocial model of health and disability could be employed towards the goal of full social inclusion as it is time to move beyond the perception of “fixing” the person with a disability and develop a more facilitatory social and physical environment that enables individuals’ full inclusion in society (Koutsogeorgou 2018).

The book is structured with the aim to provide the reader with an overview of the definitions and aspects of the main concepts, along with the rationale for conducting this study (in chapter one), and the description of this social research and its findings in the following chapters. Chapter two includes an extensive description of the main issues related to sociology and medicine, and the perception of “normal” in society, as well as a discourse of the main models in medicine and the sociology of health related to the three types of disability explored in this study. Chapter two also includes a review of the literature on gender differences and issues of social inclusion of persons with disabilities, presented by type of disability. The reader in this chapter will become familiar with not only the Italian but also the broad international policy context on the topic of social inclusion of persons with disabilities, along with a focus on the issues of discrimination and abuse against women with disabilities in Europe specifically. In addition, qualitative research on persons with disabilities, and women in particular, is presented in this chapter, as well as a short description of the methodology of the qualitative research this book is based on.

Chapter three includes the evidence which emerged from this research for each type of disability, with the themes divided into two main areas (i.e. body, the self, and disability; and social relationships, social participation, and disability). Chapter four presents the main findings of the present study across type of disability under each core theme that emerged. All patterns discerned among participants in this research, both within and across type of disability, are presented in chapter five, including comparisons across type of disability based on social capital components.

Finally, chapter six describes the implications and recommendations of this study for improving the experiences of women with disabilities, based on the suggestions of participants and the discussion in the current literature on the main issues that emerged.

Given that this book is based on a research I conducted for my doctoral thesis, I wish to thank a number of people who assisted me in conducting it. Firstly, I wish to thank my supervisor Prof. Mario Cardano for his valuable guidance and constructive feedback throughout my doctoral work, with his methodological expertise and impeccable eye for detail. I also wish to thank Prof. Monica Santoro, my co-supervisor, for her advice, particularly on the preparation of the study and assistance in finding participants.

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London, February 28, 2020

CHAPTER ONE

INTRODUCTION

Social Relationships, Social Networks, and Social Support

Social relationships, and the networks formed among them, are an integral part of social life and essential for the sociality of individuals. Our knowledge of the comparative effects of various social relationship dimensions is limited due to the inconsistency of the terminology used, since studies often define social support as part of social networks, while others treat social networks and social support as two distinct dimensions of social relationships (Valtorta et al. 2016; House and Kahn 1985). For example, House and Kahn (1985) define social support as the functional content of social relationships, such as "the degree to which the relationships involve flows of affect or emotional concern, instrumental or tangible aid, information, and the like" (85). The same authors define a social network as the structural dimension of social relationships, encompassing aspects such as size, density, reciprocity, frequency, and homogeneity (House and Kahn 1985). Similarly, Berkman et al. (2000) define social networks as the ties between people within social groups, based on their common characteristics, such as kinship, residence, and social class. Furthermore, social interaction is the mutual influence between two or more people on another person's behaviour, which creates a relationship, and these relationships form the basis of a community's social structure (Soleimani et al. 2014). Social support is perceived in this book as the functional aspect of social relationships, covering a wide range of types of assistance, such as provision or receipt of information, instrumental, psychological, or emotional support, institutional or financial support, and advice (Valtorta et al. 2016), and as a concept which is distinct from social network, yet closely linked. Social networks can be divided into formal (such as religious, political, and other organised social groups) and informal (such as among friends, colleagues, and neighbours) (Kaasa and Parts 2008).

Social Capital

Social networks have also been considered as one of the components of social capital, a notion based on the work of Bourdieu (1986), Coleman (1988; 1994), and Putnam (1993; 1995; 1996; 2000). More specifically, according to Pierre Bourdieu, "social capital is the sum of the resources, actual or virtual, that accrue to an individual or group by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and recognition" (Bourdieu and Wacquant 1992, 119). One of the most widely recognised definitions of social capital – particularly in relation to health research (Koutsogeorgou et al. 2015) – is that by Putnam (2000): "social capital refers to connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them" (Putnam 2000, 19). Furthermore, participation in formal and informal social networks constitutes one of the two dimensions of individual-level social capital – the structural dimension. The other dimension of social capital is the cognitive one, which refers to the trust a person has towards other people in general ("general trust") and institutions ("institutional trust"), as well as the civic norms of the surrounding environment (Kaasa and Parts 2008). To date, there is no universally accepted definition of social capital, however the most established definitions used extensively by scholars internationally overlap in the dimensions of social capital mentioned above. This book acknowledges the vagueness and lack of a universally-accepted definition and measurement/indicators of social capital, and thus it should be clarified that social capital has been employed as a *sensitizing* concept, and not as a *definitive* one. As defined by Herbert Blumer (1954) "whereas definitive concepts provide prescriptions of what to see, sensitizing concepts merely suggest directions along which to look" (7). Accordingly, in this book, social capital has been considered as a sensitizing concept providing a sense of reference and guidance to approaching the current empirical work, since it does not yet have a clear and widely-accepted definition of its attributes.

