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SOCIAL RELATIONSHIPS AND SOCIAL PARTICIPATION OF WOMEN WITH DISABILITY

Doctoral thesis by

Eleni Koutsogeorgou

Supervisor: **Prof. Mario Cardano (UniTo)**
Co-Supervisor: **Prof. Monica Santoro (UniMi)**

Director of Doctoral Program: Prof. Mario Cardano

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i. Declaration

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ii. Abstract

Aim: The aim of this study was to explore structural, functional, and cognitive characteristics of social relationships of women across and within three 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 were: sensory (deafness), physical (inability to move lower limbs), and mental (psychotic disorder).

Methods: In the study participated 30 women – 10 per type of disability – aged 22-44, living in the metropolitan area of Milan (Italy), and having at least one role of relative autonomy. Qualitative semi-structured face-to-face interviews were conducted. All interviews were held in Italian language [or Italian Sign Language (LIS) for six deaf participants], and were audio recorded and transcribed verbatim. Data analysis was conducted using the template analysis technique of thematic analysis. Comparisons within and across the three types of disability were performed as well.

Main findings: The findings highlighted barriers that women with disability face within their social and physical environment. In specific, it emerged that women with mental disability faced prejudice, discrimination, stigmatisation, and/or lack of empathy towards them from other people of the wider population which hinder their social participation. All women with physical disability faced barriers to social participation related to numerous accessibility hindrances of the physical environment, and most of them had also faced prejudice and mentality barriers towards them from persons of the wider population. Women with sensory disability encountered mostly barriers for social participation related to lack of resources for communication with people of the general population, whether in private or public places, when there is no sign language interpreter or subtitles, while they have also limited opportunities for employment compared to hearing persons. From comparison across types of disability various common patterns emerged. Women with mental disability appeared to have the lowest level of social participation, whereas women with physical disability the highest.

Conclusion: It appears compelling to focus on the exploration of aspects of the social relationships and social participation of persons with disability since the barriers they face relevantly are numerous, multi-faceted and related to their personal and social development. The biopsychosocial model of health and disability could be employed towards the goal of full social inclusion.

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CHAPTER ONE: INTRODUCTION

1.1 Definition of main concepts and topic overview

1.1.1 Social relationships, social networks, and social support

Social relationships, with the networks formed among them, are 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, Kanaan, Gilbody, & Hanratty, 2016) (House & Kahn, 1985). For example, House and Kahn (1985) defined 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"* (p. 85). The same authors defined social network as the structural dimension of social relationships, encompassing aspects such as size, density, reciprocity, frequency, and homogeneity (House & Kahn, 1985). Similarly, Berkman et al. (2000) have defined social networks as the ties between persons 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, Negarandeh, Bastani, & Greysen, 2014). Social support in this study was perceived 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, Kanaan, Gilbody, & Hanratty, 2016), and as a distinct concept 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 & Parts, 2008).

1.1.2 Social capital

Social networks have been considered also as one of the components of the 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 institutionalized relationships of mutual acquaintance and recognition. Acknowledging that capital can take a variety of forms is indispensable to explain the structure and dynamics of differentiated societies (Bourdieu & Wacquant, 1992, p. 119).

From the most widely recognised definitions of social capital – particularly in relation to health research (Koutsogeorgou, et al., 2015) – is the definition by Putnam (2000), according to whom: *"social capital refers to connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them"* (Putnam, 2000, p. 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, which refers to the trust a person has towards other people in general ('general trust') and towards institutions ('institutional trust'), as well as the civic norms of the surrounding environment (Kaasa & Parts, 2008). To date there is no universally accepted definition of social capital, however, the most established definitions of social capital used extensively by scholars internationally overlap on the dimensions of social capital mentioned above. This study acknowledges the vagueness and lack of a universally-accepted definition and measurement/indicators of social capital, thus, it should be clarified that social capital has been employed in this study as a *sensitizing* concept, and not as a *definitive* one. As defined by Herbert Blumer (1954, p. 7):

> A definitive concept refers precisely to what is common to a class of objects, by the aid of a clear definition in terms of attributes or fixed bench marks. This definition, or the bench marks, serve as a means of clearly identifying the individual instance of the class and the make-up of that instance that is covered by the concept. A sensitizing concept lacks such specification of attributes or bench marks and consequently it does not enable the user to move directly to the instance and its relevant content. Instead, it gives the user a general sense of reference and guidance in approaching empirical instances. Whereas definitive concepts provide prescriptions of what to see, sensitizing concepts merely suggest directions along which to look.

Accordingly, in this study, social capital has been considered as a concept providing a sense of reference and guidance to approach the current empirical work, since this concept does not have yet a clear and widely-accepted definition of its attributes.

1.1.3 Social participation

A previous qualitative study on perceptions of participation found that persons with diverse disabilities viewed participation also as a means in order to experience social connectedness with communities and other people, indicating issues of social capital (Hammel, Magasi, Heinemann, Whiteneck, Bogner, & Rodriguez, 2008). Based on the same source, persons with disabilities defined participation *"as a multifaceted, transactive process involving interaction with and within physical, social, cultural and political environments and communities"* (Hammel, Magasi, Heinemann, Whiteneck, Bogner, & Rodriguez, 2008, p. 1458). Moreover, there has been discussion in the scientific literature about the use of terms of 'participation' or '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, & Lentin, 2015); therefore this definition was employed in this study for 'social participation', considering also aspects of the person's physical, social, cultural and political environments, as it has been suggested previously (Hammel, Magasi, Heinemann, Whiteneck, Bogner, & Rodriguez, 2008).

1.1.4 Definition of disability

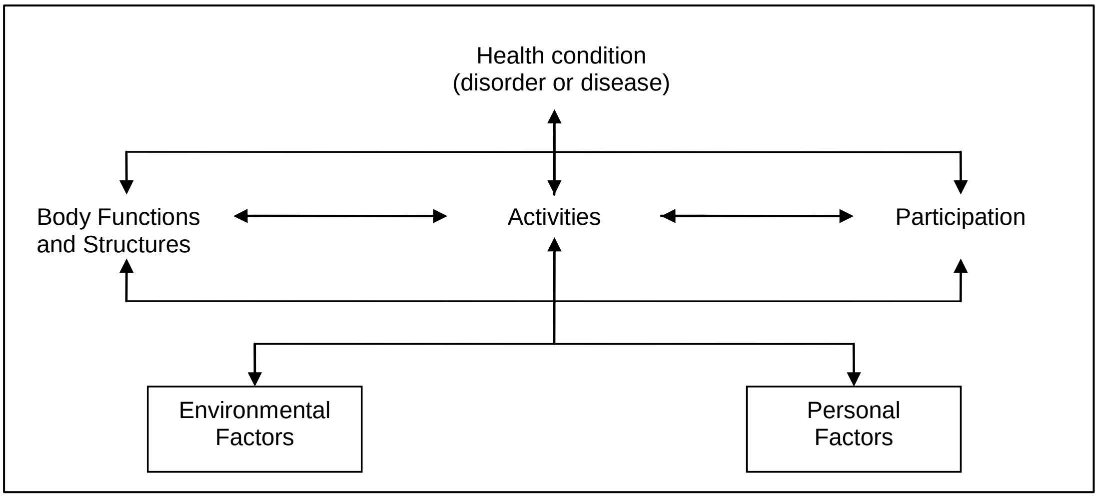
The definition of disability adopted by the United Nations' (UN) Member States stated in Article 1 of the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) is the following:

> 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, p. 1).

The same exact 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 is 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 in specific, in this study, disability was conceptualised following the biopsychosocial model of functioning and disability (Figure 1) of the World Health

Organization (WHO)'s International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001).

Figure 1. The ICF biopsychosocial model of functioning and disability



Source: World Health Organization, International Classification of Functioning, Disability and Health (2001, p. 18) . Reproduction of image without prior authorisation of its rightful owner(s).

According to the ICF biopsychosocial model of disability, disability has been defined as an interaction between underlying health conditions and contextual factors (Leonardi, Bickenbach, Ustun, Kostanjsek, Chatterji, & on behalf of the MHADIE Consortium, 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, Leonardi, Bickenbach, Cerniauskaite, Quintas, & Raggi, 2014). It has been suggested that a combination of parts of these two ICF components together 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, Leonardi, Bickenbach, Cerniauskaite, Quintas, & Raggi, 2014).

It has to be stressed here, that the word 'disability' has not been used as a synonym to 'impairment' in this thesis. Although 'impairment' is found in the origins of the social model (Oliver, 2004), the term 'impairment' 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 un-socialised and universal concept, whereas it is always already social, or others 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 using the word 'impairment' in this thesis, 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 persons, in general, with health issues experience disability necessarily. 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 related to the built and social environment) – according to the biopsychosocial model.

1.2 Association of social capital to 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 on 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 & Harsløf, 2010) (Schulz, et al., 2008). According to empirical evidence on the components of social capital, the existence mainly of higher levels of general trust, social participation and networks, close and strong friendship-based ties, perceived neighbourhood cohesion and extra-neighborhood network, and/or social support have been positively associated with good health status and psychological well-being (Nieminen, Martelin, Koskinen, Aro, Alanen, & Hyyppä, 2010) (Gele & Harsløf, 2010) (Yiengprugsawan, Khamman, Seubsman, Lim, & Sleigh, 2011) (Moore, Bockenholt, Daniel, Frohlich, Kestens, & Richard, 2011) (Koutsogeorgou, et al., 2015). Social capital has been 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 & Suhrcke, 2012), individual social capital is an important health determinant of a person only when persons 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, appears that the sense of belonging to social networks of mutual trust and support – which constitute cognitive and functional aspects of social relationships – decreases significantly the probability to exhibit common mental disorders (Ζήση, 2013). Still, less consistent have been found to be 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 towards the expected direction (Ζήση, 2013). However, according to research, social engagement is important for recovery from severe mental illness, since it helps to build social capital, but persons with mental health issues are often stigmatised and experience discrimination, which in turn are barriers for 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, Calkins, Jackson, Walker, & Beckmann, 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 persons with disabilities into the wider society it is essential the creation and development of the appropriate foundations for supporting them, especially through the enhancement of their social networks starting from their interpersonal environment. Likewise, according to Sapp et al. (2003), social influence and behavioural norms within a social network can influence the health-related quality of life of an individual in various ways. For example, it has been found that the enhancement of QoL for persons with multiple sclerosis may be achieved through increased social capital, and *vice versa* (Rimaz, Mohammad, Dastoorpoor, Jamshidi, & Majdzadeh, 2014). A person’s good level of QoL depends significantly on the degree of the person’s inclusion in family and social networks, as well as on the characteristics (quality and diversity) of these social networks (Saraceno, Olagnero, & Torrioni, 2005). Concerning the enhancement of social capital for persons with disabilities, the following critical implications for persons with disabilities 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 that 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 that their social networks are mainly composed by ties with other persons with disabilities as well, and not persons of the wider community (Chenoweth & Stehlik, 2004).

1.3 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 (Berry & Welsh, 2010) found notable gender differences in terms of social capital, with women having overall higher levels community participation and social cohesion than men. Women also reported having more trust towards others and more friends than men, however had greater feelings of loneliness too (Berry & Welsh, 2010). Although social capital has been argued to be a protective factor for mental health, women have reported poorer mental health, with men reporting overall better physical and mental health than women, so this can be an indication that there might be a gendered relationship between social capital and mental health (Berry & Welsh, 2010). Men, diversely to women, appeared to have larger and more heterogeneous social networks, which were characterised by bridging, with weak ties, which usually have greater potential to provide various resources (Berry & Welsh, 2010). Thus, it is possible that women contribute, in general, more to generating social capital, while deriving lesser of its benefits (Berry & Welsh, 2010). For this reason, it was suggested that the conceptualisation of social capital for research should be attentive to gender differences (Berry & 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 safety of the living environment was important, there were gender-based differences regarding their experiences of feeling safe in their living environment (Eriksson & Emmelin, 2013). The same study suggested that men may benefit more from rural social capital, whereas women may benefit more from urban social capital (Eriksson & Emmelin, 2013). In any case, it has been argued that persons with disabilities, in general, are 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 (CSDH), 2008, p. 60).

1.4 Rationale, setting, and overview of data collection strategy

The main objective of this thesis was to discern barriers and facilitators of social inclusion for persons with disabilities through patterns of their reported experiences, which can potentially influence policy-making and improve personal experiences of persons with disabilities in terms of their social relationships and social participation. For a long time it has 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, Chatterji, Badley, & Üstün, 1999, p. 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 – both for populations with or without disabilities –, the number of interventions focusing on social support and social skills is limited (Robinson-Whelen, Taylor, Hughes, & Nosek, 2013). Therefore, there has been need for additional research in order to advance our understanding of social isolation experienced particularly by women with physical disabilities, who are at high risk of social isolation (Robinson-Whelen, Taylor, Hughes, & Nosek, 2013). This was one of the issues this thesis attempted to explore. It had been suggested by a previous study on social relationships of young adults with psychosis, that future research could involve gathering descriptions from young people regarding phenomena of their social relationships, to determine whether essential components of these phenomena are common for young adults who have or have not experienced psychosis or have other long-term illnesses (MacDonald, Sauer, Howie, & Albiston, 2005). Similarly, this thesis has focused on both young adults with psychosis and other long-term health issues. It has been also argued that there is a limited number of studies focusing on the intersection of disability and gender, therefore this study sought to address also this gap and contribute to the knowledge of experiences of disability from a feminist or gendered perspective (Mohamed & Shefer, 2015). Consequently, these are the knowledge gaps that this study mainly aimed to fill in and hopefully contribute to the discussion for full integration of women with disability 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. 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 & Emmelin, 2013) and age and gender-based differences have been reported for various types of disabilities [e.g. for mental disability see: Angermeyer, Kühn, & Goldstein (1990) and Häfner (2003)]. Furthermore, based also 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, p. 2). Given that this study was a within- and cross-disability study, a specific gender (i.e. women) and age range (i.e. 18-45) were selected to allow comparisons within and across types of disability. For data collection, qualitative methods have been deemed as ideal in order to capture more in-depth the experiences of participants.

1.5 Aim of study

Based on all above, the aim of this study was to explore structural, functional, and cognitive characteristics of 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 were: a) sensory (relating to hearing difficulty – deafness), b) physical (relating to movement-related difficulty – inability to move both lower limbs), and c) mental (relating to mental health issue – psychotic disorder).

1.6 Structure of thesis

The thesis has been divided in five main chapters: Introduction, Background, Methodology, Empirical Results, Conclusions and Recommendations. The content of each chapter is the following:

1. *Introduction* chapter: includes an overview of the topic and definition of main concepts, rationale, setting and aim of study.
2. *Background* chapter: includes an extensive literature review of the previous scientific literature based on the aim of the study, specifications and state-of-the-art on issues identified by previous studies for each type of disability. Also, the research framework of the thesis is presented, including research questions, methodological grounds and the policy-related context.

3. *Methodology* chapter: includes detailed description data collection and analysis processes, such as sample definition and characteristics, tools and material for data collection, and method and process of data analysis.
4. *Empirical Results* chapter: includes description of the procedure and reflection on the fieldwork process (including limitations of study), description of sociodemographic characteristics of participants, findings within each type of disability, findings across types of disability, and patterns discerned within and across types of disability.
5. *Conclusions and Recommendations* chapter: includes the main conclusions based on the findings of this study, as well as suggestions for application of findings in practice, policies and/or future research.
6. Appendices: includes supplementary material [i.e. A) Interview and sociodemographic information; B) Interview guide (list of topics/questions); C) Informed Consent Form; and D) Sample of interview in original language].

CHAPTER TWO: BACKGROUND

PART I: Theoretical Framework

The first part of the Background chapter includes a literature review on the main concepts per each type of disability of focus in this research. More specifically, here are presented both generally accepted knowledge, through established works in the field, and recent scientific knowledge, through current publications relevant to the aspects explored in this thesis. In addition, below are presented information relevant to the issues that each of the three types of disability of focus experience in terms of social relationships, social participation, and gender issues, which was also used in order to design the research framework of this research.

2.1 Sociology and medicine: positions in between

2.1.1 Theoretical foundations and perceptions of 'normal'

Historical origins on the important role of the social and political environment on health can be found since the Hippocratic writings and other references of ancient Greece, with the social environment having been recognised since then as important, not only for achieving empowerment, autonomy, and self-sufficiency of individuals, but also for affecting persons' health (Tountas, 2009). Many centuries later, one of the most famous sociologists, Erving Goffman (1922-1982), in his book *Stigma* (1963) analysed social identity of persons 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 persons when they are reduced in our minds from a whole person to an incomplete one (Goffman, 1963); a stereotype of rejection. Goffman (1963) identifies three types of stigma referring to persons with: a) physical/body deformities, b) imperfections of individual character (for example due to a mental disorder, or addiction, etc.), and c) the tribal stigma (of race, nation, and religion). The first impression we have for someone is her/his virtual identity, while the attributes the person really possesses are her/his actual social identity, with a potential discrepancy existing in the case of stigmatised persons (Goffman, 1963). In particular, Goffman (1963) distinguishes between two perspectives of the term stigma: the discredited and the discreditable. When a stigmatised person considers that her/his difference is evident/visible or already known to others on the spot, then this person has the discredited perspective (Goffman, 1963).

Instead, the stigmatised person who has the discreditable perspective considers that her/his 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 persons or persons with mental health issues or deafness – relevantly to this study –, whereas persons 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 disability 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 both as a threat to oneself and a resource (Grytten & Måseide, 2005, p. 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 often self-identification as a 'person with a disability' is 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, Chatterji, Badley, & Üstün, 1999). Nevertheless, there are also persons with health issues who do not self-identify as 'persons with disability', potentially seeking other forms of collective representation and basis for self-empowerment.

Goffman in *Stigma* (1963) discerns also that it is crucial the relationship of the stigmatised person with her/his informal community and formal organisations of her/his kind; in other words her/his peer groups. The socialisation process of the stigmatised person has several phases. One of them is when she/he learns and incorporates 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 (Goffman, 1963). Another phase is when the stigmatised person learns that she/he has received a stigma and the consequences of this label. Consequently, there are different patterns formed by these phases of socialisation of a stigmatised person, which shape the person's development, which are (Goffman, 1963): a) those who were born with a stigma and become socialised without having realised yet fully 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 cannot be protected from); c) those who become stigmatised later on in their life, or learn later that they had a stigma, but had 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 be their real and valid identity. On this latter pattern, Goffman discerns that post-stigma acquaintances may see the person simply as a faulted person, while pre-stigma acquaintances, which have been attached to a conception of what the person was before, may be incapable to treat the person tactfully or with the acceptance she/he was familiar with previously (Goffman, 1963).

Clearly when Goffman focuses on the analysis of mixed contacts, meaning how stigmatised and ‘normal’ persons interact in the same social situation, it appears that usually the stigmatised individual is making more arrangements in her/his 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’. That was the reason the word ‘normal’ has been used in quotation in this study, not only as an attempt to use a 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’ persons 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 not be used as a terminology either, to describe in an absolute and universal manner persons who are different from the majority (for example persons with 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 all of them be considered as ‘abnormal’ in relation to the average, whereas should be considered as ‘normal’ all the *“perfect strangers”*, such as random Mr. X. or surveyor Mrs. Y. just because they fall into the average (Gambirasio, 2016, p. 16).

Relevant to the meaning of ‘normal’, according to Sinding (2004), two famous scholars, Georges Canguilhem (1904-1995) and Michel Foucault (1926-1984) – the first one being the official supervisor of the second’s doctoral thesis – both in their works started mainly from the violation of norms in order to illuminate them, in other words, started from what is considered to be as ‘abnormal’ by societies in order to illuminate what is considered by societies as ‘normal’. Canguilhem wrote in 1966 about *Le normal et le pathologique*, which was later on translated in English and published with an introduction by Foucault (Canguilhem, 1989). So in *The Normal and the Pathological* (1989), Canguilhem asks whether sciences of the ‘normal’ and the pathological exist. According to Canguilhem (1989), 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 for them to 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 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 (Canguilhem, 1989). According to Canguilhem (1989, p. 131), *“it is life itself and not medical judgment 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 (Canguilhem, 1989). Furthermore, in order to be normative in a specific occurrence, what is considered as ‘normal’ can become pathological in another situation (Canguilhem, 1989). Therefore, Canguilhem (1989, pp. 200-201) 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 having myopia, who would be ‘normal’ for a specific context, such as agricultural work, but ‘abnormal’ for another, such as sailing. Foucault in his book *The Birth of the Clinic* (2003), first published in 1963, was also interested in ‘normality’ and health, and the way both concepts were evolved within the past centuries, with medicine before the 18th century being regulated more with health than ‘normality’, whereas from the 19th century medicine was regulated more with ‘normality’ than with health. According to Foucault, the act of medical seeing, what he calls ‘medical gaze’, started after the 19th century to focus not only on the surface on medical examinations of the body that the eye can see, but also of what lies beneath, which emerges through discourse with the patient:

> In this regular alternation of speech and gaze, the disease gradually declares its truth, a truth that it offers to the eye and ear, whose theme, although possessing only one sense, can be restored, in its indubitable totality, only by two senses: that which sees and that which listens. This is why the questionnaire without the examination and the examination without the interrogation were doomed to an endless task: it belongs to neither to fill the gaps within the province of the other. (…) A hearing gaze and a speaking gaze: clinical experience represents a moment of balance between speech and spectacle. A precarious balance, for it rests on a formidable postulate: that all that is visible is expressible, and that it is wholly visible because it is wholly expressible (Foucault, 2003, p. 112 & 115).

Moreover, the connection between Disability Studies and Foucault’s work has been placed since one of his lectures, on 17 March 1976, during which he stated that a new technology of power, a bio-power, or else bio-politics, which began to establish itself in the late eighteenth century:

> involves a set of measurements such as the ratio of births to deaths, the rate of reproduction, and the fertility of a population. These processes, together with a whole set of related economic and political problems, become bio-politics’ first objects of knowledge and the targets that it seeks to control (Tremain, 2005, p. 4).

Based on this, bio-politics introduces mechanisms whose functions are statistical estimates and overall measures, with the purpose to intervene at the level of 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’ (Tremain, 2005). Foucault during his lectures of 1978-1979 associated his views on bio-power with those of government (Tremain, 2005). Government, for Foucault (1982), should be perceived in its 16th century meaning, referring to any form of activity which aims to shape, affect, or guide the conduct of one or more persons, in other words, government meaning ‘the conduct of conduct’. This Foucauldian ‘conduct of conduct’ conception of power as government is contrasted to the same scholar’s ‘juridico-discursive’ conception of power too (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 persons (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”* (p. 9). Furthermore, Lennard

J. Davis (2006) has argued that ‘normal’ is a notion based on the power of bourgeoisie and there is even ‘hegemony of normalcy’, in specific, the ‘normal’ is:

> A configuration that arises in a particular historical moment. It is part of a notion of progress, of industrialization, and of ideological consolidation of the power of the bourgeoisie. The implications of the hegemony of normalcy are profound and extend into the very heart of cultural production. (…) One of the tasks for a developing consciousness of disability issues is the attempt, then, to reverse the hegemony of the normal and to institute alternative ways of thinking about the abnormal (Davis, 2006, p. 15).

Based on all above, it appears that the labels ‘normal’ and ‘abnormal’ lack of a universally-acceptable and purely subjective definition, and indicate advantageous versus disadvantageous characteristics of a person, respectively – depending on the context and 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, p. 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, p. 3). To illustrate this more vividly, Herbert George Wells in his novel *‘The Country of the Blind’* (Wells, 1911) describes a person who can see, named Nunez, as an invader in a country of blind persons. These blind people consider Nunez as childish and clumsy and as a person taken over by his vision that confuses his mind, so they believe that if Nunez removes his eyes surgically, then 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 in ‘normal’ could be ‘common’, ‘typical’, ‘pattern’, which are based on the frequency of appearance of a phenomenon, action or state, without any insinuation of whether it is more advantageous/useful or not for persons 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 using a car as ‘abnormal’ families; 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 the modern times inappropriately still consider it to be. Moreover, it is common for persons to supress their true will and feelings with fear of being labelled as ‘abnormal’, thus this fear has maybe partially led persons 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 that is what the person does, although the same person does not consider it as ‘normal’. In other words, this endless circle does not help to discern whether individual’s unbiased judgement on what is ‘normal’ influences society’s idea of ‘normal’, or the generalised idea of the members of the society of ‘normal’ carried through from older periods of time and passed on through generations influences individual’s judgement on what she/he should consider as ‘normal’, and then 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 developed socially later on, when children begin to observe the symbolic meaning behind each expression and start to imagine how other persons perceive them, and thus act and judge themselves accordingly. Cooley (1922) parallelises this imaginative idea of ourselves to the image we have through a looking glass, 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 (Cooley, 1922). For the latter, we are not instinctively drawn to this self-feeling, but we develop it as *“the imagined effect of this reflection upon another's mind”* (Cooley, 1922, p. 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 from the life period of our early infancy when we have 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 been also opposing arguments, such as by the famous sociologist Talcott Parsons, who argued for example in *The Social System* (1951) that illness and the *“sick role”*, as he called it, 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, p. 193). Such positions of Parsons were rejected by disability theorists, who claimed that Parsons presented persons with disabilities as responsible for their situation (Grytten & Måseide, 2005), and Parsons's theory was also critiqued by later generations of scholars, who claimed that he also neglected the experience of persons with chronic illnesses (Pescosolido, Martin, McLeod, & Rogers, 2011). The most severe criticism seems to be about Parsons's focus on the 'outsider perspective' and that:

> Parsons failed to acknowledge that patients have agency in constructing their illness experiences and identities and do not simply conform to what physicians, and the larger society, demands of them. In response, many researchers have sought to recover the individual's voice; and, as a result, much of this research draws upon qualitative narratives. As mentioned earlier, these studies also generally focus on the negative impacts of illness, and posit identity changes in response to illness (Pescosolido, Martin, McLeod, & Rogers, 2011, p. 506).

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

2.1.2 Biopsychosocial vs. biomedical approach in mental health

An important challenge of the disability-rights movement has been the medical approach to disability (Sabatello & 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, Monteiro, Zagalo-Cardoso, & Cunha-Oliveira, 1993). As such, sociology and psychiatry have both similarities and large differences, with psychiatry focusing mostly on a

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[1] Persons with health issues in Italy ask for recognition of *'invalidità civile'* [civil invalidity] in other words recognition of their congenital or later-on-acquired physical or cognitive health issue 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 persons with a health issue and/or disability.

biomedical perspective, while sociology giving focus to the biopsychosocial and social models of mental health – in this case. As it has been argued by the person who introduced the biopsychosocial model, George Engel, *“the biopsychosocial model is a scientific model constructed to take into account the missing dimensions of the biomedical model”* (Engel, 1980, p. 535). However, social psychiatry aims to bridge these differences, with its professionals working more commonly on the impact of socioeconomic determinants on mental health. Bentall (2010) – with an intense 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 of sociology with psychiatry, the same author claims that genes cannot determine the human characteristics directly, but there is a long and complicated process from our DNA we inherit from parents to our behaviour later on in adulthood, which can be influenced in various occasions by the surrounding environment (Bentall, 2010). 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 life’s anguishes under a mental health label/classification (Bentall, 2010). Bentall also claimed (2010) that substantial amount of resources has been spent on the genetic origins of mental illness, whereas the social origins of mental illness 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 who experiences these problems, just as tinkering around with the internal components of a television set will not provide a better programme. We should not use the language and logic of pathology to frame psychological problems (Thomas & Bracken, 2011, p. 13).

Since one of the types of disability this study has focused on is relevant to mental health issues, if one should have to give a definition of mental illness, which is not purely medical-oriented nor purely social-oriented, could employ the statement of Littlewood and Lipsedge (1997), that:

> Mental illness may be regarded as a spectrum ranging from organic psychiatric reactions of this type, which have a biological cause in the individual, to vaguer and more diffuse patterns of adaptive or maladaptive behaviour which can only be looked at in relation to the culture of a particular society: overdoses, suicide

> attempts, possession states or delinquency. The recognition of these conditions as abnormal depends solely on the norms of behaviour in a particular community at a particular time. (Littlewood & Lipsedge, 1997, p. 187).

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 (Littlewood & Lipsedge, 1997). Given that in our society there is cultural emphasis on the internal mental events, psychotic illness is considered as a disorder within the individual herself/himself, with biologically-oriented psychiatrists focusing on the genetic factors of psychoses (e.g. identical twin with schizophrenia), whereas psychiatrists who see mental illness from the social perspective suggest that mental disorders have not only ‘organic’ and biologic explanations in them, but also psychological and cultural ones (Littlewood & Lipsedge, 1997). For example, regarding schizophrenia, the environment in which it occurs is important, including family and social organization along with the physical state of the body (Littlewood & Lipsedge, 1997).

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 (Ζήση, 2013). The social model focuses also on the importance of culture and social structure, as the main elements shaping social relationships beliefs and practices (Ζήση, 2013). Categories of psychiatry based on the biomedical model fit poorly with the distress persons experience due to stressful social conditions (Horwitz, 2002). In particular, persons 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 for the future, unsatisfactory job, financial issues, and for many other reasons, react in appropriate ways to the stimuli of their environment (Horwitz, 2002). If these symptoms disappear as these persons’ circumstances change, that means that their symptoms are not caused by a mental disorder and do not have internal dysfunctions (Horwitz, 2002). However, the biomedical diagnostic classification categorises mistakenly such expected reactions to stressful events as equal to mental disorders (Horwitz, 2002). A related example is the case of Ron Coleman, who had 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).

Nevertheless, it has to be mentioned also that biopsychosocial model of the ICF has received criticism particularly by social scientists regarding its lack of *“a coherent theory of social action as a new basis for understanding disability”* (Barnes & Mercer, 2010, p. 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 persons with disability have a social basis and thus can be eradicated through social changes (Barnes & Mercer, 2010). Thus there seems to be no golden standard in terms of approach towards disability, but the biopsychosocial model presents a more ecological perception of disability compared to 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 apply mostly the biopsychosocial model in their practice.

2.1.3 ‘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) (Oliver, 2004). From that point on changed the understanding of disability completely, and later on, 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, p. 19). Oliver has presented the following three general points about the social model:

> Firstly, it is an attempt to switch the focus away from the functional limitations of individuals with an impairment on to the problems caused by disabling environments, barriers and cultures. Secondly, it refuses to see specific problems in isolation from the totality of disabling environments: hence the problem of unemployment does not just entail intervention in the social organisation of work and the operation of the labour market but also in areas such as transport, education and culture. Thirdly, endorsement of the social model does not mean that individually based interventions in the lives of disabled people, whether they be medically, rehabilitative, educational or employment based, are of no use or always counter-productive (Oliver, 2004, p. 21).

Furthermore, Tom Shakespeare (2006, p. 198) has presented as key to social model thinking two dichotomies: 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 as 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 the defect or lack of a part of the body, and *disability* as a form of disadvantage or restriction of an activity due to the social organisation of the context they live in, when this does not allow or facilitate the participation of these persons 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 & Schulze, 2014, p. 15), while disability as a feature that needs 'correction', 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 & Schulze, 2014, p. 15). On the other hand, it has been argued that people with disabilities *"do not need to be 'fixed' or pitied, they need human rights protection guaranteed in law, representation in the political process and full integration of disablement issues into social policy"* (Bickenbach, Chatterji, Badley, & Üstün, 1999, p. 1174). Such issues are not considered by the medical model of disability. An illustrative example of how the social model differs from the medical one is shown through a photo captured during a rally (Max and Colleen Starkloff-Starkloff, n.d.) in which we can see a protester in a wheelchair holding a sign that says *'Fix The System: Not Me!'* (Figure 2).

Figure 2. Protester at a rally holding a sign.

Source: Action for Access website – Courtesy of Max and Colleen Starkloff-Starkloff Disability Institute - A protester who uses a wheelchair holds up a sign that says 'Fix The System: Not Me' (Max and Colleen Starkloff-Starkloff, n.d.) Reproduction of image without prior authorization of its rightful owner(s).

This message synopsises basically the fights of disability rights activists against the typical medical model of disability that seeks primarily to 'correct' and 'fix' persons with health issues, whereas as this person in the wheelchair protests, the system is the one that needs to be fixed, in order to integrate fully persons with health issues within society and remove barriers that cause disability – as the social model of disability endorses. Based on the social model, *"while impairment may impose personal restrictions, disability is created by hostile cultural, social and environmental barriers"* (Oliver & Barnes, 2010, p. 552). In addition, it has been argued that *"people with impairment are disabled, not just by material discrimination, but also by prejudice. This prejudice is not just interpersonal, it is also implicit in cultural representation, in language and in socialization"* (Shakespeare, 1994, p. 296). Thus it is not only physical barriers that should be considered in a model of health and disability, but also barriers in terms of interpersonal relationships and attitudes that might entail prejudice and discrimination toward persons with health issues, as in the biopsychosocial model (World Health Organization, 2001), which considers such factors within its components of activity and participation and environmental factors.

Oliver (2004) also argues that too many resources are invested in individual-based interventions with lesser returns, whereas modifications to the environments tend to be neglected, despite the potentially greater benefits the latter may have. An environment without barriers may benefit not only persons with disabilities, but the general public too, such as mothers with baby strollers, whereas physical rehabilitation aims to benefit only the ones who have the resources to access it (Oliver, 2004). Nevertheless, there has been also criticism on the social model, regarding, for example, its conceptual distinctions of disability and impairment, in terms that the embodiment of disability does not exist in the social model, defining disability as socially constructed, but *“the social model – in spite of its critique of the medical model – actually concedes the body to medicine and understands impairment in terms of medical discourse”* (Hughes & Paterson, 1997, p. 326). In any case, according to a recent scoping review of studies on facilitators and barriers for societal participation of persons with disability in Europe, it was found that there are unfavourable perspectives on disability, meaning that persons with disability are viewed as “abnormal” in line with the medical model of disability, in the sense that they are seen as “the others”, as a distinct homogeneous group in need of charity, rather than peers in line with the social model of disability (Hästbacka, Nygård, & Nyqvist, 2016, p. 210).

2.1.4 Deaf persons sign language and the ‘culturo-linguistic model’

According to the World Health Organization (WHO), hearing loss can be mild, moderate, severe, or profound. The term ‘hard of hearing’ refers to people with hearing loss ranging from mild to profound, while the term ‘deaf’ has been used for people with profound hearing loss and implies that they have little or no functional hearing and often use sign language for communication (World Health Organization, 2012).

Historically, first references to gestural communication, the sign language that deaf persons use to communicate with others, can be traced in the writings of Plato (c.427-

c.347 BC). For Plato, the gestural communication of deaf persons is a natural form of expression, based on imitation and representation, and for Aristotle (384-322 BC) deaf persons by birth are usually also mute because they have never had the possibility to listen to words, therefore cannot reproduce them (Russo Cardona & Volterra, 2007). Accordingly, deaf persons do not lack of an articulatory organ, only the exercise of hearing (Russo Cardona & Volterra, 2007). The idea that the difficulty in comprehension and integration of deaf persons is intrinsic and permanent started to be reflected in the cultural and linguistic world of Classical Latin, for example, in the *Codex Iustinianus* (in early 6th century BC), which deprived from deaf persons fundamental rights, such as to do a testament, stipulate a contract, or be a witness (Russo Cardona & Volterra, 2007). Another motive for exclusion of deaf persons emerged during the medieval theological disputes with many further issues appearing in later centuries as well, whereas from the 18th century onwards sign language was developed more systematically, with Charles-Michel de L'Épée (1712-1789) in Paris developing signs based on logical relations and grammar of French language, called *signes méthodiques* (methodical signs) (Russo Cardona & Volterra, 2007). Many sign languages with greater or smaller variations across countries are currently used, and in Italy (the country of focus of this study) since 1980s the sign language used was called *Lingua Italiana dei segni*, but nowadays Italians refer to it commonly as *Lingua dei Segni Italiana* (LIS) ('Italian sign language') (Geraci, 2012), with regional variations and dialects within the country too. Nevertheless, although United Nations and European Commission encourage the recognition of national sign languages as the languages of the respective countries' deaf communities, the Italian LIS has not been yet (up to the time of writing of this thesis) recognised as a linguistic minority, given that the Italian state recognises officially only languages that exist within a local community, and are not spread across the country – as in the case of LIS (Geraci, 2012). Moreover, it has been argued that the distinction between pathological and sociocultural views of deafness will continue to exist in Italy, until bilingualism – in terms of sign and verbal language – starts to be credited as positively interfering with spoken language, and not negatively; as it is currently widely considered (Geraci, 2012).

Although deafness is commonly considered by lay persons as a condition of the few, there have been cases where deafness had not been treated as a condition of a small minority within the community, the most famous one being Martha's Vineyard, in Massachusetts, where in the mid-19th century the prevalence of deafness increased to one in four persons, thus the entire community learned the sign language, and communication between the hearing and the deaf members of the community was free and complete (Groce, 1985) (Sacks, 1990). In this case, persons with deafness were seen as a cultural minority with another language, which the rest of the community learned as well (Sacks, 1990). Apart from the perception of deafness by lay persons, there has been conceptual distinction also among deaf persons between deafness and Deafhood, with the first concept representing a sensory deprivation based on biological experience, whereas the second concept differentiates from the first one as it represents the non-static process of deaf persons of struggling to explain their existence to their world to both their deaf peers and non-deaf persons (Hauser, O'Hearn, McKee, Steider, & Thew, 2010). When a person is born deaf, the cultural dimension this person experiences, places her/him in an extraordinary situation by exposing the deaf person to a range of linguistic, intellectual, and cultural possibilities, which hearing individuals in a world of speech can barely imagine, as the latter do not discover or create a new language as deaf persons did (Sacks, 1990).

What is more, there have been differences in terms of self-identity and existential situation among deaf persons, with some of them seeing themselves solely as persons with a hearing difficulty, whereas others see themselves primarily as a distinct cultural group and a language minority (Munoz-Baell & Ruiz, 2000) (Ladd, 2003), who prefer to be called 'Deaf' with a capital 'D' in order to indicate their belonging to a group of people, a minority linguistic group, while others prefer to be described as 'deaf' with a lowercase 'd', or as 'hearing-impaired' (*'audiolesi'* in Italian), or as 'non-hearing' persons (Dolza, 2017). More specifically, there is semantic distinction between lower case ''d'eaf', which refers to deafness from a medical and pathological perspective, whereas capitalised ''D'eaf' refers to a linguistic trait and cultural identity, with the 'd'eaf community being more pro-cochlear implant, whereas 'D'eaf community is more critical of cochlear implant (Chang, 2017).

Thus, given fundamental differences of self-identity among deaf persons, with the rise of the disability movement in the 1980s and the approach of the social model of disability, at first deaf persons also embraced it, but later on many of them considered that they were uncomfortable with their inclusion in the disability social model, given that this meant that they accepted the medical concept of deafness as an impairment, thus both 'medical' and 'social' models of deafness were thought to view them as disabled persons (Ladd, 2003). Therefore, distinct from the medical and social models, sign language-using communities constitute a third model: the 'culturo-linguistic model' of deafness (Ladd, 2003). The ‘culturo-linguistic model’ refuses the categorisation between ‘medical’ and ‘social’ models of deafness and *“denies that degree of hearing impairment has relevance for cultural membership”* (Ladd, 2003, p. 35) and the degree of deafness is secondary to their hereditary cultural influences. The core of the culturo-linguistic model is rooted in *“ideas about individualism and collectivism in Western societies. Deaf cultures are not cultures of individualism, but of collectivism, a trait which they share with 70% of the global population”* (Ladd, 2003, p. 16). Other aspects of self-identity of deaf persons are explored in following chapters of this thesis too.

2.2 Social relationships and social participation by type of disability

In this subchapter are presented findings from previous studies on aspects relevant to social relationships and social participation of persons with each type of disability, based on the aim of this thesis – but not limited to the specific health issues that participants of this thesis had.

2.2.1 Sensory disability

Regarding research on sensory disability, a study conducted in Ireland across various physical and sensory types of disability, found that the domain of greatest difficulty also for persons with blindness and deafness was participation in society, with 27.2% of deaf participants experiencing difficulty in social participation due to barriers in the world around them (Gallagher & Mulvany, 2004). The sensory disability explored in this study has been related to hearing difficulty or deafness. The history of deafness is in fact the history of a otherness which has an immediate impact on a person’s life since the moment of birth, given that for communicating with others, the spoken language is the first instrument a child uses in order to access information, education, and all forms of sociality in general (Russo Cardona & Volterra, 2007). Commonly, deafness is perceived solely as a physical deprivation, without reflecting upon the consequences deafness has for the social identity of a person (Russo Cardona & Volterra, 2007). The biologic and sociocultural dimensions of deafness are both in play and only by renouncing traditional categorisations (e.g. nature versus culture, or biology versus sociality) we can have the complete picture of this complex condition (Russo Cardona & Volterra, 2007). It has been argued that individuals receive by their society the knowledge of how to live in and experience their bodies (Hauser, O'Hearn, McKee, Steider, & Thew, 2010). Accordingly, the way persons within a society interact with deaf persons impacts on what deaf persons learn, thus also on their attitudes, values, and interests (Hauser, O'Hearn, McKee, Steider, & Thew, 2010).

Regarding socio-cultural characteristics of deaf persons, a characteristic example is that it has been observed that some deaf persons prefer to have a deaf child on purpose by seeking deaf partners or sperm donors, and celebrate when their newborn is deaf *"not because of their child's hearing loss, but rather their biological propensity to be more visually oriented"* (Hauser, O'Hearn, McKee, Steider, & Thew, 2010, p. 487). Thus, according to the deaf culture, having a deaf child can be a reason to celebrate, whereas having a hearing child might cause deaf parents depression (Hauser, O'Hearn, McKee, Steider, & Thew, 2010). Even in terms of intimate relationships, 90% of deaf persons choose to marry deaf partners, and when they choose to marry a hearing partner, they usually have some kind of connection through their family, for example, with deaf persons' culture and language (Lane, Pillard, & Hedberg, 2011). It has been also stated that deaf adults are securely attached to other deaf adults, but not securely attached to other hearing adults, and have more difficulty leaving abusive relationships, while deaf college students are not as well-informed about health and sexuality compared to their hearing peers (Hauser, O'Hearn, McKee, Steider, & Thew, 2010). Therefore, before exploring the attitudes and beliefs of deaf persons, one should consider that they do not necessarily have the same attitudes, norms and values as hearing individuals do, and should respect their individuality. As such, it has been suggested that the intentions of professionals should focus on promoting a healthy and well-adjusted deaf child, rather than trying to 'correct' the child's medical condition (Hauser, O'Hearn, McKee, Steider, & Thew, 2010). By the viewpoint of many deaf persons, as for many other groups of persons with disability, their struggle is not to alter their biological status in order to fit the majority of the society, but to be recognised by their community as full members of it, and thus reduce educational and health inequalities they face in the wider society (Hauser, O'Hearn, McKee, Steider, & Thew, 2010). One of the main barriers deaf persons face relates to their employment access and opportunities. A recent study (Kim, Byrne, & Parisha, 2018) compared the economic well-being of people with and without hearing impairment in the United Kingdom and found that economic well-being was significantly worse for people with hearing impairment than people without hearing impairment. In specific, people with hearing impairment had lower household income and greater difficulty to make ends meet, as well as were less likely to work in paid jobs. The authors of this study recommended that policy-makers should consider increasing access and engagement for persons with hearing impairments, such as by increasing investment in better opportunities for employment for them, sign interpretation, and disability benefits (Kim, Byrne, & Parisha, 2018).

Thoughtfulness is required when referring to deaf persons as persons ‘with disability’, since many of them do not consider themselves as disabled and argue that they are identified by the wider society as a distinct cultural group with their own norms, customs, and language, with deafness being for them a cultural rather than a medical term (Munoz-Baell & Ruiz, 2000). A more representative term for deaf persons and any other persons with disability would have been an alternative term, maybe deriving from the words *different* and *ability/ies*: persons with ‘diff-abilities’ or ‘differently-abled’. The term ‘disability’ indicates a negative characteristic of the person or her/his interactions with the contextual environment, whereas the term ‘diff-ability’ indicates an interesting and positive position (Edmonds, 2012). Also, as an alternative to the term ‘disability’ has been suggested the concept of ‘neurodiversity’ (Armstrong, 2010), which about 15 years ago originated as a movement of persons with autism spectrum disorders, who claimed their right to be seen as different and not as disabled. Apart from autism, ‘neurodiversity’ has been also used in the case of deaf persons (Cardano, Preface, 2017) to describe an approach to otherness not as a biomedical condition (based on the medical model) nor as an impairment which becomes disability due to social exclusion (based on Disability Studies), but deriving from Deaf Studies, as a form of difference in which – similarly to ‘neurodiversity’ – deafness is considered as a cultural minority, with shared language and cultural characteristics. In any case, not all persons with disability are willing to self-identify as persons ‘with disability’ or using any other term in order to align themselves in a group of persons in similar position in order to form a political strategy (as mentioned above). There are persons with disability who in fact disagree with any change of the term of ‘disability’ just for reasons of political correctness, since the problem of discrimination still resides for them in practice, and prefer to be called simply by their name, as everyone else does (Gambirasio, 2016).

Resuming on the socio-cultural model, according to it there are differences even among deaf persons, which are mentioned also above, with some of them feeling proud to be deaf whereas others reject deafness, while others self-defining themselves as hard-of-hearing whereas others as deaf, thus there are apparent cultural and linguistic differences among deaf persons too (Munoz-Baell & Ruiz, 2000) – an in-group heterogeneity which needs to be taken into consideration when conducting a study on deaf persons. Accordingly, based on the context of this thesis, this in-group distinction has been evident for a long time also in Italy, even within school settings, such as in the cases explored by the ethnography of Michele Cioffi (2017), who recorded in Italy the experience of exclusion of ‘speaking’ deaf students (so-called *‘parlanti’* or *‘oralisti’* in Italian) by their ‘signing’ deaf peers (*‘segnanti’* in Italian). This in-group distinction has also been explored in this research, by including in the study sample both ‘speaking’ and ‘signing’ deaf participants. To make this distinction clearer, there have been fundamental differences in terms of self-identity for deaf persons, between those who use the signing language and those who speak and refuse to use signing language – although they might know it. Persons who are born with profound deafness either grow up learning the sign language or their parents decide that is best for them to have a cochlear implant placed surgically, so they can possibly have a sense of sound, or are both speaking and using the sign language (the so called ‘bilingual’). Cochlear implant is a surgically implanted device the application of which started in 1992 and radically changed the approach to child deafness (Ambrosetti, 2017). There have been additional assistive technologies developed for persons with hearing difficulty, which help them perceive varying levels of sound or function with vibrations or light to make easier the life of persons with hearing difficulty. Some of these assistive devices are presented in Figure 3 below.

Figure 3. Assistive devices for persons with hearing difficulty.

Source: Photo taken by the author of this doctoral thesis, during presentation of Dr. Martina Gerosa, Architect/Urbanist Disability & Case Manager[2], 2018.

Photo properties: Creator: author of this thesis; Date taken: 24 February 2018; Location: Event organised by Associazione Famiglie Audiolesi (A.F.A.) of the Province of Como and Lecco, held at Cantù, Italy; Type: JPG file, edited with Microsoft Windows 8 Paint; Dimensions: 809 x 804 pixels. Photo included in the thesis with permission of the owner and presenter of the elements shown in it: Dr. Martina Gerosa.

The following elements are displayed in the photo:

1. Hearing aids: On the left-hand side of the case is an In-the-ear (ITE) hearing aid and on the right-hand side a Behind-the-ear (BTE) hearing aid (in Italian called *'endoauricolari'* and *'retroauricolari'* hearing aids, respectively).

2. Vibrating alarm clock: Clock which vibrates when alarm goes on.

[Devices 3, 4 & 5 listed below: Radio Frequency Signalling System with Sound, Light or Vibration alert]

3. Door Transmitter: This device helps users to notice when the doorbell rings as it signals the Visit receiver that notifies users with flashes, sounds or vibrations.

4. Portable Receiver: This device alerts users with a light and sound when the doorbell or telephone rings, or when a fire should occur.