Social Participation

A previous qualitative study on perceptions of participation (Hammel et al. 2008) found that persons with diverse disabilities viewed participation also as a means of experiencing social connectedness with communities and other people, indicating issues of social capital. Based on the same source, persons with disabilities have defined participation "as a multifaceted, transactive process involving interaction with and within physical, social, cultural and political environments and communities" (Hammel et al. 2008, 1458). Moreover, there has been discussion in the scientific literature about the use of terms "participation" and "social participation," with the various definitions overlapping on the fact that they intend to describe a person's involvement in social roles and activities, which provide interaction with others, outside a person's home (Barclay, McDonald, and Lentin 2015). This latter definition was the one employed in this book for defining "social participation," also considering aspects of the person's physical, social, cultural, and political environments, as has been previously suggested (Hammel et al. 2008).

Definition of Disability

The definition of disability adopted by the United Nations (UN) Member States in Article 1 of the UN Convention on the Rights of Persons with disabilities (CRPD) (United Nations 2006) is the following:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (United Nations 2006, 1)

The exact same definition of disability was repeated in the 2018 Directive of the European Parliament and the Council of the European Union (EU) "On the accessibility requirements for products and services" (Council of the European Union 2018). Thus, it appears that this has been the official definition of disability used by the UN and EU. Although there are numerous other definitions of disability used worldwide, and in European countries specifically, in this book, disability was conceptualised following the biopsychosocial model of functioning and disability of the World Health Organization (WHO)'s International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001). According to the ICF's biopsychosocial model of disability, disability is the outcome of the interaction between underlying health conditions and contextual factors (Leonardi et al. 2006). The component of ICF which includes tasks and societal roles is called Activity and Participation, while information on the societal support and attitudes are included in the Environmental Factors component of the ICF (Koutsogeorgou et al. 2014). It has been suggested that a combination of these two ICF components could contribute to the definition of "societal participation" which should be considered based on contextual-setter factors of functioning, health, and disability (Badley 2008; Koutsogeorgou et al. 2014).

It has to be stressed here that the word “disability” has not been used as a synonym for “impairment” in this book. Although “impairment” is found in the origins of the social model (Oliver 2004), the term has received criticism from disability studies experts. For example, there are those who state that “impairment” is a medical term, whereas “disability” is a social term, while others view that the social model treats impairment as an unsocialised and universal concept, whereas it is always social, while some argue that it is alien in Deaf culture to speak about its members as “persons with hearing-impairment” (Lane 2006). Furthermore, in Italy – where this study was conducted – the word “impairment” is translated as “menomazione,” meaning losing one’s integrity or being harmed or damaged. For all these reasons, it was considered inappropriate to use the word “impairment” and thus only the terms “disability”, “health issue,” and “difficulty” have been used to describe the health-related characteristics of participants – without meaning that all participants of this study or people in general with health issues necessarily experience disability. As already mentioned above, disability in the present study is not viewed as an intrinsic characteristic of a person, but as the outcome of the interaction between the health issue and contextual factors (such as those related to the built and social environment), according to the biopsychosocial model.

Association of Social Capital with Health and Disability

Relevant to current studies on the relationship between health and societal roles, participation, attitudes, and support, there has been an increasing research interest in the relationship between social capital – including its components (i.e. social networks, trust, social norms) – and health. In particular, studies have shown that social networks relate to self-reported health status (Gele and Harsløf 2010; Schulz et al. 2008). According to empirical evidence on the components of social capital, the existence of mainly higher levels of general trust, social participation, and networks, close and strong friendship-based ties, perceived neighbourhood cohesion and extra-neighbourhood networks, and/or social support have been positively associated with a good health status and psychological wellbeing (Nieminen et al. 2010; Gele and Harsløf 2010; Yiengprugsawan et al. 2011; Moore et al. 2011; Koutsogeorgou et al. 2015). Social capital is also mentioned by the WHO’s Commission on Social Determinants of Health (2008) as one of the features that, along with social determinants of health and other traits, can affect health outcomes. However, according to another study published by WHO (Rocco and Suhrcke 2012), individual social capital is an important health determinant of a person only when people who tend to trust other people live in communities with high social capital. Similarly, based on empirical research on the association of social capital with mental health in particular, the sense of belonging to social networks of mutual trust and support – which constitute the cognitive and functional aspects of social relationships – significantly decreases the probability of exhibiting common mental disorders (Ζήση 2013). Still, statistical relationships between structural aspects of social relationships – and social capital – and mental health status, such as evidence regarding social participation, which does not always relate to mental health status and move in the expected direction, have been found to be less consistent (Ζήση 2013). However, according to research, social engagement is important for recovery from severe mental illness since it helps to build social capital, but people with mental health issues are often stigmatised and experience discrimination, which in turn are barriers to their social engagement and for enhancing their social networks, and thus have access to less social capital (Zoppei et al. 2014; Webber et al. 2014).

Regarding disability, the development of social relationships among persons with disabilities and their connection to important social structures can enhance their opportunities for decision making, which in turn affects their quality of life (QoL) (Gotto et al. 2010). Based on the same study, social capital could allow persons with disabilities to lead more self-determined lives, and therefore, for the inclusion of those with disabilities in the wider society, the creation and development of the appropriate foundations for supporting them are essential, especially through the enhancement of their social networks starting from their interpersonal environments. Likewise, according to Sapp et al. (2003), social influence and behavioural norms within a social network can influence the health-related QoL of an individual in various ways. For example, it has been found that the enhancement of QoL for someone with multiple sclerosis may be achieved through increased social capital, and vice versa (Rimaz et al. 2014). A person’s good level of QoL depends significantly on the degree of their inclusion in family and social networks, as well as the characteristics (quality and diversity) of these social networks (Saraceno, Olagnero, and Torrioni 2005). Concerning the enhancement of social capital for persons with disabilities, the following critical implications for them and their families should be taken into consideration: (a) adequate sources of psychological support are not available to them; (b) adequate financial sources are not available to them; (c) they experience social isolation as they perceive they are not welcomed and supported by their community; (d) they become receivers of discrimination, rejection, bullying, and other types of violence from other community members; (e) they make significant unrecorded contributions to society via their voluntary work (e.g. as carers for younger family members); and (f) there are strong ties of social capital among persons with disabilities and their families, in the sense of strong "bonding"; however, these ties are not "bridged" – meaning their social networks are mainly composed of ties with other persons also with disabilities, and not people of the wider community (Chenoweth and Stehlik 2004).

Gender Differences and Social Capital

There have been mixed findings on whether there are gender differences in terms of social capital components. For example, a study in Australia found notable gender differences in terms of social capital, with women having higher levels of community participation and social cohesion than men overall. Women also reported having more trust towards others and more friends than men, but also had greater feelings of loneliness. Although social capital has been argued to be a protective factor for mental health, women have reported poorer mental health, with men reporting better physical and mental health overall than women, so this can be an indication that there is a gendered relationship between social capital and mental health. Men, when compared to women, appeared to have larger and more heterogeneous social networks characterised by bridging with weak ties, which usually have greater potential to provide various resources. Thus, it is possible that women contribute more to generating social capital in general, while deriving less benefits from it. For this reason, it was suggested that the conceptualisation of social capital for research should be attentive to gender differences (Berry and Welsh 2010).

Another aspect that has been used as an indicator of social capital is the feeling of safety in one's neighbourhood, which has been associated with good self-rated health for both women and men. However, in Sweden it has been found that, although both men and women believed that the safety of the living environment was important, there were gender-based differences regarding their experiences. The same study suggested that men may benefit more from rural social capital, whereas women may benefit more from urban social capital (Eriksson and Emmelin 2013). In any case, it has been argued that persons with disabilities are, in general, vulnerable to health threats, in particular those living in urban areas "due to the challenges of a high population density, crowding, unsuitable living design, and lack of social support" (Commission on Social Determinants of Health 2008, 60).

Rationale, Setting, and Overview of Data Collection Strategy

The main objective of this book is to discern barriers and facilitators of social inclusion for persons with disabilities through patterns of their reported experiences, which can potentially influence policymaking and improve personal experiences persons with disabilities in terms of social relationships and social participation. It has long been argued by disability scholars that physical and mental disability "is not simply an attribute of a person but a complex collection of conditions, activities and relationships, many of which are created by the social environment" (Bickenbach et al. 1999, 1173). Moreover, although the enhancement of social networks has been suggested to hold potential for intervention, and in spite of robust evidence showing the importance of social relationships and social support for physical and mental health – for populations both with or without disabilities – the number of interventions focusing on social support and social skills are limited. Therefore, there has been a need for additional research in order to advance our understanding of the social isolation, particularly that experienced by women with physical disabilities, who are at high risk of social isolation (Robinson-Whelen et al. 2013). This is one of the issues this book explores. A study on the social relationships of young adults with psychosis suggests that future research could involve gathering descriptions from young people regarding the phenomena of their social relationships to determine whether the essential components of these phenomena are common for young adults who have or have not experienced psychosis, or have other long-term illnesses (MacDonald et al. 2005). Similarly, this study focuses on both young adults with psychosis and other long-term health issues. It has also been argued that there are a limited number of studies focusing on the intersection of disability and gender, and therefore this study addresses this gap and contributes to the knowledge of the experiences of disability from a feminist or gendered perspective (Mohamed and Shefer 2015). Consequently, these are the main knowledge gaps this book aims to fill in and hopefully contributes to the discussion for the full integration of women with disabilities in terms of their social relationships and social participation.