5. Bed Shaker: This device alerts users with powerful vibrations, when placed under a mattress or pillow and is plugged in another alarm clock or receiver. This device can be particularly useful for mothers with hearing difficulty, since it alerts them with vibrations while they are sleeping each time their baby cries.

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[2] Collaborator of Cooperativa Accaparlante Bologna-Milano; Team Leader of Progect PASSin - Più Accessibilità Sensibilità Semplicità per l'inclusione; Collaborator of Direzione Fondazione Pio Istituto dei Sordi; Member of the Scientific Committee of Associazione inCERCHIO for fragile persons.

The benefits of cochlear implant can be maximised when the surgery occurs before the age of five (Chang, 2017) and it has been stated that the cochlear implant represents an accelerator of psychophysical and intellectual development, to such a degree that after the implantation, children with motor difficulties can start walking in about 15 to 20 days (Ambrosetti, 2017). However, there have been a series of risks reported, for example by the Unites States Department of Health and Human Services[3], for people who use cochlear implants, such as that they may hear sounds differently, or lose residual hearing, or have their implant fail or removed, etc. Moreover, three studies reviewing more than 300 cases each on surgical and medical complications of cochlear implantation in adult and/or paediatric patients, reported both major and minor complications of cochlear implantation, including: foreign body reaction, incorrect electrode position, mastoiditis, cholesteatoma, facial palsy, vestibular, tinnitus, seroma, disequilibrium, wound infection, tympanic membrane/angle injury, and others (Brito, Monteiro, Leal, Tsuji, Pinna, & Bento, 2012) (Farinetti, Ben Gharbia, Mancini, Roman, Nicollas, & Triglia, 2014) (Migirov, Muchnik, Kaplan-Neeman, & Kronenberg, 2006). Nevertheless, surgical implications in these three studies were observed in less than 20% of the cases of cochlear implantations they explored, thus cochlear implantation was considered a surgical procedure with low complication rate (Brito, Monteiro, Leal, Tsuji, Pinna, & Bento, 2012) (Farinetti, Ben Gharbia, Mancini, Roman, Nicollas, & Triglia, 2014). Apart from the medical implications after cochlear implantation, it has been shown that there are implications also in terms of social skills, for example, based on a recent study on the longitudinal effects of cochlear implantation on social competences of deaf children it was found that children with cochlear implants *"had significant delays in social competence across time compared to their hearing peers, even 8 years after implantation"* (Hoffman, Cejas, Quittner, & CDaCI Investigative Team, 2016, p. 157).

As mentioned previously, the main basis of opposition between 'd'eaf (with lower 'd') community and 'D'eaf (with capital 'D') community is cochlear implantation, thus deaf persons who are in favour of cochlear implantation belong to the first community, whereas deaf persons who disagree with cochlear implantation and support the cultural and linguistic diversity belong to the latter community (Chang, 2017). This attitude

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[3] U.S. (United States) Department of Health and Human Services. U.S. Food & Drug Administration → Medical Devices → Products and Medical Procedures → Implants and Prosthetics →Cochlear Implants →Benefits and Risks of Cochlear Implants. Available at: https://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ImplantsandProsthetics/CochlearImplants/ucm062843.htm [Accessed 30 April 2018].

towards ‘denial’, or not, of the culture of deafness, along with the sense of self-identity as either a ‘speaking’ or ‘signing’ deaf person has been very strong among deaf persons and obviously has roots in their childhood and family attitude. Apparently, along with this distinction, follows also ethical difference among them based on the effort of ‘normalisation’ of the deaf person, meaning trying to ‘remove’ deafness from their existence as much as possible (supported mostly by ‘speaking’ deaf persons), versus embracing the pride of being deaf (supported mainly by their ‘signing’ peers). Certainly this distinction conveys also social consequences and differences, such as either social exclusion or inclusion, depending on the sense of identity adopted and the context. In particular, these social representations of deafness versus Deafhood are very different, in terms that in the first case, deafness is subjected to a medicalisation process, seen as a diminution (‘*minorazione*’), an impairment which has to be cured and repaired, whereas in the second case, deafness is perceived as a minority (‘*minoranza*’) and the focus is on the demand for and defence of one's linguistic specificity and cultural identity, which must be protected and preserved as a richness of humanity (Dolza, 2017).

As mentioned above, the ideal age for cochlear implantation is suggested to be before the age of five, thus parents have the responsibility to decide on behalf of their infant whether to have a cochlear implant or not. Specifically, a recent qualitative study (Chang, 2017) on the social processes and communicative components influencing this important parental decision, found that several parents reported how difficult it is to be part of both communities (i.e. the ‘d’eaf community and the ‘D’eaf community) simultaneously and felt that they had to choose which one their child would belong to for the rest of her/his life. There were parents also that reported feeling stigmatised and ostracised because as hearing parents they decided to get cochlear implant for their child, and as a consequence both the parent and the child become ostracised from the Deaf community, and at the same time stigmatised from the hearing community since a deaf child would be considered as part of a marginalised group (Chang, 2017). On this strong opposition of the Deaf community towards families and deaf children with cochlear implantation, it has been argued that more than 90% of deaf children are born to hearing parents, who are not aware of the deaf culture and feel additional pressure driven by their fear of ‘abnormality’ and desire for their children to be ‘normal’, influenced by a medical model *“which claims that normality can only be achieved by denying the realities of deafness and keeping their children away from Deaf communities lest they be ‘contaminated’ by them”* (Ladd, 2003, p. 35). This approach of parents has been argued to have caused psychic problems in both children and their parents, in terms of family bonding, social relationships, and even marital relationships (Ladd, 2003). Parents have also reported on how social influences of communities, particularly norms and identity concerns, influenced their decision-making process about cochlear implantation of their children, such that expectations and norms of their communities and social networks would enhance their desire for their child to fit into the norm (Chang, 2017). According to the same study, parents have on their disposal a large amount of information on this issue, for example via social support groups for parents with deaf children, internet sources, and medical advice, however, parents usually prefer seeking information from other parents who have already experienced this decision-making process (Chang, 2017). All these factors influencing the decision of parents led parents expressing their fear of their child being ostracised or feeling the same stigma that they themselves experienced from one of the 'd'eaf or 'D'eaf communities or wider hearing community in general, thus parents need support by health professionals and social support groups in order to make an informed decision, especially for hearing parents who require more time and information about all relevant issues (Chang, 2017).

Besides all above, an important consideration is that the aspects of sociality of deaf persons may differ greatly depending on whether they speak or use gestures to communicate with others in conjunction with the context they are in, and whether their social life depends on communication with speaking or signing persons similarly or differently to them. Therefore, this research explored both the cases of signing and speaking deaf persons in relation to their social relationships and social participation, to distinguish any potential patterns in that respect too, without supporting one side instead of the other. However, I support strongly the necessity for provision of adequate and objective information by health professionals and social services to parents and their children with hearing difficulty, regarding all possible scenarios in both cases, and the freedom of choice to parents and their children whether they prefer to follow a more 'speaking' or 'signing' stance towards deafness or Deafhood, without prejudice or discrimination towards them from any 'd'/'D'eaf community or person of the wider society in general.

Regarding methodological issues in social research for persons with hearing difficulties, it appears that social activity of persons with hearing or other types of disability has been investigated up to date using 'objective' tools for assessing social participation, meaning without assessing the opportunity the respondent has to live life as she/he would like to, which can be assessed when using 'perceived' participation measures (Mikkola, Portegijs, Rantakokko, Gagné, Rantanen, & Viljanen, 2015). In more detail, ‘objective’ participation assessments include how often respondents meet with friends, family members, acquaintances, etc. or engage in group or non-group activities outside their house, for example (Mikkola, Portegijs, Rantakokko, Gagné, Rantanen, & Viljanen, 2015). ‘Perceived’ participation assesses the experience as perceived by the person according to her/his needs in order to be involved in various life situations, in other words, it assesses the opportunity that a person attains in order to live her/his life in the way that she/he would enjoy (Mikkola, Portegijs, Rantakokko, Gagné, Rantanen, & Viljanen, 2015). In this study were used only ‘perceived’ participation assessments, without any categorisation of responses based on any ‘objective’ level or pre-defined scores. Responses of participants were assessed depending on their subjective viewpoint, for example, on their subjective perception of loneliness, which can be viewed by anyone as something not necessarily sad or imposed by lack of choice, but instead as a desired and relaxing situation.

2.2.2 Mental disability

It has been stated that most researchers agree that social ties have a salutary effect on mental health (Kawachi & Berkman, 2001). Social disconnectedness, which is commonly defined by low level of social contact, and perceived social isolation, which is commonly defined by the person herself/himself by feelings of loneliness, are very common in the overall population and are linked to higher risk of physical and mental health problems (Green, Horan, & Lee, 2015). Moreover, social capital has been negatively correlated with depression and severe mental illnesses, such as schizophrenia or bipolar disorder, since people in general tend to exclude those who are different from themselves, so people in general perceive persons with severe mental issues as not being able to contribute to the community’s social capital (Webber, et al., 2014). Persons with severe mental distress, such as those hearing voices, experience consequences of their suffering in all areas of their lives, from health to work, from relationships to love (Cardano, 2010), and it has been suggested that they may benefit from interventions which empower their social capabilities and confidence, and increase their ability to trust and experience interpersonal relationships which are more balanced (Mawson, Berry, Murray, & Hayward, 2011). Moreover, persons with psychosis often struggle to develop and preserve functioning relationships, have limited social networks, as well as restricted access to social support, apart from the institutional support provided by mental health services (Michalska da Rocha, Rhodes, Vasilopoulou, & Hutton, 2018).

In terms of social functioning of persons with psychoses, the social cognition abilities regarding schizophrenia in specific which have been mostly studied are: emotion perception, social perception, Theory of Mind (ToM)[4], and attributional style (Couture, Penn, & Roberts, 2006). Social perception is a person's ability to determine social cues from behaviours demonstrated within a social context and is closely related to social knowledge, which is a person's understanding of social norms (Couture, Penn, & Roberts, 2006). Social cognition can be divided into reflective and reflexive social processes (Green, Horan, & Lee, 2015). The reflective social processes which are impaired in schizophrenia, such as perception of social cues, emotion regulation, and ToM, are those requiring a controlled processing with effort (Green, Horan, & Lee, 2015). On the other hand, the reflexive processes, such as experience sharing – which was the main interest of this study – and emotion experience, both require less mental effort than the reflective ones (Green, Horan, & Lee, 2015). Furthermore, social perception has been found to have a consistent relationship with community functioning, in terms of various tasks and indices of functioning (Couture, Penn, & Roberts, 2006). Another distinctive behavioural characteristic of persons with schizophrenia is the lack of empathy, meaning the ability to comprehend and correspond to the emotional situation of another person, which also hinders social functioning for persons with this disorder (Green, Horan, & Lee, 2015).

Regarding symptoms of schizophrenia, according to Bentall (2010), it has been found that parents, close relatives, and friends can cause stress to persons with schizophrenia, with controlling behaviours from others making it harder for them to recover. On the other hand, highly emotional, hostile, or over-protective relatives seem to exacerbate the person's symptom, and thus requiring further treatment (Bentall, 2010). Moreover, children of parents who have exhibited high levels of expressed emotion were found to be more likely to develop psychotic symptoms compared to children whose parents did not exhibit such level of expressed emotion (Bentall, 2010). Regarding the effect of physical environment on psychosis, it has been argued (Bentall, 2010) that children who live in cities are likely to experience victimisation in their life, and such experiences make them more likely to become psychotic in later life. Overall, Bentall (2010) has criticised the tendency of psychiatrists towards the biomedical approach, and highlighted historical and

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[4] Theory of Mind (ToM) *"refers to the cognitive capacity to represent one's own and other persons' mental states, for instance, in terms of thinking, believing, or pretending"* (Brüne, 2005, p. 21).

current disadvantages this approach has to the improvement of the experiences of the lives and therapies of persons with schizophrenia, and confronted with great scepticism any past or current physically-induced therapies and dependence on drugs to treat mental disorders, while providing examples from findings of studies and his practice, where socially-related factors seemed more relevant and less-medicalised approaches more beneficial for the condition of patients. These beneficial approaches can occur when patients are being treated by psychiatrists as individuals, discussing with them their story, with warm and empathetic attention, and not just labelling them after 15-minute sessions with a mental disorder as if they were plants – a tendency of psychiatrists which Bentall radically characterises as *"meaningful as star signs"* (2010, p. 110) for predicting the future of these people. Similarly, if psychiatrists decide to approach the personal world of schizophrenic patients considering also their broad historical and social context, then a psychiatrist would *"be less prone to label their behaviour and experiences as incomprehensible and completely alien to normal human nature"* (Jenner, Monteiro, Zagalo-Cardoso, & Cunha-Oliveira, 1993, p. 44). Moreover, as mentioned above, distress that emerges from social conditions is neither a mental disorder nor a disease, thus should not be classified by psychiatrists as mental disorder (Horwitz, 2002). For example, post-traumatic disorder shows how the environment can actually cause dysfunctional psychological mechanisms (Horwitz, 2002) and eccentric behaviour, which is not characteristic of a psychiatric disorder, also could be misunderstood as mental illness (Corrigan P. , 2004). There are two characteristics that help distinguish expectable distress from internal dysfunctions: the severity and duration of symptoms (Horwitz, 2002). If an expectable distress becomes disproportionally more intense in terms of severity, for example, in the case that the grief of the death of a loved one causes hallucinations and other severe symptoms, then this would cross the line between anticipated sadness to internal dysfunction (Horwitz, 2002). Similarly, if symptoms persist in terms of duration, even after the cessation of the stressors (triggers), this may indicate that expectable distress has become internal dysfunction (Horwitz, 2002).

The importance of social influences on mental health has been shown by the high variability in rates of many mental disorders across time and space (Horwitz, 2002). Additionally, it seems that biological psychiatry has contributed greatly to the current crisis in mental health by emphasizing on the association between brain and mental illness, but mental disorders are more than brain disorders (Joober, 2016). It has also been argued that the industry with its powerful force has promoted greatly the *"pill solution"*, which has led also philanthropists and patients themselves to believe that a pill can treat a mental disorder (Joober, 2016). Social and contextual aspects seem to be considered by psychiatrists as if of secondary importance, despite evidence on the role of social determinants of health, presented in this study too, which show that a less parochialistic biomedical approach and more empathetic discourses on contextual aspects with patients could be proven more beneficial for them. For example, a study exploring psychosocial difficulties of persons with neuropsychiatric disorders (Coenen, et al., 2016), found that persons with depression and schizophrenia may experience problems with speaking or communication and personality issues, which are likely to receive less attention in terms of usual care of neurological disorders. In particular, the psychosocial disorders related to schizophrenia were found to be related to mental functions (i.e. energy and drive functions, temperament and personality functions, attention functions, emotional functions, memory functions) and issues related to activities and participation (i.e. organising and carrying out daily routine, communicating/speaking, interpersonal relationships, work-related issues, community life, recreation and leisure) (Coenen, et al., 2016). Specific generated psychosocial difficulties for persons living with schizophrenia have been found to be:

> Stigma, marginalization, discrimination, social withdrawal, disengagement, loneliness, fear despair and helplessness, problems with relationships and interpersonal skills (affecting family, intimate and occupational relationships), frustrations with mental health services, problems with self-esteem and overprotection, un-met needs for social reciprocity, constancy, hope and understanding, problems with finding and keeping work and a place to live (Hartley, et al., 2014, pp. 6-7).

Whereas, facilitating factors for persons living with schizophrenia have been found to be:

> Providing empathetic physical and social spaces, such as living spaces, work spaces and routine environments, meaningful occupations, often outside the home such as exercise (noted to be both a way to socialize and become healthier), supported employment, trust, knowledge in advance of what is happening, training for health workers to listen more and work in partnership and family support. (Hartley, et al., 2014, p. 7).

The finding that persons with schizophrenia themselves ask for *"training for health professionals to listen more"* (Hartley, et al., 2014, p. 7), endorses the suggestion mentioned above for a more empathetic discourse with patients. Specifically on psychotic disorders and stigma, a systematic review found six themes in relation to stigma on pathways to care among people experiencing first-episode psychosis or at clinically defined increased risk of developing psychotic disorder, including ‘sense of difference’, ‘characterizing difference negatively’, ‘negative reactions (anticipated and experienced)’, ‘strategies’, ‘lack of knowledge and understanding’, and ‘service-related factors’, and the results illustrated the complex manner in which stigma-related processes can have an impact on help-seeking and service contact among the specific target group (Gronholm, Thornicroft, Laurens, & Evans-Lacko, 2017). Another systematic review of the literature from 2005 to 2010 that explored psychosocial difficulties and their associated factors for people living with schizophrenia (Świtaj, et al., 2012) – using the ICF (World Health Organization, 2001) as the conceptual framework of the study – reported that the most frequent psychosocial difficulties explored by the literature belonged to broad areas of psychosocial functioning, such as psychopathological symptoms or global disability and functioning, while among mental functions, the most extensively studied were cognitive and emotional functions (Świtaj, et al., 2012). In relation to the ICF domain of activities and participation, the most widely investigated were difficulties in relationships with others and employment. The authors of this study argued that the findings of the systematic review showed how a large variety of psychosocial areas affected in schizophrenia are interconnected and interact with environmental and personal contextual factors (Świtaj, et al., 2012). Thus, research on schizophrenia should focus less on psychopathology and more on the investigation of perceptions and experiences of stigma, as well as temperament and personality functions of people with schizophrenia, and a deeper exploration of these areas will shed more light on the extent of the psychosocial problems faced by persons with schizophrenia and “will also be helpful in uncovering their personal strengths that make them less vulnerable to disability and social exclusion” (Świtaj, et al., 2012, p. 10).

Finally, it has been stated that it is important to explore social relationships of young persons with early and recent onset of psychosis, because: a) the onset of psychosis occurs usually in late adolescence or early adulthood, thus disruption of social development at this age can have long-term negative impact on a person’s prospects, b) persons with psychosis often experience social dysfunction and social isolation, wanting more friends, and have difficulty maintaining intimate relationships, and c) the quality of social relationships of a person is considered to have an impact on the outcome of the illness in terms of the person’s adaptive functioning (MacDonald, Sauer, Howie, &

Albiston, 2005). Similarly, this thesis has focused on young adult population with psychosis.

2.2.3 Physical disability

Persons with physical disability face various challenges in terms of social relationships and social participation as well. Based on a previous qualitative study, adults with spinal muscular atrophy (SMA) reported that their experience of living with SMA was enhanced by supportive social networks of family and friends, the ability to 'normalise' and mainstream[5] within society, a creative and innovative approach to symptom management, as well as by the ability to maintain an optimistic life outlook (Lamb & Peden, 2008). A more recent study on social participation of adults with SMA has shown that persons with early-onset SMA reported significantly more participation restrictions compared with participants with late-onset SMA (Kruitwagen-van Reenen, et al., 2018). The areas that participants of this study felt most restricted in terms of social participation were: work/education, mobility outdoors (e.g., traveling by car, public transport or bike), going out (e.g., to a movie, pub, church, or shopping), visits to family and friends, doing household tasks, and physical exercise (Kruitwagen-van Reenen, et al., 2018).

A systematic literature review (Barclay, McDonald, & Lentin, 2015) on the measures and conceptualisation of social and community participation for persons with spinal cord injury (SCI) found that the qualitative studies focused on the understanding of participation from the point of view of the person with SCI, rather than the societal perspective for them. According to the same review, studies found that for persons with SCI family relationships and social support were important for them, especially after the onset of the injury, and most of the studies found that participation in the areas of community, social, and civic life changed after the SCI, with many of them becoming socially isolated, while others replaced their previous leisure activities with new ones (Barclay, McDonald, & Lentin, 2015). Regarding environmental barriers for full social participation in community life for SCI, were mostly found to be transport issues, natural environment issues (depending on country/ies of study), or built environment issues (such as accessing someone else's home) (Barclay, McDonald, & Lentin, 2015). On social support, especially from the qualitative studies, it emerged that it was an important facilitator for social and community participation of persons with SCI, with emotional

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[5] *"Mainstreaming meant attending college, maintaining gainful employment, and being a productive member of society."* (Lamb & Peden, 2008, p. 255).

support being provided by a specific person in their life, such as family member, friend, or a mentor from their peers, while practical support was critical for community participation, and the timing of both emotional and practical support was found to be important as well (Barclay, McDonald, & Lentin, 2015). Healthcare and government policies were found to be barriers for participation as well, whereas products and technology were reported to be viewed as both facilitators and barriers (Barclay, McDonald, & Lentin, 2015). The authors of this recent review (Barclay, McDonald, & Lentin, 2015) state that further research should be conducted regarding the social and community participation after the onset of SCI, with the use of in-depth exploratory approaches.

Neurological diseases/disorders are types of conditions often accompanied by physical, motor and physical disabilities. Regarding persons with neurological diseases/disorders and the relationship between their health condition and social life, it has been found that for persons with Parkinson’s disease, for example, their health condition has had an impact on their social interactions by disrupting social connectedness (Soleimani, Negarandeh, Bastani, & Greysen, 2014). Social connectedness refers to the relationships formed between persons that results in feelings of belonging, social identity, and support, which facilitate coping with physical and psychological issues (Soleimani, Negarandeh, Bastani, & Greysen, 2014). Moreover, social connectedness of persons with Parkinson’s disease was found to be disrupted due to progress of their physical disability, mood disturbances, reduction of social activities, and isolating oneself, concluding that disrupted social connectedness seems to be a negative effect for persons living with Parkinson’s disease (Soleimani, Negarandeh, Bastani, & Greysen, 2014). Additionally, according to the same source, there has been limited evidence up to date regarding the impact of feelings of shame and embarrassment, which persons with chronic diseases experience, on their social relationships (Soleimani, Negarandeh, Bastani, & Greysen, 2014). However, these feelings of shame and embarrassment should not remain underexplored, especially in relation to social relationships, thus these feelings were considered also when interpreting the findings of this thesis. Another study, on women with multiple sclerosis, found that greater functional limitation was significantly correlated with less social support, possibly due to the fact that physical difficulty impacts on the person’s ability to maintain social relationships and participate in social activities or that as people become progressively more limited in terms of physical ability, their social networks cannot provide the adequate support to them anymore (Beal & Stuifbergen, 2007).

Communication difficulties occur for approximately half of the population with multiple sclerosis (Yorkston, Bourgeois, & Baylor, 2010). Communication is necessary for any person's functioning on a daily basis, thus impairment on this process might force persons with multiple sclerosis to change their social and personal relationships in order to adjust their activities and life roles to the new circumstances (Yorkston, Bourgeois, & Baylor, 2010). A qualitative research on adults with multiple sclerosis, explored their satisfaction with communicative participation, meaning *"taking part in life situations where knowledge, information, ideas or feelings are exchanged"* (Yorkston, et al., 2007, p. 434), and argued that disabling conditions with communication disorders are very likely to cause participation restrictions and distress to the persons experiencing them. The main themes that emerged regarding satisfaction of persons with multiple sclerosis in terms of communicative participation were comfort, success of outcome, and personal meaning of participation, whereas frequency of activities was not mentioned by participants as a key part of their satisfaction (Yorkston, et al., 2007). Fatigue is another aspect of multiple sclerosis affecting approximately 80% of persons with multiple sclerosis, with two thirds of them reporting fatigue as their main complaint, restricting their daily activities and participation in social roles, and has a major impact on their QoL too (Blikman, Huisstede, Kooijmans, Stam, Bussmann, & Van Meeteren, 2013). Furthermore, psychosocial factors have been closely connected to pathogenesis, pathophysiology, and clinical symptoms of multiple sclerosis (Liu, Ye, Li, Dai, Chen, & Jin, 2009) and severity of interpersonal functioning if monitored at pre-treatment can predict the therapeutic outcome (Howard, Turner, Olkin, & Mohr, 2006). Thus, the significant impact of psychosocial factors and social relationships on health is evident for persons with multiple sclerosis, adding further barriers due to the perceived social stigma they experience, given also that chronic illnesses, such as multiple sclerosis, can be a threat for the social network of the person experiencing them, plus, the stigma associated with chronic disease and disability is a burden for these persons and their families too (Halper, 2007).

2.3 Gender differences by type of disability

In this subchapter are presented various findings from studies regarding gender differences based on the three types of disability under question.