This study focuses on the experiences of women with disabilities living in an urban environment (i.e. the metropolitan city of Milan, Italy), since it has been found that men may benefit more from rural social capital, whereas women may benefit more from urban social capital (Eriksson and Emmelin 2013), and age and gender-based differences have been reported for various types of disabilities (e.g. for mental disability see Angermeyer, Kühn and

Goldstein (1990) and Häfner (2003). Furthermore, based on the UN Convention on the Rights of Persons with disabilities (CRPD), it has been recognised that "women and girls with disabilities are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation" (United Nations 2006, 2). Given that this study is a within and cross-disability study, a specific gender (women) and age range (i.e. 18–45) were selected to allow comparisons within and across types of disability. For data collection, qualitative methods were employed in order to capture the in-depth experiences of the participants.

Aim of the Study

Based on all the above, the aim of this study is to explore the structural, functional, and cognitive characteristics of the social relationships of women with three different types of disability, as well as aspects of their social participation in the wider community – barriers and facilitators of their social and physical environment in that respect. The three types of disability explored are: (a) sensory (relating to hearing difficulty – deafness); (b) physical (relating to movement-related difficulty – the inability to move both lower limbs); and (c) mental (relating to a mental health issue – psychotic disorder).

CHAPTER TWO

BACKGROUND

Sociology and Medicine: Positions in Between

Theoretical foundations and perceptions of "normal"

The historical origins on the important role of the social and political environment on health can be found in the Hippocratic writings and other references of ancient Greece, with the social environment having been recognised since then as important not only for achieving the empowerment, autonomy, and self-sufficiency of individuals, but also for affecting people's health (Tountas 2009). Many centuries later, one of the most famous sociologists, Erving Goffman (1922–82), in his book *Stigma* (1963) analysed the social identity of people considered as stigmatised within their society. Stigma, a word deriving from the Greek στίγμα, was used by Goffman to describe the visible or invisible traits that are attributed to people when they are reduced in our minds from a whole person to an incomplete one – a stereotype of rejection. Goffman identifies three types of stigma referring to people with: (a) physical/body deformities, (b) imperfections of individual character (for example, due to a mental disorder or addiction), and (c) tribal stigma (of race, nation, and religion). The first impression we have of someone is their virtual identity, while the attributes the person really possesses are their actual social identity, with a potential discrepancy existing in the case of stigmatised people. In particular, Goffman distinguishes between two perspectives of the term stigma: the discredited and the discreditable. When a stigmatised person considers that their difference is evident/visible or already known to others on the spot, then they have the discredited perspective. Instead, the stigmatised person who has the discreditable perspective considers that their difference is invisible or not evident or not immediately perceivable by others on the spot (Goffman 1963). The latter perspective is likely to be adopted by deaf people or those with mental health issues or deafness – relevant to this study – whereas people with physical-health issues are more likely to adopt a discredited perspective, since their disability is harder to conceal during social encounters. Thus, these two different perspectives, from which persons with disabilities have to choose during their social interactions, should be considered in this research as diverse self-perceptions of disability. In another study it has been argued that the sick body is not merely an organism with functional loss, but also the centre of attention and the medium of knowledge and expression, and “the concept of embodiment is valuable for understanding the illegitimacy of stigma,” with individuals considering the sick role as both a threat to oneself and a resource (Grytten and Måseide 2005, 241). Thus, apart from the visibility or invisibility of a disability, there is also a dimension of positive and negative consequences of disability as perceived by the person experiencing it. In any case, it has been argued that self-identification as a “person with a disability” is often made in order to align oneself with a group of individuals who are in a similar position, and in this manner constitutes a political strategy for securing social change and possibly self-empowerment too (Bickenbach et al. 1999). Nevertheless, there are also people with health issues who do not self-identify as “person with a disability,” potentially seeking other forms of collective representation and basis for self-empowerment.

Goffman in *Stigma* (1963) also discerns that the relationship of the stigmatised person with their informal community and formal organisations of their kind is crucial – in other words, their peer groups. The socialisation process of the stigmatised person has several phases. One of them is when they learn and incorporate the view of the “normal” thus possessing the beliefs of the identity that the wider society has on what it would be like to be stigmatised. Another phase is when the stigmatised person learns that they have received a stigma and the consequences of this label. Consequently, different patterns are formed by these phases of socialisation of a stigmatised person which shape their development, which are: (a) those who were born with a stigma and become socialised without having fully realised the consequences of their situation; (b) those with congenital stigma who learn to see themselves in their early life as similar to everyone else, depending on the capacity of family and local neighbourhood to protect congenitally stigmatised children from the information they receive about themselves from the wider society, and learn that they are fully human beings too (however, later in life the person will have a “stigma learning” experience which they cannot be protected from); (c) those who become stigmatised later in their life, or learn that they have a stigma, but have knowledge of what a stigmatised person is beforehand; and (d) those who are initially socialised in a confined community and then must learn a new way of being, as it is perceived by those surrounding them, to demonstrate their real and valid identity. On this latter pattern, Goffman discerns that post-stigma acquaintances may see the person simply as a person with faults, while pre-stigma acquaintances, which have been attached to a conception of what the person was before, may be incapable of treating the person tactfully or with the acceptance they were familiar with previously (Goffman 1963).

Clearly, when Goffman focuses on the analysis of mixed contacts, meaning how stigmatised and "normal" people interact in the same social situation, it appears that the stigmatised individual usually makes more arrangements in their life to adapt to the standards of the "normal" majority (Goffman 1963). At this point, I challenge the meaning of the word "normal" and its denotation nowadays, as it is often used to represent a label to describe an unwritten categorisation of what is – or is not – "normal." For this reason, the word "normal" is used with quotation marks in this book, not only in an attempt to use politically-correct terminology when discussing issues about persons with disability, but also because an objective and universally-accepted definition of what is "normal" does not exist. For every person or every group of people, in various places and eras, the features of "normal" people differ. What we consider as "normal" is a subjective view each one of us has, based on external influences. Likewise, what is "not normal" or "abnormal" should also not be used to describe in an absolute and universal manner people who are different from the majority (for example, those with a disability), since the same people can be seen as similar and "normal" by others. Moreover, if what is "normal" is commonly perceived based on the average level of the population, as if there was a statistical explanation applied to it, then a person that does not fall into this average – for example, a person with Down syndrome, or Albert Einstein and Leonardo Da Vinci – should be considered as "abnormal" in relation to the average, whereas all the "perfect strangers," such as random Mr. X or surveyor Mrs. Y are considered "normal" just because they fall into the average (Gambirasio 2016, 16).

Relevant to the meaning of "normal" according to Sinding (2004), two famous scholars, Georges Canguilhem (1904–95) and Michel Foucault (1926–84) – the first being the official supervisor of the second's doctoral thesis – started mainly from the violation of norms in order to illuminate them, in other words from what is considered "abnormal" by societies in order to illuminate what is considered "normal." Canguilhem wrote in 1966 *Le normal et le pathologique*, which was later translated into English and published with an introduction by Foucault (Canguilhem 1989). Thus, in *The Normal and the Pathological* (1989), Canguilhem asks whether sciences of the "normal" and the pathological exist. According to Canguilhem, patients are the ones who most often decide for themselves whether they have returned to "normality" or are not "normal" anymore, with "becoming normal" again meaning that they reinitiate their interrupted activity, or at least an equivalent activity as considered by individual opinions or the social value of the social environment. The roots of the definition of "normal" (deriving from *norma*, a T-square, all that is as it is owed to be, an average or standard) indicate the ambiguity of this term, designating both a fact and a value attributed to this fact, depending on the person expressing this judgement. According to Canguilhem (1989, 131), "it is life itself and not medical judgement which makes the biological normal a concept of value and not a concept of statistical reality." Facts are not "normal" or pathological in themselves; likewise, an "abnormality" is not pathological in itself either. Furthermore, in order to be normative in a specific occurrence, what is considered as "normal" can become pathological in another situation. Therefore, Canguilhem (1989, 200–1) remarks that "in order to discern what is normal or pathological for the body itself, one must look beyond the body," mentioning as an example someone with myopia, who would be "normal" for a specific context, such as agricultural work, but "abnormal" for another, such as sailing. Foucault in *The Birth of the Clinic* (2003), first published in 1963, was also interested in "normality" and health, and the way both concepts had evolved over the centuries, with medicine before the eighteenth century being regulated more with health than "normality," whereas from the nineteenth century medicine was regulated more with "normality" than with health. According to Foucault (2003), the act of medical seeing – what he calls the "medical gaze" – started after the nineteenth century to focus not only on the surface of medical examinations of the body that the eye can see, but also of what lies beneath, which emerges through discourse with the patient. Moreover, the connection between disability studies and Foucault's work was made in one of his lectures on March 17, 1976, during which he stated that a new technology of power, a bio-power, or else bio-politics, began to establish itself in the late eighteenth century (Tremain 2005).