2.3.1 Sensory disability

Deaf women do not appear in historical evidence as much as deaf men, possibly due to the position of women in general being considered as inferior to men until about a century ago, when women started to have more active roles at local or national levels, and in recent years being appointed to more important positions within communities, including deaf community (Ladd, 2003). In the United Kingdom (UK) there has been an increase in projects and health groups of deaf women, and in the United States of America (USA) women have even higher positions in community and an international organisation for them has been formed there too (Ladd, 2003). However, women with disabilities and deaf women have been often reported as victims of interpersonal violence, either at physical, emotional, or sexual levels (Powers, et al., 2009). Findings are consistent regarding the impact of interpersonal violence on women with disabilities, showing that it has negative impact on women’s ability to work, live independently, and maintain their physical and mental health (Powers, et al., 2009). It has been also found that younger women with more education, depression, social isolation, and less mobility are the ones most likely to have had an interpersonal violence-related abuse (Powers, et al., 2009). In cases of abuse, similarly to women without disabilities, deaf women usually talk about the incident to informal support networks, such as a trusted friend, rather than an institutional resource, such as police, specialised agency, etc. (Powers, et al., 2009). Moreover, it is not uncommon for deaf women to be victims of violence from intimate partners, as for women with any type of disability, with additional barriers for deaf women when seeking help in terms of communication access, health literacy, and confidentiality issues (Anderson, Leigh, & Samar, 2011). The intimate partners who abuse deaf women also block them from social interactions with hearing people, do not inform deaf women when people try to call them, etc. (Anderson, Leigh, & Samar, 2011). Therefore, the existence of trustworthy informal social relationships seems to play a crucial role for the support of deaf women, especially regarding issues of interpersonal and intimate abuse.

2.3.2 Mental disability

As mentioned above, abuse is not uncommon for women with disabilities. The consequences of domination versus subordination on mental health can vary greatly (Horwitz, 2002). For example, dominants can express more freely their feeling towards subordinates, whereas subordinates are much more limited to express their feelings and usually express through signs of depression, anxiety, etc. (Horwitz, 2002) Gender differences in distress can illustrate the effect that the systems of relational dominance have on mental health (Horwitz, 2002). At the beginning of 1990s, a study on the gender differences in the course of schizophrenia (Angermeyer, Kühn, & Goldstein, 1990) reported that women tended to have a more favourable course of schizophrenia compared to men, based on a range of outcome measures (i.e. hospital treatment, psychopathology, and social adaptation). According to the study of Häfner (2003), on a sample of the German population, from the onset of schizophrenia the social course of the disorder appeared to be more positive for women in pre-menopausal age than men. The main reason, according to this author (Häfner, 2003), was because schizophrenia's onset occurs for men when they are at an age of a lower level of social and cognitive development, whereas women of the same age have managed to reach a higher level of social development before the onset of the disorder. Based on the same study, men with schizophrenia demonstrate a higher degree of socially adverse behaviour and after the onset of the disorder they demonstrate more social dysfunctioning (Häfner, 2003). So men experience more severe social consequences compared to pre-menopausal women, with the latter ones appearing to come to terms with their disorder on average better than men, because women tend more towards social conformism and comply with therapy more (Häfner, 2003). Consequently, *"women's objective social situations (life conditions) after prolonged histories of illness are considerably better than men's"* (Häfner, 2003, p. 46). The conclusion of this study (Häfner, 2003) was that because of gender differences based on age-related hormonal and behavioural tendencies, the social and symptom-related course of schizophrenia in women and men demonstrates significant differences based on age, with men coping poorly at young age and considerably better later in their life, while women cope significantly better before menopause but worse after menopause. On the other hand, there has been evidence that schizophrenic and bipolar disorders show little variance in terms of gender, however, unlike psychoses, non-psychotic mental disorders are strongly gender-specific (Horwitz, 2002). For example, 90% of cases such as anorexia and multiple personality disorder are manifested by girls and women, whereas the vast majority of deviant behaviours including substance use disorders and antisocial personality disorders are attributed to men (Horwitz, 2002). Furthermore, cultural norms lead women to have more internalised reactions to stressful situations, whereas men more externalised ones, thus the relationship between gender and distress can be based on culture and social culture, and not on biology (Horwitz, 2002).

2.3.3 Physical disability

A study (Robinson-Whelen, Taylor, Hughes, & Nosek, 2013) suggested that although the diversity across types of disability may be seen as a limitation, women with wide variability of physical disabilities share the same challenges in terms of health behaviour and psychosocial functioning and *"larger cross-disability studies are needed to more closely examine the differences and commonalities of women with diverse physical disabilities"* (p. 2415). Based on a literature review on participation of persons with SCI (Barclay, McDonald, & Lentin, 2015), it was found that relevant studies had reported mixed findings in terms of gender differences and identified barriers to community participation. According to a study focusing on depressive symptoms in women with physical disabilities (such as joint or connective tissue disease, multiple sclerosis, SCI or other spinal impairment, and neuromuscular disorder including post-polio syndrome and cerebral palsy), it was found that significant predictors of depressive symptoms for women with physical disabilities include: pain interference, social support issues, and abuse (Robinson-Whelen, Taylor, Hughes, & Nosek, 2013). Additionally, regarding women with multiple sclerosis, it has been found that loneliness is a common experience of women with multiple sclerosis, occurring mostly for those who reported to be unmarried, have lower levels of social support and self-rated health status, greater functional limitation and social demands of illness (Beal & Stuifbergen, 2007).

PART II: Research Framework

Following the conceptual framework of the thesis of studies relevant to the terms under investigation, which have been presented in the first part of this Background chapter, lies the development of the research framework through the identification of the context of the study, not only in terms of relevant policies and laws, but also in terms of previous studies with similar focus to the aim of this thesis, as well as methodology. Accordingly, in the second part of the Background chapter are presented information regarding the policy-related context of this study; evidence from analogous studies to the current one, which employed a qualitative approach too; as well as the research questions of this study, which have determined in turn the specific research framework.

2.4 Social inclusion of persons with disabilities: the policy-related context

The exploration of subjective experiences of persons with disabilities depends greatly from the surrounding social and physical environment, since – as mentioned above – according to the definition of disability, disability is a difficulty in functioning experienced by a person with a health condition in interaction with contextual factors (Leonardi, Bickenbach, Ustun, Kostanjsek, Chatterji, & on behalf of the MHADIE Consortium, 2006). Likewise, the context in which persons with disabilities live can shape their experiences, as social and economic policies have a determining impact on whether people can grow and flourish in their full potential or their life will be blighted (Commission on Social Determinants of Health (CSDH), 2008). As it has been also mentioned above, social capital can affect health outcomes too (Commission on Social Determinants of Health (CSDH), 2008).

In terms of social capital and its relevance to social inclusion, there has been distinction between *bridging* and *bonding* social capital (Putnam, 2000). Bonding social capital refers to forms of inward-looking and homogenous groups, whereas bridging social capital refers to outward-looking and heterogeneous groups (Putnam, 2000). Accordingly, it has been argued that both dimensions can have positive social effects, with bonding social capital being good for motivating reciprocity and solidarity, while bridging networks being better for connection with external assets and diffusion of information (Putnam, 2000). Likewise, social inclusion is most relevant for bridging social capital, since the connection of a person with heterogeneous social networks can promote her/his inclusion in the wider society. As mentioned above, although persons with disabilities have strong ties with their families and other persons with disabilities, they usually lack connections with the wider community, thus have more homogeneous networks and face social exclusion (Chenoweth & Stehlik, 2004). Therefore, the lack of heterogeneous networks has been explored in this research as well. To face the issue of social exclusion, several policies and actions at both national and international level have endorsed and advocated for social inclusion of persons with disabilities, and a number of them are presented below.

2.4.1 The international context

Actions of activism at individual level by persons with disabilities first began in the 19th century, however collective actions on disability rights started in 1960s (Sabatello & Schulze, 2014). This social movement of persons with disabilities challenged the biomedical scientific perception of a specific body model (i.e. white, male, middle-class, ‘able’ body) as being the ‘normal’ body for medical examinations (Sabatello & Schulze, 2014). In line with theoretical developments by sociologists and disability scholars, social activists and advocates for persons with disabilities argued that disablement is a political issue, an issue of basic civil rights (Bickenbach, Chatterji, Badley, & Üstün, 1999). Not only medical issues relevant to disability, but also social issues, such as participation and citizenship rights, have been the focus of the disability rights movement (Sabatello & Schulze, 2014). Persons with disabilities have been discriminated in all areas of life, experiencing limitations in education, employment, housing, and transportation, not due to their medical condition, but due to the social attitudes of neglect and stereotypes towards them about their needs and abilities (Bickenbach, Chatterji, Badley, & Üstün, 1999). Therefore, since the source of the disadvantage that persons with disabilities experience is found in the failure of the social environment to integrate them fully, then the appropriate strategies for removing this inequality are political, focusing on change of attitudes, policies and laws (Bickenbach, Chatterji, Badley, & Üstün, 1999).

In 1993, the World Conference on Human Rights was the largest assembly ever on this topic, with the outcome being the Vienna Declaration (United Nations, 1993) and Programme of Action (Sabatello & Schulze, 2014). In 2006, the United Nations (UN) General Assembly adopted the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, UN Convention on the rights of people with disabilities and optional protocol, 2006), which is a milestone for the promotion of inclusive policy and protection of rights of persons with disability (Sherlaw & Hudebine, 2015). The CRPD emphasises on *"participation and social inclusion stressing the importance of autonomy and the freedom of disabled people to make their own choices"* (Sherlaw & Hudebine, 2015, p. 11). Although the CRPD urges also the full inclusion and participation of persons with disabilities in the community, it is evident that this has not been achieved yet by all Member States who signed this document 10 years ago, however, some of these countries have implemented policies in practice, whereas others, such as Ireland, although having signed the CRPD a decade ago, have not ratified CRPD yet (United Nations. Human Rights Office of the High Commisioner (OHCHR), 2017).

2.4.2 The Italian context

To begin with, the official definition of disability by the State of Italy is dated back in 1992, including outdated terminology, such as '*persona handicappata'* which has been replaced by 'persons with disabilities'. Specifically, according to article 3 of the Law 5 February 1992, n. 104 (Legge 104/92)[6]:

> A person with disabilities may be defined as any person who has a permanent or progressive physical, mental or sensory impairment that hinders the person's learning ability, social relationships or inclusion in the labour market and that may lead to social disadvantage or exclusion. (translation by the *National Observatory on the Condition of Persons with Disabilities*[7]).

Regarding further Italian legislations for persons with disabilities, although there have been laws regarding protection of the rights of persons with disabilities, such as the Law 12 March 1999, n. 68[8] on the right for employment for persons with disabilities – which is a law of the past century –, adjustments on these laws have been suggested, such as the recent request[9] (of 22nd March 2017) submitted at the Italian Chamber of Deputies (*Camera dei Deputati*) regarding the insertion of an addition to the Law 68/99, that on the

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[6] Legge 5 febbraio 1992, n. 104: 'Legge-quadro per l'assistenza, l'integrazione sociale e i diritti delle persone handicappate.' Gazzetta Ufficiale della Repubblica Italiana. Available at: http://www.gazzettaufficiale.it/eli/id/1992/02/17/092G0108/sg [Accessed 10 May 2018].

[7] National Observatory on the Condition of Persons with Disabilities - Ministero del Lavoro e delle Politiche Sociali. Available at: http://www.osservatoriodisabilita.it/index.php?option=com_content&view=article&id=292&Itemid=866&lang=en [Accessed 10 May 2018].

[8] Legge 12 Marzo 1999, n. 68: 'Norme per il diritto al lavoro dei disabili' (pubblicata nella Gazzetta Ufficiale n. 68 del 23 marzo 1999 - Supplemento Ordinario n. 57). Available at: http://www.gazzettaufficiale.it/eli/id/1999/03/23/099G0123/sg [Accessed 10 May 2018].

[9] http://www.camera.it/_dati/leg17/lavori/schedela/apriTelecomando_wai.asp?codice=17PDL0051060

total of the employment positions available for protected categories of the population there should be a minimum of 1% of these positions reserved specifically for deaf persons. The Italian Ministry of Foreign Affairs, Directorate-General for Development Cooperation (MFA-DGCS) produced the *Italian Development Cooperation Disability Action Plan* (2013), which included an action plan with five pillars, based on the guidelines for the introduction of the disability issue within the policies and activities of the Italian Cooperation. Later on, guidelines were adopted based on the pillars of this action plan, such as the *Accessibility Standard Guidelines for buildings,* which aimed *"to provide reference standards for any new construction or renovation project funded by DGDC, in order to allow access to all people, includ[ing] persons with disabilities"* (Directorate General for Development Cooperation, 2015, p. 3).

These guidelines are based on both the principles of the Italian law in the field of accessibility/removal of architectural barriers, for both building new and modifying existing structures, while considering the experience of other cooperation agencies, based on the principles of the Universal Design, etc. (Directorate General for Development Cooperation, 2015). The same source includes also a list of Italian normative references on accessibility and removal of architectural barriers, such as relevant articles of laws.

2.4.2.1 Implementation of CRPD in Italy: pending issues

The law that ratified in Italy the CRPD was Law 3 March 2009, n.18[10], which safeguarded to a more holistic level the rights of persons with disabilities in Italy too, although there have been concerns about its proper implementation – or not – in practice. In particular, Italy has been one of the Member States that also signed on 30 March 2007 the CRPD and ratified it on 15 May 2009, becoming one of the 166 States that have ratified the CRPD (United Nations. Human Rights Office of the High Commisioner (OHCHR), 2017). Thus, Italy also is required to submit regular reports to the UN Committee on the Rights of Persons with Disabilities on how it is implementing the CRPD. The latest report of Italy on the implementation of the CRPD was reviewed by the Committee on the Rights of Persons with Disabilities on 24 and 25 August 2016, who produced a series of concluding observations of their review (Committee on the Rights of

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[10] Legge 3 marzo 2009, n. 18: 'Ratifica ed esecuzione della Convenzione delle Nazioni Unite sui diritti delle persone con disabilità, con Protocollo opzionale, fatta a New York il 13 dicembre 2006 e istituzione dell'Osservatorio nazionale sulla condizione delle persone con disabilità'(Pubblicata nella Gazzetta Ufficiale n. 61 del 14 marzo 2009).

Persons with Disabilities, 2016). According to these observations, the Committee on the Rights of Persons with Disabilities noted with appreciation to Italy the adoption of the 2010 National Disability Action Plan and the ratification in 2013 of the Council of Europe Convention on preventing and combating violence against women and domestic violence (Council of Europe, 2011), and complemented Italy for striving to implement an inclusive education system free of segregation for the past three decades (Committee on the Rights of Persons with Disabilities, 2016). However, the Committee primarily discerned principal areas of concern and recommendations for the implementation of the CRPD in Italy (Committee on the Rights of Persons with Disabilities, 2016), a selection of which are presented below – relevant to the aim of this thesis – per article of the CRPD:

Arts. 1-4: General principles and obligations

The Committee reported their concern on the fact that there are multiple definitions of disability used across sectors and Italian regions and disability continues to be defined according to the medical perspective in Italy. Thus, the Committee recommended that Italy should adopt a concept of disability in line with the CRPD, and this new concept would be ensured by legislation to be incorporated across all levels and regions of Italy.

Art. 6: Women with disabilities

The Committee reported their concern that women and girls with disabilities are not systematically included in the gender equality agenda and disability agenda in Italy. Thus, recommended that gender should be mainstreamed in disability policies and disability mainstreamed in gender policies too.

Art. 19: Living independently and being included in the community

The Committee reported their deep concern about the trend in Italy to re-institutionalise persons with disabilities and that the existing funds are not being reallocated from institutions to promoting and ensuring independent living for all persons with disabilities within their community. In addition, the Committee noted their concern that women in Italy appear to be ‘forced’ to remain in the family as caregivers instead of pursuing employment in the labour market. Thus, recommended that Italy should safeguard the right to autonomous living and redirect funds from institutionalisation to community-based services to allow persons with disabilities to live independently across all regions of Italy, and have equal access to services, including provision of personal assistance.

Art. 27: Work and employment

The Committee reported their concern about the high levels of unemployment of persons with disabilities in Italy and the inadequacy to promote their inclusion in the labour market, particularly of women with disabilities, as well as, that persons with disabilities in Italy may be restricted to perform only certain professions. Thus, recommended that Italy should ensure full and productive employment, decent work and payment of equal value for everyone, including persons with disabilities, as well as to address the issue of low level of employment for women with disabilities and to remove any legislation restricting employment possibilities for persons with disabilities on any profession.

Art. 29: Participation in political and public life

The Committee reported their concern that in Italy persons with intellectual and/or psychosocial disabilities do not receive adequate support in order to vote, and persons with disabilities in general cannot vote wherever they choose and the regulations for their assistance in order to be able to vote are not consistent with the CRPD. Thus, the Committee recommended that Italy should support and provide assistance to persons with disabilities in order for them to be able to vote wherever they choose, including persons with intellectual and/or psychosocial disabilities.

Art. 30: Participation in cultural life, recreation, leisure and sport

The Committee reported their concern that Italy has not ratified yet the *Marrakesh Treaty to Facilitate Access to Published Works for Persons who are Blind, Visually Impaired, or otherwise Print Disabled* (World Intellectual Property Organisation (WIPO), 2013), thus, the Committee recommended that Italy ratifies the Marrakesh Treaty promptly.

2.4.2.2 Country and region-specific data on disability

In order to understand better the Italian context in terms of social inclusion and barriers that women with disabilities face, at national level, relevant data from Eurostat[11] are presented below. According to the *European Health and Social Integration Survey (EHSIS)*, in 2012 in Italy the majority of persons with disabilities[12] aged 15+ were women

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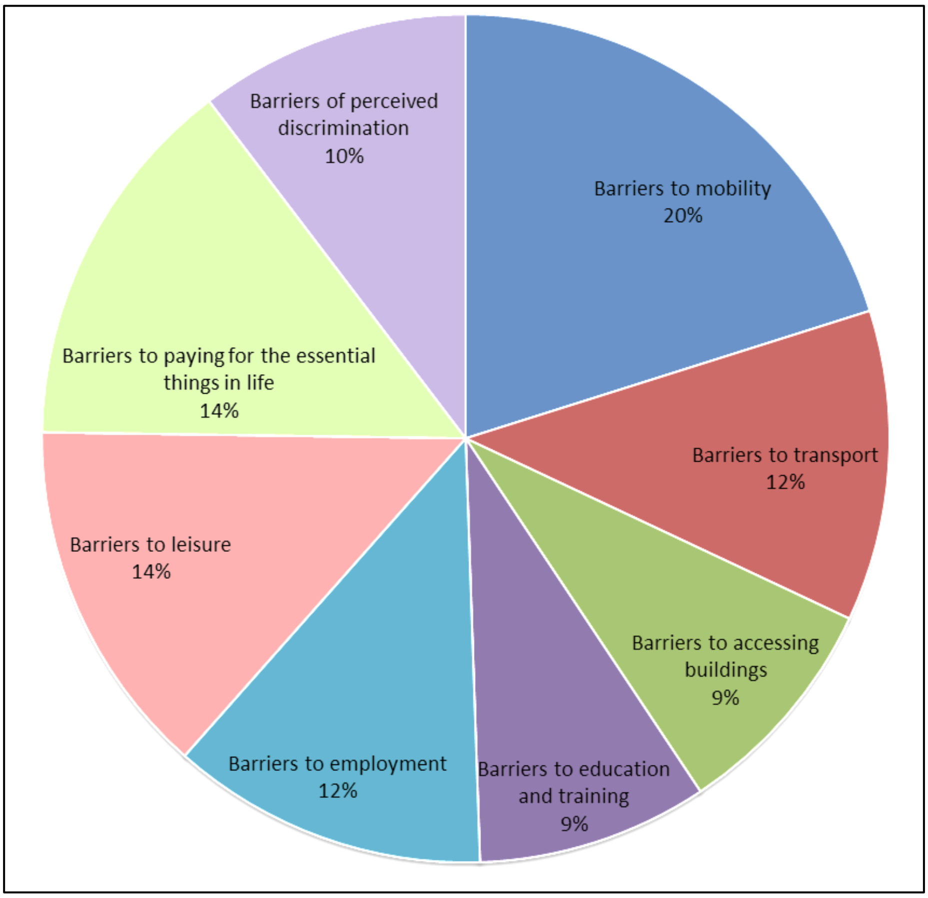
[11] http://ec.europa.eu/eurostat

[12] According to the EHSIS survey: *"People with disabilities are those who face barriers to participation in any (in other words, at least one) of the 10 life areas, where the barrier is associated with a long-standing health problem and/or a basic activity limitation. A person identifying a long-standing health problem and/or basic activity limitation as barrier in any life domain was categorised as disabled. Important note: not all people who have a long-standing health problem and/or basic activity limitation are disabled as it*

(62%). Based on the same source, in 2012 in Italy women with disabilities, aged 15-44, reported to have experienced a series of barriers in various areas of their life (Figure 4). These areas of life were identified by the creators of this survey as being the most relevant from the ICF (World Health Organization, International Classification of Functioning, Disability and Health, 2001). According to these data (Figure 4), most of the women with disabilities in Italy reported to have experienced barriers in terms of mobility, leisure, and paying for the essential things in life, whereas barriers related to education and training and accessing buildings were the life areas barriers were reported the least.

Figure 4. Life areas where a barrier was reported in 2012 by women (15-44) with disabilities in Italy.



Source: Created with data of the European Health and Social Integration Survey (EHSIS), 2012. Extracted from Eurostat database in September 2018.

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may be that these problems or limitations were not barriers to any of the 10 selected life areas." Disability statistics background - European health and social integration survey. Available at: http://ec.europa.eu/eurostat/statistics-explained/index.php/Disability_statistics_background_-_European_health_and_social_integration_survey [Accessed 25 January 2018].

As mentioned above, in Italy there have been variations in terms of legislation/policies across regions, therefore relevant information should be identified here at regional level too. Given that the location of this research was an area of Lombardy region, based on an official report of Lombardy in 2011 on the integration of persons with disabilities in the labour market (Regione Lombardia, 2011), the regional Law 13 of 4 August 2003[13] promotes access to work for persons with disabilities and disadvantaged persons by implementing at regional level the provisions of Law 68/99. Other relevant modifications and additions to policies, as well as relevant functions and provision of services from public bodies, and initiatives have been decided by the regional authorities of Lombardy in order to promote inclusion of persons with disabilities in working place at regional level (Regione Lombardia, 2011). According to the same source, it is very difficult to report the exact number of persons with disabilities in Italy, as well as how they live and what their occupation is, due to the fact that the definition of disability adopted for statistical purposes does not coincide with the definition of disability used in the various laws and policies for persons with disabilities (Regione Lombardia, 2011). Nevertheless, at regional level, it has been stated that in Italy the highest number of employed persons with disabilities can be observed in Northern Italy and in specific at the regions of Piemonte, Lombardia, Veneto and Emilia Romagna, with Lombardia being one of the six efficient regions in the implementation of the Law 68/1999 (Agovino & Rapposelli, 2013).

Regarding deaf persons in Italy, it has been stated that of a national population of approximately 60 million people, every year are registered almost 500 babies with severe and profound deafness, and in Lombardy, with a birth rate of about 8%, is expected annually a number between 90 and 100 cases (Ambrosetti, 2017).

Regarding mental health, based on a Joint Action on Mental Health and Well-being report co-funded by the EU, Italy was one of the first European countries to start the process of deinstitutionalisation, closing its mental hospitals with enactment its Law 180 in 1978 (Caldas Almeida, Mateus, & Tomé, 2017). The Italian reforms that followed based on this process resulted to 55-70% of patients having been discharged from mental hospitals and returned to their families (Caldas Almeida, Mateus, & Tomé, 2017). In Italy there are differences between its autonomous regions also regarding the models and implementation of community mental healthcare, with a common situation for many

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[13] Legge Regionale 4 agosto 2003, N. 13 ‘Promozione all’accesso al lavoro delle persone disabili e svantaggiate’ (BURL n. 32, 1º suppl. ord. del 08 Agosto 2003).

regions being the stabilisation or reduction of resources and the high demand for mental health care services (Caldas Almeida, Mateus, & Tomé, 2017).