Based on this, bio-politics introduces mechanisms whose functions are statistical estimates and overall measures, with the purpose to intervene at the level of the generality of these phenomena, while relevant regulation mechanisms are set which recommend norms, adjust and maintain an average, and compensate for possible variations within the "general population." Foucault, during his lectures of 1978–9, associated his views on bio-power with those of government (Tremain 2005). Government, for Foucault (1982), should be perceived in its sixteenth-century meaning, referring to any form of activity which aims to shape, affect, or guide the conduct of one or more people – in other words, government means "the conduct of conduct." This Foucauldian "conduct of conduct" conception of power as government is contrasted with the same scholar's "juridico-discursive" conception of power (Tremain 2005). The latter has been explained by Foucault as the power which is perceived as fundamentally repressive, owned by a centralised external authority, for example a specific social group, an institution, or the state, while it rules other people (Tremain 2005). According to Tremain (2005), the social model of disability is a typical example of the "juridical conception of power that has prevailed in disability studies" (9). Furthermore, Lennard J. Davis (2006) has argued that "normal" is a notion based on the power of the bourgeoisie, and there is even a specific "hegemony of normalcy," where the "normal" is a configuration arising in a particular historical moment, and which one could, in order to develop consciousness of disability issues, one could try to reverse the "hegemony of the normal" and introduce alternative ways of thinking about the "abnormal."

Based on all the above, it appears that the labels "normal" and "abnormal" lack a universally-acceptable and purely subjective definition, and indicate the advantageous versus disadvantageous characteristics of a person, respectively – depending on the context and the person who is making the judgement at the given time. In other words, "normalised" behaviours which are rewarded in our culture and time could be considered "abnormal" in other cultures and eras. Thus, "normality" "resides in culturally approved conventions, not in universal psychological standards of appropriate functioning" (Horwitz 2002, 7), and "the 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (Davis 2006, 3). To illustrate this more vividly, H. G. Wells in his novel *The Country of the Blind* (1911) describes a person who can see, named Nunez, as an invader in a country of blind people, who consider Nunez as childish and clumsy and as taken over by his vision that confuses his mind, so they believe that if Nunez were to remove his eyes surgically he would be sane and suitable for his blind loved one. Thus, in a community where everyone is blind, a man who sees and does not perceive the world as the rest do is considered as "abnormal."

Perhaps more accurate words to demonstrate the meaning people usually incorporate into "normal" could be "common," "typical," or "pattern," which are based on the frequency of the appearance of a phenomenon, action, or state, without any insinuation of whether it is more advantageous/useful or not for those who belong to the majority or the minority end of this frequency. For example, if the majority of families are using a car, that does not constitute the families who possess a car as "normal" and those who are not as "abnormal." About a century ago, when cars were not so widely used, the "normal" would have been the opposite in this case. Likewise, in ancient Greece, homosexuality was considered as "normal" and a major means to a good life and not as an "abnormality" (Horwitz 2002), like many people in modern times still inappropriately consider it to be. Moreover, it is common for people to supress their true will and feelings from fear of being labelled "abnormal," thus this fear has maybe partially led people to a certain way of conduct similar to the existing majority's perception of what is "normal," creating an endless circle between what is considered by the majority as "normal" and therefore what the person does, although the same person does not consider it as "normal." In other words, this endless cycle does not help to discern whether the individual's unbiased judgement of what is "normal" influences society's idea of "normal," or the generalised idea of "normal" carried over from older periods and passed on through generations, influences the individual's judgement on what they should consider "normal," after which the individual acts or thinks accordingly.

As Cooley (1922) has stated, from infancy people do not have an instinct for reactions to others' facial expressions, but these reactions are socially developed later on, when children begin to observe the symbolic meaning behind each expression and imagine how other people perceive them, thus acting and judging themselves accordingly. Cooley (1922) parallelises this imaginative idea of ourselves with the image we have through a mirror – the so-called "looking-glass self." This self-idea is formed by (a) the imagination of our appearance to others, (b) the imagination of others' judgment of our appearance, and (c) a kind of self-feeling, such as pride or shame. For the latter, we are not instinctively drawn to this self-feeling, but develop it as "the imagined effect of this reflection upon another's mind" (Cooley 1922, 184). In a similar manner, what others perceive as "normal" in their mind may be influencing us more on our individual – instinctive – perception of "normality," with the unbiased judgement of what is "normal" subjectively becoming actually inexistent, except maybe for the life period of early infancy when the child has not yet developed an understanding of the "looking-glass self."

Contrary to the abovementioned positions, which have been favourably linked to disability studies and the social model of disability, there have also been opposing arguments, such as that by the famous sociologist Talcott Parsons who argued in *The Social System* (1951) that illness and the "sick role" is a "type of deviant behaviour" and "illness is predominantly a withdrawal into a dependent relation, it is asking to be 'taken care of.' It uses disability as the basis of legitimation of this claim" (Parsons 1951, 193). Such positions of Parsons were rejected by disability theorists, who claimed that he presented persons with disabilities as being responsible for their situation (Grytten and Måseide 2005). The theory was also critiqued by later generations of scholars, who claimed that he also neglects the experience of those with chronic illnesses (Pescosolido et al. 2011).

I sought to explore individuals' experiences and make their voices heard, and I do not share the position of Parsons that people with health issues are responsible for their situation. On the contrary, every one of us has experienced or quite possibly may experience in the future an illness, so the "sick role" of Parsons is not a situation that people can always avoid or choose. In any case, we should all be reminded that "everyone is potentially a candidate for the noble category of 'civil invalids[1], because the human body is extremely fragile" (Gambirasio 2016, 9). In other words, all of us are potentially persons with visible or invisible disabilities, sooner or later in life.

The biopsychosocial approach versus biomedical approach to mental health

An important challenge for the disability-rights movement has been the medical approach to disability (Sabatello and Schulze 2014). One of the fields of medicine which has integrated sociology is psychiatry, with one of its branches being "social psychiatry" – separated from the hegemonic current of psychiatry possessing a strong biomedical orientation. After all, psychiatry is considered to be a political science, in the Aristotelian sense of the word, focusing on the "praxis" of interpersonal relationships (Jenner et al. 1993). As such, sociology and psychiatry both have similarities and large differences, with psychiatry focusing mostly on a biomedical perspective, while sociology focuses on the biopsychosocial and social models of mental health, in this case. As argued by George Engel, who introduced the biopsychosocial model: "the biopsychosocial model is a scientific model constructed to take into account the missing dimensions of the biomedical model" (1980, 535). However, social psychiatry aims to bridge these differences, with its professionals more commonly working on the impact of socioeconomic determinants on mental health. Bentall (2010)

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[1] People with health issues in Italy ask for recognition of "invalidità civile" [civil invalidity], in other words recognition of their congenital or acquired physical or cognitive health issues in order to have access to public services (e.g. benefits from the state, discounts in public transport, assistance, etc.) Thus, the term "civil invalids" is commonly used in Italy to describe those with a health issue and/or disability.

– with an intensely critical view – has argued that, throughout the history of the profession, psychiatry has been struggling for recognition of its place among other medical sciences by trying to establish physical therapies – a purely biomedical approach. Regarding the gap between sociology and psychiatry, the same author claims that genes cannot determine the human characteristics directly, but there is a long and complicated process from our DNA that we inherit from parents for our behaviour later in adulthood, which can be influenced on various occasions by the surrounding environment. Nevertheless, the strictly biomedical approach has led psychiatrists to neglect the life trajectories and self-understanding of problems from the patients' own point of view, and often misclassify the patients' ordinary anguishes under a mental health label/classification. Bentall also claimed (2010) that a substantial amount of resources have been spent on the genetic origins of mental illness, whereas the social origins are still being neglected, and no patient has ever benefited from genetic research, but many have been harmed by it. Similarly, it has been argued by Thomas and Bracken (2011) that psychological problems cannot be "cured" by "interfering" with the body of the person experiencing these problems, as if the components of a television cannot produce a better programme, and thus pathology should not be used to frame psychological problems.

Since one of the types of disability this study focuses on is relevant to mental health issues, if one had to give a definition of mental illness which is not purely medically-oriented nor purely socially-oriented, they could employ the statement of Littlewood and Lipsedge (1997) that patterns of behaviour should be looked at in relation to the particular society, while whether or not they are "abnormal" depends only on the norms of behaviour in the particular community at the particular time. According to the same source, psychotic mental illnesses, such as schizophrenia or manic-depressive psychosis, appear to have more relevance to the biological side of the spectrum of mental health illnesses, whereas neuroses, such as phobias and anxiety, appear to be closer to the social end of the spectrum. Given that in our society there is a cultural emphasis on the internal mental events, psychotic illness is considered as a disorder within the individual themselves, with biologically-oriented psychiatrists focusing on the genetic factors of psychoses (e.g. identical twins with schizophrenia), whereas psychiatrists who see mental illness from the social perspective suggest that mental disorders have not only "organic" and biologic explanations but also psychological and cultural ones. For example, regarding schizophrenia, the environment in which it occurs is important, including the family and social organization along with the physical state of the body.