Relevant to the aim of this study, the identification of the policies and gaps on implementation of legislations mentioned above facilitated the better understanding of the context of the study and was taken into consideration also during the interpretation of findings and recommendations for future research.

2.4.3 Issues of discrimination and abuse against women with disabilities in Europe

As mentioned previously, it is not uncommon for women with disability to become victims of violence from intimate partners. In fact, women with disability face multiple issues of stigma and discrimination and there are many safety concerns since they are more likely, in general, to become targets of various types of abuse (physical or emotional) compared to women without disability (Banks & Kaschak, 2003). Abusers can be persons that women with disabilities trust and meet in private, such as their personal assistants, while domestic violence and other forms of interpersonal violence on girls or women with disability from family members or intimate partners is even more prevalent (Banks & Kaschak, 2003).

Moreover, it is a known fact that women with disabilities face discrimination against them and are particularly disadvantaged in many areas of life compared to women without disabilities (Leonardi, Koutsogeorgou, Quatrini, & Covelli, 2014). Some of these areas of discrimination and disadvantage are known to be: education and training; employment; social policy; participation and access to decision-making; sexuality; prejudices and social representation; motherhood, family and domestic life (Leonardi, Koutsogeorgou, Quatrini, & Covelli, 2014). In particular, education and employment are both important areas of life for the independence of women with disabilities, and violence is a major barrier for the well-being of any person. According to evidence, 30% of about 250 million women living in Europe have suffered some kind of violence in their life, whereas the equivalent percentage for women with disability is higher, with 50% of about 40 million of women with disability living in Europe to have suffered some kind of violence, and 80% of women with disability having been exposed to the risk of psychological and physical violence, while the risk of sexual violence is greater for them compared to women without disability (Leonardi, Koutsogeorgou, Quatrini, & Covelli, 2014). To conclude, as Theresia Degener – member of the Committee on the Rights of Persons with Disabilities – has said:

> Policies for women have traditionally made disability invisible, and disabilities policies have overlooked gender. But if you are a woman or a girl with disabilities, you face discrimination and barriers because you are female, because you are disabled, and because you are female and disabled (Committee on the Rights of Persons with Disabilities, 2016).

Therefore, in order to design appropriate policies, more research is required on the social experiences of women with disabilities in specific, addressing all issues relevant to abuse, discrimination and stigma that they suffer, along with tangible and feasible recommendations for implementation of these policies in practice and their adjustment depending on the political, cultural and social context. Although this thesis has not focused on experiences of abuse *per se*, the issue of discrimination from a gender- and disability-based perspective has been examined here extensively in terms of potential barriers of the social environment that women with various types of disability experience for social participation, and in any case, gender- and disability-based discriminations derive from prejudice and attitudes exhibited through social networks and social relationships with others, which are the main focus of this study.

2.5 Research questions

As mentioned in the chapter of Introduction, this study originated from a sensitizing concept (i.e. social capital), as a background idea which formed the overall research questions and built analysis, a common technique in qualitative research (Bowen, 2006). Accordingly, below are listed the main original research questions of this study, based on the rationale for conducting this study, the aim of this study, as well as the background reading and review of the scientific literature presented in the previous chapters and the current one. In other words, relevant issues to the concept of social capital and social relationships, which persons with and without disability may experience, were selected as the main issues this study aimed to elaborate on, within and across different types of disability. In particular, this study focused on experiences of women with one of the three selected types of disability (i.e. sensory, mental and physical) in terms of social relationships and social participation, in a specific geographical location (i.e. metropolitan city of Milan). Accordingly, the main research questions of this study were the following:

1. Are there any differences in general based on sociodemographic characteristics within and across types of disability?
2. Which are the differences of experiences of disability and relevant coping mechanisms within and across types of disability?
3. Which are the structure and characteristics of social relationships (e.g. size of social network, frequency and means of communication, types of relationships) of persons with disability?
4. Do persons with disability have mostly homophilious (with persons with disability) or heterophilious (with persons without disability) social networks?
5. Regarding functional aspects of social relationships, do persons with disability receive social support from their informal social networks and/or institutional/formal social networks? If so, what type of support, by whom, and how often?
6. Regarding cognitive aspects of social relationships, do persons with disability have stronger feelings of trust towards people in general and/or towards institutions? And what is the opinion/attitude of persons with disabilities on various civic norms (e.g. that everyone should pay their taxes).
7. Which are the occasions for social participation and the common activities (employment or leisure time, hobbies, etc.) that persons with disability have in everyday life?
8. Are persons with disability involved in political groups, or have participated in any public demonstrations or signed petitions?
9. What are the conditions in which persons with disabilities experience – if it happens – feelings of loneliness? Which are their coping mechanisms relevantly?
10. What are the existing or potential barriers to social participation, and how people with disability suggest they can be overcome?
11. What are the existing or potential barriers to an autonomous life, experienced by people with disability and how people with disability suggest they can be overcome?

It has to be noted here that the above research questions of the study were not modified in any way after the data collection process began, thus all research questions were decided and pre-defined before the beginning of the data collection process. This study does not include any hypothesis. This study has been based on qualitative methodology, and as it has been stated, qualitative research *“does not start with hypotheses or preconceived notions. Instead, in accordance with its inductive nature, it involves the researcher’s attempts to discover, understand, and interpret what is happening in the research context”* (Bowen, 2006, p. 3). Accordingly, since the research interest here was to explore social relationships and social participation of persons with specific characteristics and in a specific context using qualitative methods, no hypothesis pre-exists in this study. However, I cannot claim a *tabula rasa* approach to this study, since before fieldwork starts I had already gained adequate knowledge and information in order to develop the study’s research questions. I gained this knowledge from my preparatory reading for this study, but also from previous professional and research experience, which had allowed me a deeper understanding of the experiences of persons with disabilities, in general, before the beginning of data collection for this thesis. Nevertheless, the preparatory reading for this thesis focused on experiences of persons with disabilities worldwide, and since the social and physical environment influences their experiences (Leonardi, Bickenbach, Ustun, Kostanjsek, Chatterji, & on behalf of the MHADIE Consortium, 2006), there can be made no hypotheses or expectations that findings of previous studies would apply also to the context of Italy and the city of Milan, by default.

2.6 Qualitative research on social relationships/participation and health/disability

Based on the main research questions listed above, qualitative methodology was deemed as most appropriate to provide more in-depth information on these issues, as experienced by the subjective viewpoint of participants. Furthermore, given that this study was focusing only on women’s experiences, it appears that feminist research has been more linked to qualitative research, since *“qualitative research allows women's voices to be heard and goals realized”* (Flick, 2009, p. 68), whereas quantitative research often ignores women’s voices and turns them into objects, exploring their experiences in a neutral-value way (Flick, 2009). It has been also argued that the value of qualitative narratives lies in the fact that researchers can better discover how participants define the meaning of their health condition and their related experiences, through their own voices and perspectives (Pescosolido, Martin, McLeod, & Rogers, 2011). Furthermore, qualitative approach is useful for uncovering meaning and exploring the relationship between individual and collective dimensions, as well as any potential identity changes due to their illness (Pescosolido, Martin, McLeod, & Rogers, 2011) and it has been argued that qualitative research approaches are most suitable for eliciting an in-depth understanding of the meaning of everyday social interactions (MacDonald, Sauer, Howie, & Albiston, 2005). Previous qualitative studies emerging from interpretative sociology have explored the experience of illness, and highlighted the social experience of illness and the way that individuals self-manage illness (Pescosolido, Martin, McLeod, & Rogers, 2011). In particular, relatedly to the topic of this thesis, several recently published scientific studies – within the past decade – have explored the links between social relationships and/or social participation with health and/or disability, using qualitative methodology as well, and a number of them are presented as examples below.

Firstly, a recent scoping review of European studies on societal participation of persons with disabilities (Hästbacka, Nygård, & Nyqvist, 2016) reported that there is a dominating focus of participation in the labour market and societal participation was explored mostly among persons with disabilities in general, instead of specific groups. The findings showed that the main barriers identified in the respective studies were related to financial factors, attitudes, health issues and unemployment, whereas the most reported facilitators were related to legislation and disability policies, support from people in close contact with persons with disabilities, attitudes in society, and employment opportunities for them (Hästbacka, Nygård, & Nyqvist, 2016).

A study aiming to identify key health outcomes, beyond morbidity and mortality, which are regarded as important by children and young people with neurodisability and their parents (Allard, Fellowes, Shilling, Janssens, Beresford, & Morris, 2014), employed qualitative methods with interviews and focus groups, incorporating a thematic analysis of the data supported by the Framework Approach, with the International Classification of Functioning, Disability and Health (ICF) providing the theoretical foundation. This study found that interpersonal relationships and interactions, community and social life, as well as gaining independence/future aspirations, were among the health outcomes prioritised by both young people with neurodisability and their parents (Allard, Fellowes, Shilling, Janssens, Beresford, & Morris, 2014).

Another recent study examined the meaning of participation to stroke survivors, in order to provide insight into the meaning of participation in the context of a stroke (Fryer, Baxter, & Brumfitt, 2016), and used also qualitative approach with semi-structured and a follow-up focus group, with data analysis performed using techniques of Interpretative

Phenomenological Analysis. According to the findings of the study, the themes that emerged in relation to the meaning of participation were ‘being actively involved’; ‘making meaningful choices’; and ‘being me’, while the meaning of involvement was found also beyond its social dimension, as it can include active engagement in life through being alone (Fryer, Baxter, & Brumfitt, 2016).

The relationship between social participation and identity was examined in a study including a sample of 15 lonely older adults living independently in London, England (Goll, Charlesworth, Scior, & Stott, 2015). The method employed was qualitative with semi-structured interviews and thematic analysis. According to the findings of the study, participants experienced barriers of social participation, such as illness/disability, loss of contact with friends/relatives, lack of a supportive community, lack of acceptable social opportunities, as well as avoidance of social opportunities due to fear of social rejection and/or exploitation, and fears of losing valued aspects of identity; thus authors suggested that older persons’ beliefs, fears and identities should be addressed (Goll, Charlesworth, Scior, & Stott, 2015).

In South Ethiopia was conducted a study examining day-to-day functioning in rural environment and the functional impairments associated with severe mental disorders (Habtamu, Alem, & Hanlon, 2015). The method again was qualitative, including ten in-depth interviews and five focus groups, while thematic analysis was performed. Participants were people with severe mental disorders, caregivers, health care workers, project outreach workers and religious healers. It was found that functional impairment in people with severe mental disorders occurred not only due to symptoms associated with their disorder, but also because of poverty, social exclusion and lack of social support (Habtamu, Alem, & Hanlon, 2015). In specific, almost all participants reported that people with severe mental disorders have problems in their relationships with other people, are unable to participate or have little in various community activities, and consequences of their functional impairment included stigma and family burden. Gender differences emerged as well, with participants reporting that men, compared to women, with severe mental disorders were more violent, involved in more conflict, and more likely to have very poor communication (Habtamu, Alem, & Hanlon, 2015).

Another qualitative study using open-ended semi-structured interviews and interpretative phenomenological analysis, aimed to explore everyday experiences, perceptions, and challenges of young adults with a chronic neurological condition in respect to the transition from adolescence to adulthood (Kola, Turner, & Dhingra, 2014). This study found a number of crucial areas of concern in the lives of young people with chronic illnesses, related to management of condition, social support, strive for independence, and transition. One of the important factors in participants' lives was the vast amount of support they receive from their family and close social network. Was also reported to be important for participants the provision of individualised care, access to information and support, and preparation for increased autonomy before transfer to adult health care services (Kola, Turner, & Dhingra, 2014).

A meta-synthesis (Kramer, Olsen, Mermelstein, Balcells, & Liljenquist, 2012) of 15 qualitative studies aimed to describe perspectives of school-aged youth with disabilities regarding the impact of the environment and modifications on their participation, using the ICF model (World Health Organization, 2001) as a basis for definition of the search terms. The main outcome of this meta-synthesis was that there are three factors that influence more strongly youth's participation, namely: adult and peer understanding of individual abilities and needs; decisions about accommodations; and the quality of services and policies. These three main factors of participation were all social aspects of the environment included also in the ICF. Moreover, it emerged from the meta-synthesis that youth with disabilities actively use strategies in order to further accommodate environments and support meaningful participation. The authors of this study argued that these findings are in line with the social model of disability, according to which the environment, rather than the impairment itself, influences the extent that the persons with disability can participate socially (Kramer, Olsen, Mermelstein, Balcells, & Liljenquist, 2012).

Apart from international studies, there have been also studies conducted in Italy using qualitative methods for exploring social relationships and/or social participation related to health and/or disability. Two examples of relevant Italian qualitative studies can be found in the work of Mario Cardano. In particular, in the first study (Cardano, 2007) are presented narratives of persons with schizophrenia who were hearing voices, exploring the challenges they face in their everyday lives in terms of perceiving and coping with severe mental distress, as well as the impact psychosis has on their sociality and social interactions in general. The second study (Cardano, 2010) explored the sense-making strategies of four Italians with severe mental distress, using narrative method too, illustrating three kinds of explanation for the outset of mental distress, as ideal types among participants: the biomedical, the spiritual-religious, and the psycho-social. Within the narratives were presented biographical experiences of mental distress, including issues related to the social consequences of mental suffering, such as for creating a family, finding a job, and dealing with work-related pressure.

Other examples of Italian studies on the social experiences of persons with physical disabilities can be found in the book edited by Rosalba Perrotta (2010), with contributors of the book exploring testimonies of persons with physical disabilities and their close social networks, such as family, support teachers and health professionals, on the images of persons with disabilities in the society, literature, comic books, cinema and the internet. A large part of this book (Perrotta, 2010) is devoted to qualitative research and practices of conducting qualitative research with persons with physical disability in specific, along with the challenges persons with disability and their families face in their daily lives, such as stigma, stereotypes, adapting to a new reality with disability, and concealing disability, among many other issues.

There has been recently published also an ethnography of teaching practices in Italy of deaf students, conducted by Michele Cioffi (2017), who aimed to offer a representation of how teaching is conducted for deaf students, not only in terms of structure, but also how d/Deafness[14] is socially constructed. This ethnography (Cioffi, 2017) explored the ways inclusive education is implemented in specific schools of the Northern Italy, finding schools having an approach to 'normalisation' of deaf students, meaning to teach them a way of communication more similar to non-deaf persons in order to achieve their inclusion in society, as well as social identity of d/Deaf persons within the Italian context, and not only.

The above studies are an indicative sample of all the current studies which have identified a series of issues relevant to social relationships and social participation that have an impact on health or disability, and which have used qualitative methodology in order to explore experiences of persons of various ages and with various impairments, relevant to social relationships and/or social participation. Most of the studies presented here have used semi-structured interviews and/or focus groups, while thematic analysis was the most dominant method of analysis – similarly to the method employed for this thesis.

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[14] As mentioned previously within this thesis (p.38): *"the main basis of opposition between 'd'eaf (with lower 'd') community and 'D'eaf (with capital 'D') community is cochlear implantation, thus deaf persons who are in favour of cochlear implantation belong to the first community, whereas deaf persons who disagree with cochlear implantation and support the cultural and linguistic diversity belong to the latter community (Chang, 2017)."*

However, no other previous qualitative study was found through the literature review performed here that had used similar inclusion criteria and/or comparisons across and within the three different types of disability, as it was performed in this study.

2.7 Feasibility of comparisons across types of disability

As already mentioned above, this study focuses not only on comparisons within types of disability, but also across types of disability (i.e. mental, sensory, and physical), thus it was challenging to justify the feasibility of such comparisons, due to the diversity of life experiences of persons with these health issues. However, it was possible that similarities would also emerge across different types of disability, therefore it was not predetermined in any manner by the literature review that persons with different types of disability have different experiences in terms of social relationships or social participation by default. In order to show the feasibility of comparability across the types of disability explored here, the method of proleptic argumentation (Walton, 2009) (Cardano, 2011) has been applied. Accordingly, someone could say that:

Argument 1: "How can anyone compare the experiences of persons with different types of disability since these types of disability have many differences between them (i.e. one refers to hearing difficulties, another one to physical inability to move lower limbs, and the other one to a psychotic disorder)?"

Counter-Argument 1: Although persons with diverse health issues face different challenges regarding disability, does not mean that they there might not also be similarities between persons with various health issues in terms of life experiences, and life challenges (Robinson-Whelen, Taylor, Hughes, & Nosek, 2013). The way social relationships and social participation are experienced by anyone has a lot to do with the context and the personal or environmental (physical or social) circumstances as well. No person is identical to another, just because they might share a similar health issue or disability, thus comparison of social experiences between any persons can be possible within a shared physical and social context. Accordingly, the study setting across all types of disability was the metropolitan city of Milan, so a similar physical environment applied for all participants, and a specific gender and age group was chosen to allow comparisons as well. Moreover, only participants with a relative autonomy were included for comparability purposes too. Consequently, the main difference in experiences lies on the personal factors and social environment of each person, and the interaction with each individual and/or the environment. Nevertheless, this depends more on resources, personal factors, individual perception, and attitude of others, and can vary also within a group of people, not only across groups – regardless of whether they have a disability or not. So any differences in experiences that have emerged in this study could be due to either personal characteristics or influenced by the social or physical environment, irrelevantly of their type of disability or not. Thus, regardless of the health condition of a person, the themes explored in this study can indicate either similarities or differences of social life experiences, or even both, not only within types of disability, but also across them.

Therefore, this research is considered as the first one – to the best of my knowledge – to have explored this specific issue using this specific methodology and in the specific context, with comparisons within and across different types of disability. Detailed information regarding the methodology employed in this thesis for data collection and analysis is presented in the following chapter of Methodology.

CHAPTER THREE: METHODOLOGY

3.1 Data collection

3.1.1 Participants

3.1.1.1 Exploratory interviews

Starting in late 2016, several months before the data collection began and during the preparation of the research design, I conducted exploratory interviews in order to define the sample characteristics for this study, with experts/professionals who have had long-term professional experience in various European and Italian disability-relevant projects, based at leading health institutions in Milan. I decided to include participants with physical (movement-related), mental health, or hearing difficulties – who use either sign language or verbal communication with cochlear implant/prosthesis/hearing aid –, given the variety and diversity of challenges they may face in terms of social relationships and social participation within an urban environment, based on the heterogeneity of these types of disability in regards to their visibility or invisibility aspect.

A large part of the early exploratory interviews were conducted to determine the diagnoses of potential participants with severe mental health issues, understand better the characteristics of persons with these specific types of disability, and collect information prior to interviews about potential practical challenges during fieldwork with participants with the specific health issues. For example, mental health experts pointed out that, persons with schizophrenia who take medications often have higher social functioning compared to those who refuse medication intake. It has been also reported (Cardano, 2007) that persons with mental disorders usually have difficulty accepting medication intake, a fact which can trigger crises for them. Another example of information from exploratory interviews was that some persons with schizophrenia who have excessive tendency to suspicion might have difficulty accepting being audio-recorded, thus any researcher should try to gain their trust before the interview starts, as well as persuade them that all ethical considerations have been taken for this research to ensure that anonymity was safeguarded for all participants by signing an informed consent form; this was indeed encountered during this fieldwork, since participants with mental disability were the ones mostly concerned with privacy issues before the beginning of interviews.

Later on, during the period in which interviews were being conducted (May 2017 to March 2018), additional advice from experts on deafness in Italy was sought in order to understand better the various social, practical, medical, biological, ideological, and cultural differences among deaf persons with cochlear implant/hearing aid and those using sign language. Within this period, a larger number of experts were contacted (more than 50) as key informants to assist to the recruitment of participants and learn more about social inclusion and aspects of social relationships of persons with a disability who live in Milan. Further communications via e-mail or telephone or meetings in person were arranged with experts who responded positively to the outreach (less than 20). As such, meetings were held with: presidents/directors of various associations based in Milan promoting social inclusion of persons with disabilities (on physical, sensory and mental disability), the University of Milan's Disability Service[15], a psychiatrist of a psychosocial centre, two professors/delegates of the Dean of two universities based in Milan, a person responsible of a social policy service of the trade union centre of Milan (*Camera del Lavoro*), a city councillor of Milan, an educator/interpreter of sign language, a researcher with experience on qualitative study of persons with hearing difficulty, and an urban architect with deafness working on Disability & Case Management. Although all experts seemed positive during meetings for assisting me to find participants for interviews, only a small number of them provided such support in practice. Nevertheless, every one of the experts, with whom further communication was established, provided useful information – to a larger or smaller extent – relevant to the topic explored in this study.

3.1.1.2 Study site

Data collection was performed between May 2017 and March 2018, in the metropolitan city of Milan, during one-to-one face-to-face meetings with each participant individually – except for interviews with signing deaf participants during which a sign language interpreter was also present.

The specific location of the study (i.e. metropolitan city of Milan) was selected due to the large size and high density of the population. Milan is the capital of the Lombardy region in Italy and the second most populated metropolitan city of the country, with about 3,218,201 persons living in the metropolitan city of Milan in 2017 (Istat Statistics, 2018) – an area containing 134 metropolitan municipalities (*comuni metropolitani*)[16]. Within

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[15] University of Milan → Disabled Students Support – Disability Service (English version). Available at: http://www.unimi.it/ENG/student/31204.htm [Accessed 22 April 2018].

[16] Città Metropolitana di Milano → Territorio e comuni. Available at: http://www.cittametropolitana.mi.it/portale/territorio/in_cifre/index.html [Accessed 20 April 2018].

this largely populated area was more likely to find a sufficient number of participants for this study and in a limited period of time – considering the time restrictions of the doctoral thesis. Thus, all participants included in the study were living at the time of the interview in the metropolitan city of Milan for at least two years prior to the date of the interview.

For participants with physical disability the place of meetings was commonly their own home or outdoor locations (e.g. public parks), apart from three participants, with whom interviews were conducted via video call using an online communication software (i.e. Skype). For all participants with mental disability – apart from one with whom the meeting was held at a local cafeteria – the places of interviews were local psychosocial centres (CPS) [*'Centri Psico-Sociali'* in Italian] of Milan, belonging to the Lombardy region's public health system. The CPS represent the cornerstone of the territorial organisation of psychiatric care in Lombardy, as the first point of access and place of coordination of care programs, with 91 CPS active in the region of Lombardy, which consist of multidisciplinary teams of psychiatrists, psychologists, nurses, social workers and educators[17]. All participants with mental disability, who were recruited via communication from the CPS, agreed to conduct the interview within the premises of the CPS, except from the participant with whom the interview took place in a cafeteria – she was recruited via an invitation of the study posted on social media. Given that the participants were recruited through the CPS poses a limitation of the study in terms that it was reasonable to expect that the participants, who were selected from the personnel of the CPS, did not have a negative attitude towards the psychiatrists of the CPS or psychiatry in general. Thus, the vast majority of participants with mental disability were expected to probably have a less anti-psychiatric attitude and be more docile to their psychiatric treatment; however, it cannot be presumed that this is always the case for all CPS service users nor persons with mental health issues. For participants with deafness, the vast majority of interviews took place at a lecture room of the premises of the University of Milan and with one deaf participant with hearing aid the interview took place at a local cafeteria.

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[17] Regione Lombardia → Servizi per la tutela della salute mentale → Le Unità Operative di Psichiatria. Available at: http://www.regione.lombardia.it/wps/portal/istituzionale/HP/DettaglioRedazionale/servizi-e-informazioni/cittadini/salute-e-prevenzione/Cure-specialistiche-e-consultori/tutela-salute-mentale/tutela-salute-mentale [Accessed 29 January 2018].