Moreover, according to the social model of mental health, mental illness is a temporary maladaptive reaction to difficult life situations, which may relate to poverty, unemployment, social stress, social isolation, and lack of emotional ties. The social model also focuses on the importance of culture and social structure as the main elements shaping social relationship beliefs and practices (Ζήση 2013). Categories of psychiatry based on the biomedical model fit poorly with the distress that people experience due to stressful social conditions. In particular, those who become depressed or anxious or exhibit psychosomatic symptoms because they struggle with stressful events in their life, for example difficulties in social relationships, uncertainty about the future, an unsatisfactory job, financial issues, and many other reasons, react in appropriate ways to the stimuli of their environment. If these symptoms disappear as their circumstances change, that means that their symptoms are not caused by a mental disorder and do not have internal dysfunctions. However, the biomedical diagnostic classification mistakenly categorises such expected reactions to stressful events as equal to mental disorders (Horwitz 2002). A related example is the case of Ron Coleman, who had a diagnosis of schizophrenia and was hearing voices, and testified that his healing process was grounded in the work of Marius Romme and Sandra Escher, who claim that voices and psychoses are "normal" responses to "abnormal" situations (Rueca 2016). Additionally, Oliver Sacks (1985) mentions Purdon Martin's idea that patient and physician are helping each other, learning from each other, and are coequals, both contributing to treatment and new insights. Sacks provides examples from his clinical practice with his neurology patients, with whom he experienced this type of contribution to the treatment from both the patients' side and his.

Nevertheless, it also has to be mentioned that the biopsychosocial model of the ICF has received criticism, particularly from social scientists regarding its lack of "a coherent theory of social action as a new basis for understanding disability" (Barnes and Mercer 2010, 39). However, other models, such as the social model of disability, have also received criticism, for example that it is wrong to presume that activity restrictions by those with a disability have a social basis and thus can be eradicated through social change (Barnes and Mercer 2010). Thus, there seems to be no golden standard in terms of an approach to disability, but the biopsychosocial model presents a more ecological perception of disability compared to the one-sided biomedical or social models.

Undoubtedly, the critiques and differences between the two disciplines mentioned above should be considered by social researchers, to help us discern the different approaches applied for the therapy of participants by mental health professionals with a strong biomedical approach and their colleagues who mostly apply the biopsychosocial model in their practice.

"Fix the system, not me!": the social model of disability

The starting point for the social model for disability was in 1976 with the publication of the *Fundamental Principles of Disability* (1976) by the Union of the Physically Impaired Against Segregation (UPIAS). From that point on the understanding of disability changed completely, and later Mike Oliver, the creator of the term "the social model of disability," argued that it is not impairment that is the main cause of the social exclusion of persons with disabilities, "but the way society responded to people with impairments" (Oliver 2004, 19). Oliver presents the following three general points about the social model: (a) it is an attempt to focus away from the functional limitations of a person to the issues caused by disabling environments, cultures, and barriers; (b) it refuses to view issues isolated from the totality of disabling environments; and (c) endorsements of the social model do not mean that individual-based interventions are useless or counterproductive.

Furthermore, Tom Shakespeare (2006, 198) has presented two dichotomies as key to social model thinking: (a) impairment is distinguished from disability – impairment is individual and private, whereas disability structural and public; and (b) the social model is distinguished from the medical or individual model – disability is defined in the social model as a social creation, whereas in the medical or individual model it is an individual deficit. In other words, the main difference between the medical model of disability and the social one is that the medical model makes no distinction between impairment and disability, whereas the social model defines impairment as a defect or lack of a body part, and disability as a form of disadvantage or restriction of an activity due to the social organisation of the context the individual lives in, when this does not allow or facilitate the participation of these people in mainstream social activities (Tremain 2005). The medical view of disability tends to regard persons with disabilities as "having something wrong with them," and that is the source of the problem (Oliver 2004). Specifically, according to the medical paradigm, persons with disabilities "were viewed merely for their inabilities in comparison to an expected definition of 'health'" (Sabatello and Schulze 2014, 15), while disability was a feature needing "correction," and therefore modern societies have adopted policies in order to "eliminate" the disease/disorder and promote the integration of persons with disabilities into the "functional" society (Sabatello and Schulze 2014, 15). On the other