3.1.1.3 Participant characteristics and inclusion criteria

First of all, the specific **three types of disability** (i.e. mental, physical and sensory) were selected as the focus of this study given the diversity among them in terms of visibility and/or invisibility of disability, since persons with visible or invisible disabilities may face similar or diverse challenges, for example, *"traditionally, people with invisible disabilities are not stigmatised as readily as those with visible disabilities. They are, however, still subject to forms of rejection, humiliation and social disapproval"* (Esmail, Darry, Walter, & Knupp, 2010, p. 1153). Specifically, the three types of disability were selected based on whether they can be obvious to the general public through appearance or interaction during a first encounter (Esmail, Darry, Walter, & Knupp, 2010). Accordingly, a physical health issue can demonstrate a visible disability, a mental health issue an invisible disability, while hearing difficulty can demonstrate either an invisible or invisible disability – depending on whether someone from the general population can see or understand that the person has a hearing difficulty (e.g. by seeing the hearing aid). Certainly a person might have more than one types of disability, for example both physical and mental disability, one of them being visible and the other invisible, but here was investigated only the primary type of disability, without any participants with overlapping types of disability being included in this study – to my knowledge. Other health issues (e.g. blindness, reproductive issues, respiratory issues, etc.) could have been selected as the focus in this study, but the three types finally selected for inclusion in this study were considered as more eloquent cases of visible and/or invisible disability, as well as attainable in terms of feasibility of finding adequate number of participants with these specific health issues.

The **sampling strategy** in this research was determined in advance, in other words there was an *"a priori determination of the sample structure"* (Flick, 2009, p. 115). Accordingly, the purposive sampling method was applied (Flick, 2009) and characteristics of participants relating to their types of disability and other sociodemographic characteristics were used in order to guide the selection of cases for this study.

Regarding **sample size**, 10 persons by type of disability were included in the data analysis, resulting to 30 participants in total – a pre-defined number of participants that allowed comparisons within and across types of disability. The number of participants recruited in this study was decided as adequate based on the purpose of the study and for enabling meaningful comparisons to be conducted during data analysis (Mason, 2002).

The inclusion criteria for participants, which determined eligibility of participants to be included in this study, were the following:

1. Participants with one of the following **types of disability** were included in the study relating to respective health issues: a) sensory (deafness), b) physical (with inability to move lower limbs – e.g. due to tetraplegia), or c) mental (psychotic disorder). Participants with multiple, overlapping types of disability were excluded so as to allow explicit comparisons within and across types of disability. In addition, to guarantee heterogeneity within each type of disability, persons with various diagnoses were included in the study.
2. Diagnoses of participants indicating a **severe** health issue, related to the three specific types of disability, were selected, in order to explore aspects of social relationships and social participation of persons with severe health issues, not mild or moderate ones.
3. **Participants with physical disability:** No specific diagnoses were included for this type of disability, but participants should have had for at least two years (prior to the date of the interview) inability to move their lower limbs. Both persons with congenital and later-on acquired physical difficulty were included in the study.
4. **Participants with sensory disability:** In the study were included only persons with profound deafness, either speaking due to having a cochlear implant/hearing aid or only using signing language to communicate. Specifically, the ten participants with deafness were divided into two groups based on their means of communication: i) four participants with deafness using verbal communication with cochlear implant/hearing aid and ii) six participants with deafness using non-verbal communication with sign language. This heterogeneity was intentionally pursued in order to explore any potential differences between the two groups in terms of their experiences of social relationships and social participation. Based on the preparatory literature review and exploratory interviews performed for this study it was clear that in the Italian context there have been strong cultural and social differences within the community of deaf persons, between those who communicate verbally (having cochlear implant/hearing aid) and those who communicate non-verbally (using sign language) (i.e. ‘oralisti’ versus ‘segnanti’) – as described in more detail in the previous chapter of this thesis. Accordingly,

for the cases of deaf participants using sign language were included: deaf persons with congenital deafness or hearing difficulty diagnosed before the age of 3. For the cases of deaf participants having cochlear implant/hearing aid were included: persons with profound hearing loss, having cochlear transplant or hearing aid, with hearing difficulty diagnosed before the age of 3.

5. **Participants with mental disability:** Persons with various diagnoses demonstrating psychotic disorders were eligible for inclusion, according to the assessment/evaluation of the psychiatrists who were following them. The diagnoses of the included cases corresponded to the definition of psychotic disorders according to the *Diagnostic and Statistical Manual of Mental Disorders (fifth edition)* (DSM-5) (American Psychiatric Association, 2013):

   > Schizophrenia spectrum and other psychotic disorders include schizophrenia, other psychotic disorders, and schizotypal (personality) disorder. They are defined by abnormalities in one or more of the following five domains: delusions, hallucinations, disorganized thinking (speech), grossly disorganized or abnormal motor behavior (including catatonia), and negative symptoms (American Psychiatric Association, 2013, p. 87).
   >
   > Psychotic disorders are heterogeneous, and the severity of symptoms can predict important aspects of the illness, such as the degree of cognitive or neurobiological deficits (American Psychiatric Association, 2013, p. 89).

   It has to be noted here that at the beginning of data collection process, the selected mental health issue for participants to be included was only schizophrenia, but given the difficulty in finding adequate number of participants with schizophrenia who would meet also the rest of the inclusion criteria, it was decided to broaden the selected mental health issue to the broader category of psychotic disorders.
6. Participants with **adequate ability and skills** of social functioning were included, meaning that they were able to choose whether they wanted to stay at home alone or go outside their home (either with or without assistance) to socialise. In most cases this was made known to me in advance from the key informants/experts during participants' recruitment phase or was verified during interviews. For any of the three types of disability in question, it was a prerequisite that participants would be able to socialise and go outdoors as well.

7. **Only women** participated in the study, mainly for comparability reasons, but also since, as mentioned previously, it has been found that there is gender specificity in terms of social capital aspects (Eriksson & Emmelin, 2013) (Berry & Welsh, 2010), and limited number of studies focusing on the intersection of disability and gender (Mohamed & Shefer, 2015), thus this study explored experiences of disability from a gendered perspective.
8. Eligible participants were **young adults**, between 18 and 45 years old (at the time of the interview). A specific age group was selected to allow more robust interpretation and comparison of collected data, within and across types of disability. This specific age group was selected given that, in general, young adults are commonly involved in social relationships and social participation more often compared to older adults.
9. Only persons **living in the metropolitan city of Milan** (for at least two years prior to the date of the interview) were included in the study.
10. The specific **health issue and level of its severity** was self-reported by participants with physical and sensory difficulties, whereas for persons with psychotic disorders the health professional/expert (acting as key informant/mediator) informed me the diagnosis of each participant prior or after interviews – apart from the case of the only participant with mental disability who was not recruited via a CPS.
11. The **duration of disability** (based on the onset of health issue) varied among participants. However, the onset of the health issue was at least two years prior to the date of the interview, so as to avoid including cases that the disability had begun too recently to the date of interview for participants to have been adjusted to the new conditions of their social life.
12. Participants were able to fully **comprehend and provide informed consent**.
13. All participants had sufficient expressive **language abilities** (whether in terms of verbal Italian or Italian sign language) and obvious **intellectual capacity** that could allow them to take actively part in an interview and understand all interview questions.
14. Only **community-dwelling adults** participated in the study. Persons living in hospitals or institutions, at the time of the interview, were excluded, because institutionalised persons have limited opportunities for interaction with the wider society and do not live autonomously.

15. Regarding **sociodemographic characteristics**, there were no inclusion criteria concerning marital status (e.g. single, married, etc.), living arrangements (either living alone or cohabitating), employment status (e.g. student, employed, unemployed, etc.), education level (e.g. high-school or university graduates, etc.), and ethnicity or religion. Only gender (i.e. women), age of participants (i.e. 18-45) and role of relative autonomy were set as inclusion criteria in terms of sociodemographic characteristics.
16. The final inclusion criterion, called '**role of relative autonomy**', was an indicator of social functioning, which was created by me and the principal supervisor of this study. In specific, an indicator of interdependence with relative autonomy was deemed necessary in order to include in the study participants who were more active socially, for comparability reasons. Specifically, participants should have had at least one of the following societal roles, as an indication that they were living with relative autonomy, whether by taking care of themselves on their own or taking care of others – but not living only with their family of origin or alone without having any other societal role. These societal roles/indicators of relative autonomy were: mother, worker, student, and/or living with partner/husband. Accordingly, only cases of women who had one of these roles of relative autonomy were explored.

3.1.1.4 Recruitment of participants

Purposive sampling method (Flick, 2009) was adopted to recruit participants, in order to select *typical* cases, as well as *critical* cases – whenever possible – of advocates or politically active women with the specific types of disability under question. The purposive sampling was mainly based on homogeneity of some of participants' characteristics. In summary, all participants should have been: women, young adults, with identical or similar level of severity of their health issue (among the same type of disability), living in the metropolitan city of Milan, and being a worker and/or student and/or mother and/or cohabitating with husband or partner.

Almost all participants were recruited after my **direct or indirect invitation** through key informants/experts/associations or other participants acting as mediators, while only one of the participants contacted me after seeing my study invitation posted on social media (i.e. Facebook groups/pages). For participants with sensory and physical disability recruited through a mediator, I contacted them first via e-mail or online social media (i.e. Facebook messenger) or mobile texting application (i.e. WhatsApp) and informed them about the scope and process of the interview, and then if there was consensus by the participant, arranged a face-to-face appointment for the interview to take place whenever and wherever it was most convenient for the interviewee. The **key informants/experts/mediators** were people working at the private or public sector, in organisations, associations or health services for persons with relevant health issues to the types of disability in question. In the case of participants with mental disability, I did not have access to the personal medical history/record of the participants nor their contact details, for privacy reasons. Therefore, appointments for interviews with persons with mental disability at CPS were arranged by the respective CPS, after discussion on the characteristics of potential participants with the collaborating health professionals of the CPS.

Moreover, during the period of recruitment of participants, I encountered great difficulty finding enough participants for this research, and although all (known to me) relevant public bodies, organisations, and institutions in Milan were contacted with my request to share the invitation for participants with their members, only a very small number of them responded positively. Therefore, also **snowballing technique** (Flick, 2009) was used for the recruitment of the sample, meaning that some of the interviewees (with physical or sensory disability) were asked to suggest directly to their acquaintances to participate in this research as well, or gave me the contact details of their acquaintances so that I would contact them directly to invite them to participate in the study. In order to thank participants for their time and compensate for their travelling expenses to the meeting place for the interview I offered to almost all participants a €5 voucher for shopping at a local store (no sponsors involved). This was also considered as an incentive for finding more participants, since small incentives can decrease refusals from potential participants (Neuman, 2014). Regarding participants with mental disability, the snowballing technique was not possible, since I did not recruit them directly, but the staff of the CPS did, so it was not appropriate from my part to ask them to provide me contact details of other persons they might know with psychotic disorders. For this reason, it was even more difficult for me to discover participants with psychotic disorders to invite them to the study, plus associations, private psychiatrists, and CPS of the metropolitan city of Milan that I contacted for collaboration, at multiple times, refused to assist me with recruitment of participants. Finally, given that near the deadline set for conclusion of the process of data collection the necessary number of participants with psychotic disorders had not been reached yet, I resulted in the solution to write again to CPS and psychiatrists in the metropolitan city of Milan with the offer of potential co-authorship in a future peer-reviewed publication of the results of the study, in exchange for their help in finding more participants. After that, some of them responded positively and allowed me access to interview their patients with psychotic disorders at the CPS where they were working, and eventually the adequate number of participants for the study was reached.

3.1.1.5 Excluded cases

Participants who were later on found to not meet all inclusion criteria (e.g. were older than 45 or did not have any role of relative autonomy) were excluded from the analysis. Specifically, since I was not aware of all sociodemographic characteristics and diagnosis of participants before interviews, there were six surplus interviews performed with women who were not eligible to be included in this study, since they did not meet all inclusion criteria. Namely, two interviewees (one with physical disability and another with mental disability) did not have any role of relative autonomy (i.e. were not mothers, or working, or studying, or living with partner or husband), and a third interviewee had a substance/medication-induced psychotic disorder with onset during intoxication, so was not comparable with the rest of the cases who had a primary psychotic disorder. Specifically, according to the DSM-5 (American Psychiatric Association, 2013):

> A substance/medication-induced psychotic disorder is distinguished from a primary psychotic disorder, such as schizophrenia, schizoaffective disorder, delusional disorder, brief psychotic disorder, other specified schizophrenia spectrum and other psychotic disorder, or unspecified schizophrenia spectrum and other psychotic disorder, by the fact that a substance is judged to be etiologically related to the symptoms (American Psychiatric Association, 2013, p. 115).

Thus, these cases were excluded from the sample, however, the interviews with them were transcribed as well to be used as raw data for comparison if diverse from the findings of this thesis. These three interviews were treated as supplementary material having emerged from the same study and given that the main sociodemographic information of participants (such as age, location, and type of disability) met the inclusion criteria. Two more cases were excluded during interviews, because interviewees were older than the age limit of the study – one with physical disability who was 50 years old;

and one with deafness who was 53 years old –, and the sixth case was excluded because the interviewee did not have a health issue related to her lower limbs, but her hand, so was not eligible for this study either. This occurred because the latter interviewee was misinformed about the prerequisites for this study by a website, where it was not published properly the full invitation for participants of the study, so the interviewee supposed that the study concerned persons with any type of disability. In the latter three cases, although I was aware from the beginning of interviews that they were not eligible for inclusion in the study since they did not meet main sociodemographic inclusion criteria, I proceeded with the interview in any case due to politeness and to avoid causing any distress potentially to the interviewees who dedicated part of their time to arrange an appointment for the interview.

3.1.2 Procedure and material

3.1.2.1 Method of interviews

One-to-one[18] open-ended semi-structured interviews were conducted using an interview guide (list of topics/questions) for discussion (see Appendix B), which was self-developed based on the aim and research questions of this study. In semi-structured (guided) interviews the interviewer shows a pathway of the discussion to the interviewer, to collect information on specific topics; semi-structured interviews can be considered as a series of unstructured (or ‘open’) micro-interviews (Cardano, 2011). Moreover, in semi-structured interviews, the interview guide includes several topical areas of the issues explored in the study, and during these interviews the target of the interviewer is to use several types of questions in order *“to reconstruct the interviewee's subjective theory about the issue under study”* (Flick, 2009, p. 156). In other words, during semi-structured interviews are reconstructed the contents of the subjective theory of interviewees, which is the *“complex stock of knowledge”* the interviewee has developed on the specific topic under study (e.g. participants have a subjective theory about how disability barriers or trust are perceived) (Flick, 2009, p. 156). In addition, the interviewer’s role is to help participants unravel this stock of knowledge and to discern patterns across various respondents. Following the distinction by Flick (2009), the types of questions used in this study were: mostly *open* questions (e.g. which barriers persons with deafness face?);

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[18] All interviews were one-to-one apart from interviews with deaf participants using a sign language, during which a sign language interpreter was also present.

theory-driven questions, particularly related to the notion of social capital and its components (e.g. do you trust people in general?); and *confrontational* questions (e.g. what do you suggest could be done so that persons with physical disability could lead a more autonomous life?)

3.1.2.2 Tools and schedule of interviews

All interviews were held in Italian language, and in the case of four deaf persons using sign language, interviews were held in the Italian sign language (LIS). Although I am not a native Italian speaker, I have very good knowledge of speaking and understanding of Italian language, so interaction in Italian language was feasible with interviewees, with occasional minor grammatical or syntactical errors. Whenever the respondent did not understand a question, I repeated the question and explained it to them further, if necessary. All interviews were audio-recorded with the participants' permission, using a digital voice recorder device, which was connectable to laptop (with 'Universal Serial Bus-USB' cable), so then I transferred each recorded audio file of each interview to an archive on my personal computer (in 'MP3' format sound file). At the beginning of the meeting with each participant, I asked the interviewee to read carefully the informed consent form (Appendix C) and completed and signed two printed copies of it, one of which was kept in my archive, and the other one was given to the interviewee. All informed consent forms signed by participants are in my possession. Each participant was given a 'participant number' during data collection and later on a pseudonym, to safeguard anonymity of participants.

The exact chronological order of actions followed during each interview, or else interview schedule, was the following:

1st) Each interview was starting by introducing myself to the interviewee, stating my name and affiliation. For interviews with women using sign language, the sign language interpreter would introduce herself and her role at the beginning of interviews as well. I also offered to each interviewee refreshments (i.e. water and biscuits) to create a cosy atmosphere.

2nd) I was then stating the aim and purpose of the study and checked with the interviewee if she understood these or had any questions.

3rd) I was asking the interviewee to read carefully and sign two printed copies of the informed consent form, if she agreed with the content. Once the interviewee signed them then I signed them as well, and I was giving one of the signed copies to the interviewee and I was keeping the other signed copy for my archive.

4th) Before initiating the audio-recording of the interview, I was filling in a form including interview information (i.e. date of interview and number of participant) and asked the interviewee sociodemographic questions (Appendix A). Sociodemographic information that were collected included: first name only, district of residence (not address), level of education, marital status, employment status, health issue, living arrangements, and role of relative autonomy (i.e. whether a worker and/or student and/or mother and/or living with partner or husband).

5th) Once the sociodemographic information was collected, I was informing the participant that the audio-recording would start. Before each audio-recording I was doing a test to ensure the volume of the voice of the interviewee and the position of the recorded was appropriate for the interview to be registered. The typical question I was doing to all participants during the audio-recording test was "what do you think of the weather today?" which was used in order to 'break the ice' as well with the interviewee.

6th) Then the recorded interview started, following the order of topics included in the interview guide (list of topics/questions) (Appendix B).

7th) Once the interview had finished, I was switching off the audio recorder and thanked the interviewee for her time and honesty, and asked her if they knew any other woman with the same type of disability that might have been interested to participate in the study as well (apart from participants with mental disability). A voucher was given to the majority of participants at the end of the interview to thank them for their time to participate in the interview.

During collection of sociodemographic information and recorded interviews, questions were repeated or reframed in order to ensure understanding of participants, if necessary, without altering their meaning. General and specific probing[19] and prompting during interviews was used as well, such as by asking for further details or explanations on some

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[19] *"General probing provides further "material" and details of what has so far been presented. For this purpose, additional questions like "What happened there in detail?" or "Where do you know that from?" are used. Specific probing deepens the understanding on the part of the interviewer by mirroring (summarizing, feedback, interpretation by the interviewer) what has been said, by questions of comprehension, and by confronting the interviewee with contradictions and inconsistencies in his or her statements."* (Flick, 2009, p. 163)

of the topics, asking for examples or a clearer answer on the question, or – whenever necessary – redirecting interviewees back to the research questions whenever they went off topic, or simply nodding so as to encourage them to continue talking. Within the interview guide used here, were also included three items as indicators of civic norms within the society, in other words, as part of the cognitive dimension of social capital and trustworthiness, similarly to the study of Kaasa and Parts (2008). These three items examined opinion of respondents on justifiability of a person avoiding to pay taxes, claiming government benefits that she/he is not entitled to, and accepting a bribe during her/his duties. Responses were considered collectively for all participants, as to whether the majority responded in a consistent manner or not.

3.1.2.3 Field notes

The traditional medium for documentation in qualitative research has been the researcher’s notes, or else field notes, which in the case of interviews should contain the essentials of the interviewee's answers and information regarding the proceeding of the interview (Flick, 2009). Accordingly, field notes were taken by me within 24 hours after each interview took place to assist me in the interpretation of data and recollection of participants’ non-verbal and facial characteristics, as well as attitude or anything else that made me an impression during interviews and could be valuable for the interpretation of findings. In particular, field notes included information on off-the-record comments of the interviewee, or facial expressions of interviewees on specific responses or other non-verbal signs during interviews, as well as an overall personal impression and characteristics of respondents, based on my subjective viewpoint.

3.1.2.4 Specificity of interviews in sign language

Interviews with deaf persons, who were using the sign language, were conducted with the assistance of an interpreter, who had excellent knowledge of the Italian signing language (*Lingua dei Segni*-LIS) and long-term professional experience with the social context of deaf persons living in Milan, through various projects she had worked on before. The sign language interpreter performed simultaneous interpretation from the signing language to spoken Italian during interviews to assist me to fully understand the statements of the interviewee. I had also gained basic knowledge of the Italian signing language, prior to fieldwork, to be able to introduce myself to interviewees in sign language and follow to a minor extent the non-verbal part of interviews.

Given the verified excellent knowledge of the Italian sign language by the appointed interpreter, no video recording was deemed necessary during interviews, thus all my questions and answers by respondents were translated simultaneously by the sign language interpreter, using a digital voice recorder device to record interview questions (in my voice) and responses of participants (in the voice of the sign language interpreter). Video recording of interviews with participants using sign language could have been used too, however I would not have been able to cover the payment of a LIS transcriber, who would check interpretation from video-recorded interviews and transcribe any features of the LIS interpretation that might have been omitted to be translated at the time of the interviews. In addition, audio recording was considered as more impersonal and anonymous compared to video recording, so interviewees would feel more comfortable to share their personal experiences during interviews without a video recording. On the other hand, video recording would have allowed me to perform a linguistic analysis of the interviews in LIS as well, but this can be applicable only if a researcher has excellent knowledge of the LIS – which was not the case in this study. For this reason, it was essential the involvement of a sign language interpreter during interviews with deaf participants who used only the sign language, so these interviews were not conducted solely one-to-one with me, contrary to the rest of the interviews of this study.

3.1.2.5 Access, ethical approval and informed consent

This study did not require any **ethical approval** from an official body since it involved a research of adult participants who voluntarily agreed to participate in the study. However, for the recruitment of participants with **mental disability**, I requested approval from the psychiatrists or clinical psychologists of the respective CPS in order to gain access to interview their patients. For the approval of the study protocol were submitted to the health professionals/directors: a letter by one of the supervisors of this study, a copy of the informed consent form, the interview guide (list of topics/questions), and a short description of the sample characteristics, according to the inclusion criteria of this study. When the study procedures were approved and permission was provided by the health professionals/directors of the CPS, then I proceeded with the fieldwork. Permission was not given to me to access any of the medical history/records of participants, thus the selection of eligible participants was made by the health professionals of the respective CPS based on their diagnoses and characteristics, commonly after discussions with me to verify the inclusion criteria set for the study, without me knowing any of the diagnoses of the potential candidates for interviews who psychiatrists were thinking about. Since I did not have any access to personal and contact details of participants, all communications with eligible patients to invite them to participate in interviews and arrangement of appointments were performed by the personnel of the CPS and not through my direct communication with patients. Similarly, all diagnoses of patients were made known to me by the personnel of the CPS, since I did not have access to their medical records[20].

For participants with **physical and sensory disability** all communications and arrangement of appointments were performed by me directly with individual contacts. For physical disability, no specific organisation/association provided access to their members, but individuals belonging to relevant associations suggested me potential participants. To this end, was very helpful the contribution of a city councillor, who introduced me to key informants on physical and sensory disability. For participants with sensory disability, access was permitted by an association to attend two support groups for persons with sensory disability and invite them in person to participate in the study, and another two associations for persons with sensory disability sent an e-mail inviting their members or other associations to participate in the study. There were also other less official mediators, who introduced me to directors of relevant associations, key informants, and potential participants.

As mentioned previously, all participants prior to each interview signed an **informed consent form** (Appendix C), with which they all gave me their consent to record their voice during the interview, before the interview started. The consent form also included a statement from the Italian law on privacy of data collected (i.e. *Decreto Legislativo 30 giugno 2003 n. 196 "Codice in materia di protezione dei dati personali"*), a short description of the purpose of the project, and specified that participants gave their consent to the researcher to reproduce anonymously direct quotes from their statements within this thesis and further publications or presentations. The informed consent form included guarantee of anonymity of participants, stating that their real names would not be disclosed to anyone else apart from the researcher conducting the interview. Accordingly, I have not shown to anyone – not even the supervisors of this thesis – the real names of

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[20] The diagnosis of patients was verified also by the patients themselves, since prior to interviews all participants were asked to state their diagnosis if they wanted.

participants, and have used pseudonyms in English for each participant within this thesis, and will continue to do so in any potential publication or presentation of the findings thereafter. Regarding interviews conducted via video call using an online communication software (i.e. Skype), the inform consent form was read and shown on camera to participants who gave their verbal consent on-the-record, while being audio-recorded.

Not everyone who was contacted agreed to participate in the study, and there was also one case of a woman with deafness having a cochlear implant/hearing aid, who initially agreed to participate in the study, but when the meeting for the interview occurred, she withdrew from the study, because she did not want her voice to be audio-recorded. I did not suggest to this potential participant to proceed with the interview even without using an audio recorder, because I would not have been able to take notes fast enough in order to record all responses of the interviewee in Italian, since I am not a native Italian speaker, so I would not have reported with accuracy in my thesis the statements of the interviewee. Respondents with mental disability seemed to be particularly concerned about the privacy aspects of the interview, whereas participants with physical disability were the ones less preoccupied about privacy issues and some of them were even familiar with participation in interviews in other studies. Given that participants with physical disability seemed to be the ones less concerned about privacy issues, I asked on the record some of them to take a photo together, and if they gave their consent during the audio recording, a photo was taken with them at the end of the interview, with their permission that the photo would be used only during the presentation of this thesis.

3.1.2.6 Practical resources

All research material and costs (i.e. the €5 voucher, payment of transcriber and sign language interpreter, purchase of digital voice recorder, and refreshments for participants) were covered entirely by me; apart from printed interview material (e.g. copies of the inform consent forms, invitation flyers, and forms of sociodemographic information) which were printed for free at the premises of the University of Milan.

3.2 Data analysis

3.2.1 Transcription of interviews

In this study interviews were held in Italian language while participants’ voice was recorded digitally (in ‘MP3’ format sound file), and all interviews recorded were then transcribed *verbatim*; meaning word-by-word transfer into text of what was said during the interview. In the case of deaf persons using sign language, the voice of the sign language interpreter was audio-recorded, instead of the interviewee's, and then transcribed as well. Given that interviews were held in a language which was not the researcher's mother tongue, for the purpose of accuracy of the collected data, an Italian professional transcriber was involved to conduct the direct transcription of all interviews following a set of specific instructions which I indicated to the transcriber[21].

The accuracy of verbatim transcriptions was verified by me, by double-checking the text of transcription simultaneously while hearing the respective audio recordings, so as to ensure that the transcribed text matched exactly the statements of the interviewees. The reason for presenting here a detailed description of the procedure of transcription of interviews is that according to a literature review in a 30-year period (Davidson, 2009) the majority of qualitative studies have overlooked the description of the transcription process, and so there is need for more empirical studies that consider transcription in qualitative research (Davidson, 2009). Accordingly, employing a transcriber – such as in this thesis – constitutes one way to address trustworthiness, provided that instructions are given to the transcriber for the purpose of the study and the requirements of transcriptions (Davidson, 2009) – as it was described and performed in this study as well.

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[21] The transcriber was recruited via an Italian online advertisement website and communication with the transcriber was performed from distance. The researcher first asked the transcriber to do a transcription of a sample, and when this was checked by the researcher for accuracy, the researcher informed the transcriber in detail about the purpose of the study and the main inclusion characteristics of participants, and gave the following instructions to the transcriber: to share a private folder online (on 'Dropbox' – an online file hosting service) where anonymous audio files of each interview would be uploaded by the researcher and the transcriber would upload in turn the document of each transcribed interview once completed (using the same file name as the audio file); to format the text of transcriptions using the Microsoft Word programme and create a single document for each interview; to use font Garamond 12 for each transcript, with the name of the respondent as a title and bold at the beginning of the document; to put the initial of my name ("E:") and the initial of the pseudonym of the respondent consecutively at the beginning of each sentence during the dialogues each time the persons speaking changed; to do a direct transcription without altering or correcting any of the statements of the recorded audio files, even when grammatical or syntactical errors occurred by me or interviewees; to record in transcriptions all pauses made by interviewees during interviews, by placing dots ("…") for each pause the interviewee made, so as to note whenever respondents needed more time in responding a question; and to make a comment on the text with the exact time of the audio-recording in case any of the statements was not clear to the transcriber.

3.2.2 Method of thematic analysis and technique of template analysis

In this study, data analysis was based on the **method of thematic analysis**. Thematic analysis has been defined as *"a way of seeing. (...) Observation precedes understanding. Recognizing an important moment (seeing) precedes encoding it (seeing it as something), which in turn precedes interpretation. Thematic analysis moves you through these three phases of inquiry"* (Boyatzis, 1998, p. 1). In this study thematic analysis is considered as different from other methods of analysis which seek to describe patterns of qualitative data (e.g. grounded theory, 'thematic' discourse analysis, interpretative phenomenological analysis, etc.) in the sense that grounded theory requires analysis to be directed towards theory development, but thematic analysis does not require that too (Braun & Clarke, 2006). In thematic analysis, a theme captures an important aspect within the data relevantly to the research questions of the study and represents a patterned response or meaning within the data collected (Braun & Clarke, 2006), which in this study were interviews. According to thematic analysis, all transcripts of interviews have to be thoroughly read, and then text segments (i.e. sentences or paragraphs of meaning) to be coded under appropriate themes, based on the key concept/meaning of the text segment in relation to the aim of the study (Flick, von Kardorff, & Steinke, 2004). More specifically, coding is the process during which the researcher codes the text in order to answer the research questions (Joffe & Yardley, 2004). For example, a text segment referring to difficulties in making new friends from the wider society would be coded as 'issues with social relationships' or 'regarding bridging social capital' or 'heterophilious social networks', that described the main aspect that this text segment concerned, depending on whether text segments which referred to the same issue formed a pattern with a focus on the lack of opportunities for making such social relationships or rejection from the wider society, or due to personal choice of not wanting friends from the wider society or having too much stress in making new friends.

It was considered appropriate for the nature of this study to apply the **technique of template analysis**, which belongs to the method of thematic analysis, given the multidimensionality of the topics explored here (i.e. structural, cognitive and functional aspects of social relationships, barriers for social participation and autonomous living, etc.) Template analysis is not a distinct method, rather a related group of techniques to thematic analysis, in terms that it is used for thematically organising and analysing textual data (King, 2004) (King, 2012), elsewhere described also as *"a style"* or *"a form of thematic analysis"* (Brooks, McCluskey, Turley, & King, 2015). In particular:

> The essence of template analysis is that the researcher produces a list of codes ('template') representing themes identified in their textual data. Some of these will usually be defined a priori, but they will be modified and added to as the researcher reads and interprets the texts. The template is organized in a way which represents the relationships between themes, as defined by the researcher, most commonly involving a hierarchical structure (King, 2004, p. 256).

Template analysis was chosen based on the analytic necessities of this study, in terms of a both theory-driven and data-driven approach. Template analysis allows flexibility to the researcher to analyse data by combining both a partly theory-driven and party data-driven approach to analysis, deriving from the aim and background literature of the study, and the data that emerge from fieldwork, respectively. More specifically, an analytical template starts to be developed using a list of pre-defined codes or else analytical categories. According to Nigel King (2004), often the best starting point for the development of an initial template for analysis is the interview topic guide used by the interviewer, and that is what in this study has been used as the initial template. Accordingly, the main questions from the interview guide were used initially as higher-order analytical categories, with subsidiary questions and probes or other information that emerged from data as lower-order analytical categories (King, 2004). In short, *"in qualitative template analysis, the initial template is applied in order to analyse the text through the process of coding, but is itself revised in the light of the ongoing analysis"* (King, 2004, p. 259).

As soon as the initial template was constructed, the text of interviews was read repeatedly to identify text segments (i.e. paragraphs or phrases) and conduct the preliminary coding, meaning to identify text segments based on the initial template and aim of the study (King, 2012) (King, 2004). Regarding the process of coding: *"put simply, a code is a label attached to a section of text to index it as relating to a theme or issue in the data which the researcher has identified as important to his or her interpretation"* (King, 2004, p. 257). During this process, modifications of the initial analytical categories occurred in terms of insertion, deletion, changing scope, and/or changing higher-order classification, and in terms of levels of hierarchy, highest-order analytical categories that emerged included one to three levels of lower-order analytical categories, similarly to the paradigm of King (2004). Template analysis *"encourages the analyst to develop themes more extensively where the richest data (in relation to the research question) are found"* (Brooks, McCluskey, Turley, & King, 2015, p. 203).

In terms of interpretation of data, there are no general rules in template analysis to follow, since it depends on the aims and content of each study (King, 2004). Nevertheless, it is advisable to keep in mind some suggestions as starting point, which King (2004, pp. 266-267) offers: a) *listing codes* (to compile a list of all codes occurring in each transcript, with some indication of frequency, but not relying on their frequency[22]); b) *selectivity* (to seek to identify those themes which are of most central relevance to the task of building an understanding of the phenomena under investigation); c) *openness* (not be so strongly guided by the initial research questions that all themes which are not obviously of direct relevance become disregarded[23]); and d) *relationships between themes: beyond the linear template* (the standard linear template presents a structure which has advantages in terms of clarity, however, the researcher should feel free to use these kinds of strategies in building their interpretations, and not feel that analysis has to stop at the point where a full linear template is produced.)

Regarding the presentation of findings, King (2004, p. 267) suggests that *"through summarizing detailed notes about themes, selecting illustrative quotes, and producing a coherent 'story' of the findings, the researcher continues to build his or her understanding of the phenomena the research project has investigated."* In addition, there are various approaches to presentation, again depending on the nature of data, and for any approach it is essential to use quotes from the participants, whether shorter or longer quotes, which give the reader a flavour of the original text (King, 2012). For this study the most appropriate approach for presentation of findings was considered to be:

> *An account structured around the main themes identified, drawing illustrative examples from each transcript (or other text) as required*. This tends to be the approach which most readily produces a clear and

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[22] *"A word of warning about the counting of codes is required. While patterns in the distribution of codes within and across cases may suggest areas for closer examination, the frequency of codes per se can never tell us anything meaningful about textual data."* (King, 2004, p. 266).

[23] *"Themes which are judged to be of marginal relevance can play a useful role in adding to the background detail of the study, without requiring lengthy explication. More problematic are those themes that are clearly of great importance to participants, but that seem to lie well outside the scope of the study, and perhaps were even deliberately excluded from it. In such cases, you must carefully consider whether investigation of the 'excluded' theme casts any significant light on the interpretation of central themes in the study. If it does, then it should be included in the analysis."* (King, 2004, p. 267).

> succinct thematic discussion. The danger is of drifting towards generalizations, and losing sight of the individual experiences from which the themes are drawn (King, 2004, p. 268) .

Therefore, generalisations, from studied cases to unstudied ones, have been avoided – as much as possible – in the interpretation of the data of this study, but a form of pattern-seeking among themes that emerged, also in the form of the ideal type. In other words, the ideal types were formed based on the common characteristics and elements found within the data in respect to the main concepts of the aim of this study, meaning, social relationships and social participation. Regarding the definition of ideal type, the classical Weberian term of 'ideal type' was employed to describe observed phenomena, which have emerged from the analysis. According to Max Weber:

> An ideal type is formed by the one-sided *accentuation* of one or more points of view and by the synthesis of a great many diffuse, discrete, more or less present and occasionally absent *concrete individual phenomena,* which are arranged according to those one-sidedly emphasized viewpoints into a unified *analytical* construct *(Gedankenbild).* In its conceptual purity, this mental construct *(Gedankenbild)* cannot be found empirically anywhere in reality. It is a *utopia.* (Weber, 1949, p. 90).

The ideal type does not refer to an ideal experience, person, or characteristic, but is based on ideas formed from common characteristics and elements found within a cluster of data, and not within a sole case. Accordingly, the ideal type was employed here to facilitate the interpretation of findings in terms of comparisons across and within types of disability, based on the aim of the study. Moreover, patterns were also discerned within and across types of disability based on the sociodemographic characteristics of respondents.

In summary, this study employed a twofold procedure in the analysis to compare information collected through qualitative method, both within and across types of disability, where social aspects of the experiences of participants who have different health issues were investigated as well. To make even clearer the steps of the data analysis followed in this study, is illustrated the specific analytical process in Figure 5 below.

Figure 5. The steps of the present data analysis process and comparison of findings.

Step 1

- **Theory-driven procedure:** Creation of initial template of analysis including analytical categories based on the study's research questions and sub-questions/topics for discussion during interviews. The same initial template was used as a starting point for each type of disability.

Step 2

- **Data-driven procedure (preliminary phase):** Familiarisation with data by re-reading transcribed text of interviews multiple times and field notes. Preliminary coding of text by identification of material relevant to the study and considering whether any of the themes of the initial template represent this material.

Step 3

- **Data-driven procedure (final phase):** Creation of a list of analytical categories representing themes identified in the textual data. Revising the initial template by generating new analytical categories under the predefined Core themes, to create the themes of the final template for each type of disability. The template was considered final when there were no other text segments from the interviews, which were clearly relevant to the research questions, that had not been coded to this final template for each type of disability.

Step 4

- **Interpretation of findings:** Followed the abovementioned suggestions in terms of: a) listing analytical categories, b) selectivity, c) openness, and d) relationships between themes (beyond the linear template).

Step 5

- **Presentation of findings:** Followed the abovementioned suggestion for using an account structured around the Core themes identified, and drawing illustrative examples (i.e. quotes) from each transcript as required.

Step 6

- **Comparison within type of disability:** Based on the new themes that emerged under Core themes, respective patterns and deviant cases were discerned. Patterns based on sociodemographic characteristics of respondents were discerned too for each theme within each type of disability.

Step 7

- **Comparison across types of disability:** Based on ideal types found across the three types of disability and patterns across and within types of disability were discerned. Patterns based on sociodemographic characteristics of respondents were discerned too for each theme across types of disability.

Source: Steps 1-5 above are based on the procedures for conducting template analysis found in King (2004) and Brooks, McCluskey, Turley, & King (2015).

In practice, during coding and themes selection, first coding was performed on the document of transcripts by highlighting text segments which corresponded to the analytical categories of the initial template and/or including meaningful concepts to the aim of the study, and using comments on the Word document (Microsoft Office software) to do the preliminary coding and description of the meaningful text segments, relevantly to this study. Then for the analysis was used also an Excel spreadsheet (Microsoft Office software) – similarly to a previous study (Malcolm, Mein, Jones, Talbot-Rice, Maddocks, & Bristowe, 2016) – where extracts were placed under the core themes of the initial template for each respondent and then a theme was selected based on the meaningful text segments that emerged from each interview, and in this manner was facilitated the process of coding and theme selection for each type of disability. The themes that emerged from the first phase of analysis were cross-checked by me and there was a continuous cycle of re-reading the transcriptions and checking analytical categories and themes, for ensuring that all meaningful concepts were extracted, and reviewing appropriateness of selected themes (Braun & Clarke, 2006). As such, in this study comparisons of cases were conducted with an attempt to develop an overall understanding of the experiences explored here (Mason, 2002), in specific relevant to social relationships and social participation of persons with disability, through relevant patterns which emerged in the form of themes, following the technique of template analysis, and ideal types, as well as based on sociodemographic characteristics of respondents.

Moreover, apart from the fact that the coding process was based initially on background literature and research questions for this study, there was also an *a priori* subjective view on my part existed during the coding process, considering that I was aware before data collection on the main issues persons with disability face in terms of social relationships and social participation, also through my professional experience in previous relevant research projects, thus it was inevitable to avoid bringing the influence of my pre-existing theoretical ideas into the coding process. This has been recognised as an anticipated issue in thematic analysis, since researchers cannot *"free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum"* (Braun & Clarke, 2006, p. 84). Nevertheless, the technique of template analysis allows flexibility to the researcher to code the text and form themes, without any prerequisite that the personal opinion of the researcher should not influence the analysis, on the contrary, it is recognised that in qualitative research themes are not objective 'facts' (King, 2012). Relevantly, in the following chapter of the thesis is a reflection of the researcher in the form of a chronicle of all issues I encountered during this study, to explicate any pre-existing ideas I brought into the analysis, along with an account of potential bias and limitations of this study. The findings from the analytical procedure explained above are presented in detail in the following chapter of Empirical Results.

CHAPTER FOUR: EMPIRICAL RESULTS

In this chapter are presented all findings from the data analysis performed. Findings are also discussed in relation to previous studies which have focused on relevant topics and the relevant scientific literature on the themes that emerged.

4.1 Researcher reflexivity

Before the presentation of empirical results, it was considered essential, as in any qualitative study, for me to provide a detailed subjective reflection on all phases of the research. Reflexivity of sociology, otherwise the 'return' of science upon itself, is a term analysed also by Pierre Bourdieu, who stated that:

> I believe that the sociology of sociology is a fundamental dimension of sociological epistemology. (…) What distresses me when I read some works by sociologists is that people whose profession is to objectivize the social world prove so rarely able to objectivize themselves, and fail so often to realize that what their apparently scientific discourse talks about is not the object but their relation to the object. (Bourdieu & Wacquant, 1992, pp. 68-69).

Bourdieu argued that apart from the issues of reflexivity of sociology already discerned by others, such as the social location (e.g. class, gender, ethnicity) of the researcher, and the position of the researcher in the field of cultural production (along with the researcher's position among possible theoretical, substantive and methodological stances), there is also what Bourdieu called the 'intellectualist bias', referring to the scholarly gaze that the sociologist casts upon the social world. In specific:

> As soon as we observe (*theorein*) the social world, we introduce in our perception of it a bias due to the fact that, to study it, to describe it, to talk about it, we must retire from it more or less completely. This *theoreticist* or *intellectualist bias* consists in forgetting to inscribe into the theory we build of the social world the fact that it is the product of a theoretical gaze, a 'contemplative eye'. A genuinely reflexive sociology must constantly guard itself against this epistemocentrism, or this 'ethnocentrism of the scientist', which consists in ignoring everything that the analyst injects into his perception of the object by virtue of the fact that he is placed outside of the object, that he observes it from afar and from above. (Bourdieu & Wacquant, 1992, pp. 69-70).

In this manner, I tried to consider my role regarding the impact of the research process on the findings, and to be as transparent as possible about all issues encountered when conducting this study, not only in order to set the scene of the data collection and analysis process for the reader, but also to reveal most of the theoretical or practical personal stances through a ‘contemplative eye’, the interpretive lens of the researcher. The fact that I have had long-term involvement in research projects and dissemination of research, relevant to the topics explored in this thesis, prior to this study, enlarges the ‘intellectual bias’ since my theoretical and practical existing knowledge has been brought into the data collection and analysis, unavoidably. Moreover, my academic and professional background has been based mainly on qualitative research (e.g. structured and semi-structured interviews, focus groups, systematic literature reviews, thematic analysis, etc.) with a focus on the field of sociology of health, from undergraduate studies to doctoral studies, and from the beginning of my research career up to the day this thesis has been written. Thus there is major, yet inevitable, influence by my previous theoretical knowledge and practical experience on the interpretation of findings. However, the fact that I had never conducted before any fieldwork in the specific city or country, allowed predispositions from my part to be diminished considerably, thus had no expectations or hypotheses on the data collected – as it has been specified in the previous chapters of the thesis. The information included in the reflection of the researcher contains setbacks or preconceptions from my subjective view, as well as limitations of this study. Accordingly, below is provided a thorough description of my reflection on the preparation, implementation, and analysis of this study, based also on the field notes I took after each interview.

4.1.1 Phase of research design

At the **phase of preparation** of this research, it was considered important for me to learn and comply with any ethical issues and unwritten rules regarding research in the specific region and the possible ways to approach potential participants. In addition, I sought from key informants also to learn about any specific words or terms in Italian used by persons with the specific types of disability (for example the terms ‘oralisti’ and ‘segnanti’ to describe persons speaking or using the sign language respectively) or any kind of disability, so as to create invitations in an appropriate manner. Research ethics is important when planning and conducting one’s research (Flick, 2009). Therefore, I first asked the university where I was conducting my thesis whether I should obtain an ethical approval from the university in order to conduct this research and I was told that no ethical approval from the university was required. Ethical issues were considered when creating the inform consent form (Appendix C), regarding the guarantee of anonymity of participants. As stated in the previous chapter of this thesis, for the recruitment of participants with mental disability, I requested approval from the psychiatrists or clinical psychologists of the respective CPS in order to gain access to interview their patients and when the approval was given to me then I proceeded with the interviews. Ethical issues were also considered in numerous occasions during data collection, when it was essential for me to behave appropriately to participants in order to not disturb them or create any negative feeling to them with the questions I posed. As such, I tried to remain calm and neutral with the statements of the interviewees, even if my personal opinion was different or the statements of interviewees were shocking or sad from my point of view. In other words, I tried to do what Flick has suggested, to *"consider the participants' role and think from their perspective how would it be for you to do what you expect them to do in your research"* (Flick, 2009, p. 43).

During preparation also there was uncertainty from my part regarding **appropriateness of the terminology** used in the thesis. Specifically, the uncertainty was whether to use the term 'disability' or 'impairment' in order to describe the groups of participants with similar health issues, that would be included in the study, given that according to the biopsychosocial model of disability – which has been used here as a conceptual basis – disability is not a synonym to impairment, as explained in previous chapters of the thesis as well. However, since health issues included in this study were quite diverse in terms of onset, body functions and structures, and limitations in activity and participation in general, participants had to be grouped using categories of diagnoses or impairments which are more medical-based, therefore considered more appropriate to use the terms 'disability', 'health issue', and 'difficulty' (as already mentioned previously), which are more diffused – in the specific context – and less medical terms, to my personal opinion. Nevertheless, there were participants with deafness and psychotic disorders who reacted non-verbally with a discontented facial expression to the sound of the word 'disability' for their condition, during interviews, which would probably had not occurred if I had used other terms such as 'otherness' or 'health issue' to refer to their condition. Thus, I avoided during face-to-face contacts to mention the word 'disability' in the following interviews, and after the first few interviews were conducted, I started using only the wider term of 'health issue/problem' to interviewees instead.

A practical issue during the preparation and implementation of this study was the fact that I had to cover by myself almost all **expenses for fieldwork**, such as for equipment, thank-you vouchers given to participants, interpretation during interviews to Italian sign language, and transcription of interviews. This is considered as a common difficulty for doctoral students. This issue is underlined here to point out a substantial practical barrier for conducting a limited-time one-person research, not only for me, but for any doctoral student, who might find stressful the fact that they have to cope both with living and research expenses with a minimum funding, and possibly also to deal with a lot of imprecise bureaucratic procedures which require physical presence of the researcher or a lot of time to be completed. Consequently, doctoral students have to be very careful to clarify in advance such practical and financial issues with academic and administrative staff of their university and verify accessibility to resources available to them, before reaching the decision of the site of their study – which I had not done in advance, but in retrospect I believe it could have limited the added stress caused by these issues. Therefore, apart from the theoretical and methodological part of the design of research, it appeared important – even crucial – in terms of completion of the research, to assess in advance any potential practical, financial and bureaucratic implications during the design of the research, as I should have done as well.

Before interviews and during the recruitment process, I was aware of the possibility that when researchers **conduct a study in a foreign country** than their own, they confront challenges in performing interviews, not only in terms of language and lack of knowledge of cultural references of participants, but also in terms of finding participants who would trust someone who is a foreigner to them and share their personal experiences with this person in an interview. Therefore, this issue was expected as a personal speculation, since it is possible that persons, in general, trust more easily a person from their own country, whereas may react with more suspicion about the motivations of a foreigner. The fact that I am not Italian was obvious in advance through communications to organisations and potential participants from my name and surname on the invitation for participants (in cases of written communication) and my accent (in cases of verbal communication). This speculation, from my part, was neither confirmed nor unconfirmed, but I did confront difficulty in finding Italian participants to accept to participate in the study, while more than half of the those who accepted to participate in the study with sensory disability actually were non-native Italians too, similarly to two of the participants with mental disability, however, none of those who did not accept to participate in the study admitted to me openly that it was due to the fact that I was a foreigner or not. On the other hand, the fact that I was a foreigner to the participants could have been considered as a kind of bridging instrument in the relationship with interviewees, given that they could sympathise with me possibly since I was considered a minority of the wider population, similarly to them.

The fact that I was a foreigner was a weakness of the study, but on the other hand, given that I am a woman and a doctoral student affiliated to a university of the same city that the participants were living in, were considered as **characteristics of social location** – as mentioned above (Bourdieu & Wacquant, 1992) – of the researcher, acting as facilitators for creating an appropriate amount of trust from participants in order for them to accept to share their experiences with me. To boost this effort of mine to build trust with potential participants and relevant organisations or key informants, at the first contact with them, apart from the invitation for participants in the study I was sending/giving them also a copy of a letter written by the principal supervisor of this thesis, who stated the purpose of the study and commended its importance.

4.1.2 Phase of recruitment of participants

The **recruitment process** was quite long in terms of time and challenging for me given the difficulty in finding adequate number of participants within the limited time of the doctoral thesis. This problem was larger given that I was not a native or long-term inhabitant in Italy, thus did not have an already-existing adequate number of personal connections working with people with the specific types of disability, on top of the other issues mentioned previously, so there was a lack of mediators for my research in Milan, which might have been avoided if I had conducted my research in another Italian city or another country (such as my country of origin). Additionally, for gaining access to prestigious hospitals of Milan, where a great number of patients with the types of disability explored here visit their health professionals, I was told by experts working in these hospitals that I would have to wait for months to receive an ethical approval for my study from the managing boards of the respective hospitals, which again was not feasible given the time restrictions for conducting this thesis. Moreover, I was told by one of the key informants/experts consulted about deafness that it is difficult to find young participants who do not have a hearing aid because of the advances in audiology within the past 20 years, so the vast majority of younger deaf adults in Italy have a cochlear implant. Near to the deadline for completion of data collection, my added worry due to lack of the adequate number of participants in my study, led to my decision to propose to psychiatrists/clinical psychologists a co-authorship in a publication in exchange for their help to find participants, because it seemed to me the only way at the time to motivate them to give me permission to interview their patients. This could be considered potentially as a reciprocity norm, meaning the unwillingness to provide voluntary assistance – in this case to support a research project – without any gain from it; either material or as favour owed to an acquaintance. Only one psychiatrist at the beginning accepted to help find participants for this study, who was an acquaintance of the co-supervisor of the thesis. Thus, it seems that in the country the study was conducted in – and possibly in other countries too – if a researcher does not have any connections already and access to organisations/associations for finding participants, would have to create a network of key informants by personal contact through introduction by others, or give something in return to key informants, otherwise the data collection could be jeopardised and the number of adequate participants might not be reached for the study.

In fact, in the initial research design, before data collection started, it had been decided to have 45 participants in this study (15 per type of disability), but once the data collection process started, given the difficulty in finding participants and the unwillingness of relevant organisations (especially in relation to physical and mental disability) to help me in finding participants, it was decided to reduce the initially decided **sample size** and include 30 participants in total (10 per type of disability) instead. Additionally, in the initial research design it had been decided to include within the mental disability only participants with schizophrenia, however, given the difficulty to an adequate number of participants with mental distresses, it was decided during the phase of interviews to broaden this inclusion criterion and include also participants with psychotic disorders, without specifying the health issue they would have (similarly to the rest of the types of disability explored here) – as mentioned above as well. Undoubtedly, the issue of finding participants for this study was the most difficult and challenging issue encountered during data collection, in my perspective.

It was also difficult to **arrange appointments for interviews**, meaning to find an agreeable time and place with the interviewee to conduct the interview, especially regarding potential participants with physical disability, who would have to arrange also with a family member or a carer to help them reach the location of the interview. Some seemed also uncomfortable meeting at their home, while others where quite happy about it since they stated that it was more convenient for them. There were five cases of participants with physical disability and three cases of participants with sensory disability who withdrew from the study during the recruitment process, although at first were willing to participate in it, usually because they were too busy to find free time for the interview or changed their mind for participating in the study. Reconsidering this now, probably I was too patient for them to contact me back about arranging an interview, whereas I could have insisted more for fixing an appointment with all potential participants for interview from the beginning, which might have eventually convinced more of them to participate in it. About participants with sensory disability, I had been told from experts that women with deafness usually prefer going to places in pairs or more together as a group, not alone, so there were cases of arranging appointments with more than two deaf women together at the same, so while the interview was conducted with one of them, the rest of them were waiting for everyone to finish the interview, and then would go away all together again. This required an extra effort for arranging appointments for interviews, given that I had to arrange a convenient date and time not only for all participants, but also for the sign language interpreter. One of the participants with sensory disability (i.e. Dorothy) confirmed during the interview that she prefers going to places with friends who are also deaf.

It has to be stressed here as well that according to the inclusion criteria, participants with relative autonomy were recruited in this study, thus it was likely that **participants had a sociality that was more elevated** than the average level of sociality for persons with disability. Additionally, given that the participants agreed to be interviewed – some of them also within their houses – it is an indication that they were open to others and sociable, which again might not be the average tendency for persons with similar types of disability.

Another issue, mentioned also previously, was that the vast majority of participants with mental distresses were recruited through the CPS, without my involvement in the selection or recruitment process, given that I had no access to their medical history/records to decide their eligibility and know their contact details. Thus, there was a mediator (i.e. the psychiatrist and/or nurse and/or other personnel of the CPS) involved in the recruitment process, who based on the study inclusion criteria selected eligible service users with psychotic disorders to be contacted by staff and recruited for interviews. However, this **mediated selection process** of participants poses a limitation of the study in terms that it was reasonable that the CPS personnel would not choose for the interviews service users who were, for example, dissatisfied with the psychiatrist of the CPS or their services in general or against psychiatric approach to treatment or have had a negative experience with the specific CPS. On the contrary, it was expected that more docile, satisfied and compliant with their treatment provided by the CPS service users would be recruited by the CPS personnel for interviews. This was a reasonable expectation since the sample was recruited using purposive sampling method, which in this case was applied by a mediator/collaborator, who knew patients/participants in advance, so it is highly possible to not have been unbiased in her/his selection of eligible participants.

In terms of **snowball sampling technique**, as mentioned previously, participants with physical and sensory disabilities suggested other potential participants for interviews and facilitated the recruitment process, but participants with mental disability were not asked if they know anyone with a similar mental health problem to suggest as a participant as they were not recruited by me directly so I did not have their contact details, thus would not have been appropriate from my part to ask for contact details of their acquaintances who might meet the inclusion criteria for this study. In any case, participants with mental disability gave me the impression of having a less homogeneous extended social network than the other two types of disability, which was expected given the lesser visibility of their health issue. This assumption has been analysed further in the following parts of the current chapter of the thesis.

4.1.3 Phase of interviews

Regarding issues encountered **during interviews**, first of all, given that I was not a native speaker of Italian, it was challenging to conduct interviews in Italian, especially regarding the part of asking questions to interviewees and in cases that participants did not speak clearly. For this reason, I repeated the question if the interviewee did not understand it completely, or I asked the interviewee to repeat her response if it was not clear to me. In any case, it was stimulating for me to conduct my research in Italy and learn from the inside the experiences of persons with disability in another country than my country of origin.

Moreover, I considered very important to create a trustworthy and relaxing **atmosphere during interviews** for participants, and make them feel as much comfortable as possible, leaving to them the choice of the place of the interview as they preferred, offering to them refreshments, and trying to show a non-judgemental, kind, calm and empathetic attitude towards them during face-to-face contact. In particular, I often made remarks about the interviewees’ statements that were of personal interest to me or due to my empathy for them. For example, to one participant who said she was drawing and helping students with their homework voluntarily, I remarked that these things are nice, or when a participant was talking about her boyfriend breaking up with her for another woman who was thinner, prettier and healthier than her, I remarked that these are typical things that can happen, to show compassion to her, or when another participant said she had never asked for disability benefit although she deserved it, I told her that if she has the right to any kind of help, she could claim it. However, I tried to maintain a reasonable emotional and physical distance from the interviewees, especially the ones with mental disability, so as not to show overly empathetic or caring to them, which then could maybe cross the line of an interviewer-interviewee relationship, thus did not engage also in any kind of physical affection towards them to show empathy, for the same reason. The only physical contact made with participants was to shake hands during introductions, before interview starts, and to greet them the same way when the interview finished. No particular evident emotional difficulty was encountered during interviews from the part of the interviewees, with the exception of two participants with psychotic disorders, the first one was crying while she was speaking about her husband and social relationships, but without altering her voice or any other sign of sadness, and continued speaking without interrupting the interview, and the second one while she was speaking about her fear of being left alone with her babies, she had a change in her voice as of crying, asked her if everything’s ok, and she nodded her head showing that she is fine, and continued describing her biographical story of her health issue. For the first one of these two interviewees, given my previous inexperience of interviews with persons with severe mental health issues, I became overly worried of the reaction of the interviewee when she cried during the interview and informed her psychiatrist about this incident immediately after the interview finished. The psychiatrist called the participant to check if she was feeling well, with the excuse to find out what her impression from the interview was. As the participant was very positive about her experience from the interview and reassured the psychiatrist that she was feeling fine, the psychiatrist informed me that the emotional state of the interviewee had been vulnerable due to the history of her case and the fact that she was pregnant when the interview occurred, so it was not strange that she had these changes in her mood. In general, during interviews participants seemed quite relaxed and open to share their experiences, particularly those with physical disability, whereas participants with mental disability were the ones who seemed less willing to share the history of their condition in detail. In specific, two of the participants with mental disability stated that they did not know or were not certain of their diagnosis, while one of them stated a different, more general diagnosis (i.e. she said she has a mood disorder instead of schizotypal disorder) – a phenomenon mentioned elsewhere using the French word *'décalage'*, to describe the tendency of narrators with mental health issues to deny or lessen the discreditability of their condition (Cardano, 2007). The same participant, who stated a more general diagnosis to describe her health issue, also was the only participant in the study who refused to talk about her biographical experience and onset of her mental health issue, because it involved members of her family and did not want to disclose this information during the interview. However, at the end of this interview, off-the-record, the same participant apologised to me about not sharing this information and I reassured her that there was no problem that she did not disclose this information since she did not want to. In cases that any of the interviewees was avoiding a question, I repeated the question once more, in a kind manner, and if the interviewee refused to answer again, then I moved on to another topic, without further insisting or pressuring them in any way, so as to avoid causing them any distress during interviews.

Given my impression that interviewees with mental disability were not feeling as comfortable as participants with physical disability during the interviews, I did not ask any of the first ones to take a **photo with me** after the interview for the purpose of presentation of the study, for fear they might become suspicious about the purpose of the study or my intentions about the usage of their photo. This could be considered as a predisposition I had based on the feeling of suspicion received during face-to-face contact with participants with mental disability regarding the purpose of the interview. A similar feeling existed from my subjective perception during interviews with the majority of women with sensory disability, who although seemed quite comfortable talking about their experiences, the ones who were not native Italians had an unexpected facial expression and response to the topic of general and institutional trust, meaning trust in people in general and towards institutions (such as police, justice, etc.) In particular, during the interview these participants asked for further explanation of the meaning of trust by the sign language interpreter, showing that they were extremely surprised that this was asked to them, some laughed a bit too when the sign language interpreter asked this question to them, and seemed as if they found it really weird or were suspicious as to the purpose of the question. Maybe their reaction was due to the fact that most of them were foreigners and the concept of trust might be perceived or translated differently in their native sign language, or because in sign language trust could not be accurately translated as a concept for them to understand it. For this reason, I also had the predisposition that should not ask participants with sensory disability as well to take a photo with me after the interview, to avoid creating any further suspicion to them. Of course, not all participants with deafness or psychotic disorders would have refused to take a photo with me if I had asked them eventually, but I preferred not to risk creating any distrust or feeling of discomfort from their part. Regarding the concept of trust and the reaction of participants to the questions about it, also another participant who was a non-native Italian with mental health issues did not understand the question of trust either and asked me to reformulate the question, which I did.

Given that **some of the participants were foreigners**, it was reasonable that they would be facing also difficulties in terms of institutions, such as related to citizenship or language, apart from potential difficulties due to their health issue. This could be also considered as an issue of intersectionality in terms of being both women with disability and foreigners.

Another issue encountered during interviews was that some of the interviewees were **not as descriptive of their personal experiences** as the rest of the participants. In specific, most participants were quite shy during the first few minutes of the interview, and then seemed more relaxed and talked a lot about their experiences. There were however some participants who from the beginning until the end of the interview were giving one-word or very short responses, without explaining their position further. This resulted to having large differences in terms of **time duration of interviews**, with a range from 14 to 90 minutes. The average duration of all included interviews was approximately 33 minutes, while the average duration of interviews per type of disability was approximately: 38 minutes for interviews with participants with physical disability; 30 minutes for interviews with participants with sensory disability; and 32 minutes for interviews with participants with mental disability.

The **attitude of participants** was very kind and pleasant in general, with all of them smiling by the end of the interview, even those who seemed a bit sadder at times during the interview than the rest. Non-verbal signs of defensive attitude, as well as awkwardness and nervousness existed, such as putting both arms crossed in front of the chest, or moving one leg nervously, or looking the other way and not directly at me when they were speaking during the interview. Moreover, although most participants seemed quite shy as mentioned above, there were some participants who appeared quite confident, from all three types of disability; however, they were the minority.

A non-verbal characteristic recorded in field notes in order for me to remember each respondent, was also the **appearance of the interviewees** in terms of outfit and physical characteristics, with differences noted between respondents. In specific, it seemed that the participants with sensory disability were the ones who almost all of them were more attentive of their physical appearance, fashionably dressed and had make-up on, compared to the majority of women with mental and physical disabilities, who were more natural-looking and simple in their outfits and physical appearance, with few exceptions of them who had make-up on and were more stylishly dressed. Of course I am not judgemental about any of the choices of outfit of the participants – and I personally prefer natural-looking make-up and casual outfits for myself too – and it is not a finding that contributes to the knowledge of the topic explored in this study, but I considered it worthwhile to be mentioned since a pattern was discerned, and for presenting also to the reader a more visual image of participants.

4.1.4 Phase of analysis of data

Given that only one person was involved in the analysis of data, my **personal opinion and viewpoint** might have influenced and possibly determined the selection of the specific analytical categories and themes during the analysis, as well as their interpretation. For example, regarding the topic of loneliness explored in the study, I am personally in favour of loneliness for reasons of relaxation, meditation and concentration for productivity in work, thus loneliness is not seen by me as an indicator of lower quality of life, on the contrary, loneliness might be fulfilling, constructive, and productive for individuals too. Similarly, even the notion of social capital, used as a sensitizing concept in this study, has been confronted with personal scepticism by me, and the use of it in this study does not mean that for me social capital constitutes a panacea, meaning that any society rich in social capital would be a society with healthier members, better quality of life, and well-being, necessarily. As any concept under development still the conceptualisation and assessment of the notion of social capital has inconsistencies and vagueness. Moreover, I believe that well-being and happiness are not universal terms, objectively perceived by everyone in the same manner; possibly they are a utopia and constitute what each person thinks and feels as a personal state of well-being or happiness in terms of social relationships and social participation. Thus, it is clear that I have no intention to judge or label participants or their responses, nor recommend a specific paradigm of social relationships or social participation as being optimal or not.

Another major issue confronted in terms of data analysis is the fact that given that I am not a native Italian or English speaker, poses an issue regarding **interpretation of findings and translation of the quoted text** from interviews used in the findings of this thesis. In particular, this study was conducted in a country (i.e. Italy), which is not my home country, nor am I a native speaker of the language spoken in it (i.e. Italian) or a native speaker of the language the thesis was written in (i.e. English). Also, since the language of interviews was not English, I translated from Italian to English the text quoted in the thesis from interviews, with the help of a researcher/psychologist. Nevertheless, I have tried to address this issue and to illustrate the level of accuracy of my translation of the quoted text by placing a sample of the original text of one of the interviews in Italian (see Appendix D) and having another person – the researcher/psychologist – to assist the translation process; thus all translated quotes have been checked by two different persons. In particular, at the end of the thesis (see Appendix D) are presented the quotes used in the main body of the thesis from one of the interviews conducted in original language (i.e. Italian) as a sample to prove the quality of the translated text in this thesis from Italian to English. There was no specific reason for selecting this specific interview as a sample. A limitation related to the translated text can be that some statements of the interviewees in Italian language might have been misunderstood by me, or the quotes from interviews included in the thesis in English might have not been precisely translated by me from Italian. As it has been remarked elsewhere:

> Quotations of participants are commonly being used in qualitative research articles. Translation of quotes poses specific challenges, because it may be difficult to translate concepts for which specific culturally bound words were used by the participants (Van Nes, Abma, Jonsson, & Deeg, 2010, p. 315).

Thus challenges during translation of quotes are reasonable in qualitative research when conducted by a non-native researcher, however, another researcher (fluent in Italian and English) has checked the translations of all text included in the thesis in English in order to minimise potential translation errors.

Moreover, as mentioned above, I did not have adequate knowledge of the **Italian sign language** to be able to conduct interviews with signing participants on my own, so the transfer of meaning of the statements of the interviewees from the sign language interpreter to me and backwards could have altered the meaning of translation from verbal language to sign language too. On the issue of losing the meaning in translation during qualitative research, it has been stated that challenges of interpretation and representation of meaning *"are more complicated when cultural contexts differ and interlingual translation is required"* (Van Nes, Abma, Jonsson, & Deeg, 2010, p. 314). Language differences generate additional challenges in qualitative research since they might hinder the transfer of meaning to the reader, so the result might be the loss of the original meaning and, in turn, loss of the validity of the qualitative research (Van Nes, Abma, Jonsson, & Deeg, 2010). These challenges could have been addressed by using the services of a professional translator, as Van Nes, Abma, Jonsson, & Deeg (2010) suggest, producing a qualified translation from Italian to English of all transcribed text of interviews, but the cost would have been too high for me to cover independently. Nevertheless, my academic and professional experience in Italian and English language allowed me to conduct the interviews and understand and translate the meaning of the statements of interviewees, as well as to grasp the social context of the Italian country as much as possible for a non-native inhabitant. Also, initially I was not fully aware of the policy context of Italy on the types of disability explored here, but I was informed about it through key informants and the literature review performed for this study.

The fact that another person (i.e. the sign language interpreter), apart from me, mediated interviews with deaf participants who used the sign language adds to the limitations of this study. In particular, given that with the rest of study participants I conducted one-to-one individual and private interviews, the fact that in some of the interviews another person made the questions to them, might have jeopardised the meaning of the questions, due to the double translation procedure something can be lost in translation, and in terms of the confidentiality of the interview. However, the sign language interpreter was a trustworthy and commended professional by a colleague and all participants using sign language were informed in advance, before the interview started, and in agreement that the sign language interpreter would be present, given also that I did not have adequate knowledge of their language to communicate with them directly. In fact, it was even requested by most of them as a condition/prerequisite for their agreement to participate in the interview that someone who knows sign language would be present during the interview too. Therefore, it was clearly acceptable by all involved parties before each interview started that it was necessary for a sign language interpreter to be present, thus consent was implied or directly stated by participants. Moreover, given that an interpreter mediated the communication between the interviewees and me, it is probable that during the simultaneous interpretations performed by the sign language interpreter, the meaning of statements of the interviewee or my questions might have been **altered by the sign language interpreter unintentionally** during the interpretation, since an interpreter cannot replace fully the role of the researcher and be aware fully of all the topics explored in the study. Unfortunately I was not able to check the correctness of the interpretation since I am not a proficient user of the Italian sign language.

A common issue in social science research related to the quality of the data collected is that participants might not state their honest opinion, thoughts, actions, and/or feelings relevant to the topics under investigation, because they know they are being observed by a researcher. This is commonly referred to as the reactivity issue. Reactivity has been defined as the outcome of a *"general threat to external validity"* which occurs when participants know that they are being studied (Neuman, 2014, p. 306), in other words, respondents during a research might have diverse attitude/statements compared to their real life, because they are aware that someone is studying/observing them (Neuman, 2014). This could possibly have been the case for some of the participants of this study too, but given that I had never met any of the participants before the interviews were held, I could not have known if their statements and reactions were honest or not, however, it is possible that the reactivity issue was present in this study too.

The data analysis was performed as described in the Methodology chapter above, with my continuous checks of the content of interviews and the appropriateness of coding and themes selected. However, there were some analytical categories and/or themes selected that **overlapped in meaning**, which was unavoidable due to the high relevance of the main concepts explored in this study (i.e. social relationships and social participation). For example, an interviewee described her experience of being called 'crazy' by some of her friends because they do not understand her mental health issue, so this text segment could be appropriate both for a theme on difficulties with friendships and a theme on received prejudice.

During the **phase of familiarisation with data** collected, when re-hearing the interviews and checking the transcriptions, it occurred to me that I had used a lot the word 'okay' after each statement of the interviewee, possibly more often than I should have, but I did that in order to show to the respondent that their response was fine and I was accepting their response as valid in a neutral manner, without showing if I agreed with their statements or not.

About my understanding and consequent interpretation of the statements of interviewees, it has to be clarified here that I reported the statements of interviewees as real, at least based on their perception, without investigating whether these **perceptions/statements of participants were real or fictional**. For example, when a participant with psychotic disorder shared with me her experiences of being sexually assaulted in the past, I treated this information as real, although due to her mental health issue she might have had a distorted image of reality, or exaggerated in her statements to me to increase my sympathy towards her. Given that I am not a psychologist or psychiatrist, I did not have the capacity to evaluate whether their statements were true or false. However, since the participant treated these events as real, they seemed to have had an impact on her mental state and possibly social relationships, therefore I treated them as real according to the perception of the interviewee.

Moreover, it was most likely that participants had not understood correctly the topic of **institutional support**, and during the analysis I realised that I should not have used the term ‘institutional support’ to the participants as it might have been unclear to them what institutional support means.

What is more, due to the small sample size of the study, it is not possible to neither **generalise results**, nor claim that the sample was representative of the population studied. Nevertheless, patterns among responses of participants were discerned across and within types of disability, in terms of ideal types and sociodemographic characteristics, as explained previously, and despite the small number of participants; indicating that results might have been similar even if there had been a larger number of participants from the same metropolitan area included in the study.

In any case, the fact that the women who participated in this study **had at least one role of relative autonomy**, as an indication of being more socially active, could be considered as a limitation of the study in terms of generalisation of results, however, it could be also considered an advantage of the study given the lack of previous studies focusing mainly on socially active participants with disability.

Last, but not least, I felt affected by the research too, in a manner of **retrospective reflexivity** – the other side of prospective reflexivity, which is represented in the reflection of the researcher described in the subchapters above. Specifically, *“prospective* *reflexivity concerns itself with the effect of the whole-person-researcher on the research. Retrospective reflexivity concerns itself with the effect of the research on the researcher."* (Attia & Edge, 2017, p. 35). As such, after the end of the fieldwork, I felt more empathetic towards persons with psychotic disorders, than I was before, and was surprised by the intelligence, self-knowledge and multi-tasking abilities of women with any of the three types of disability explored here, and felt self-motivated by their views and admired them as powerful women, who despite their kind of otherness they are productive and lead their social lives actively. The fact that most of the participants were of similar age to me and that I have also experienced personal and family physical health issues of minor severity compared to participants', as well as having friends and acquaintances with severe movement-related health issues, had a significant part in terms of prospective and retrospective reflexivity of the researcher in the specific study, and a bias of attachment more towards participants with physical disability. However, I have treated equally and impartially the three types of disability explored here in terms of interpretation of findings, thus distributed similar amount of space throughout the thesis to all three types of disability explored.

4.2 Sociodemographic characteristics of participants

This section of the thesis includes all collected sociodemographic information of participants of this study and their health issues and types of disability. Table 1 below includes all sociodemographic information of participants collected; apart from their area of residence, for confidentiality reasons. The real names of participants have been replaced with random pseudonyms in English to safeguard anonymity of participants. Next to each pseudonym there is an initial in brackets, for assisting the reader to distinguish the type of disability of each participant, in a discreet manner. As such, the initial '(M)' implies participants with mental disability, '(S)' those with sensory disability, and '(P)' the ones with physical disability.

Table 1. Sociodemographic characteristics, type of disability and health issues of the 30 included study participants.

Type of disability	Pseudonym (initial of type of disability)	Age	Level of education	Marital status	Employment status	Living arrangements	Role(s) of relative autonomy	Health issue
Physical	Diana (P)	36	Upper or post-secondary school certificate	Single/Never Married	Paid employment	With mother	Worker	Spastic tetraplegia
	Rebecca (P)	42	Bachelor's degree	Married	Paid employment; Student	With husband and parents	Worker; Living with husband; Student	Disease of muscular form (congenital)
	Amy (P)	30	Upper or post-secondary school certificate	Single/Never Married	Student	With parents	Student	Spastic tetraplegia
	Phoebe (P)	35	Upper or post-secondary school certificate	Cohabitating/ not married	Paid employment	With partner and daughter	Worker; Mother; Living with partner	Spinal muscular atrophy (SMA)
	Janet (P)	44	Master's degree	Single/Never Married	Paid employment	Alone (with care-worker)	Worker	Spinal muscular atrophy (SMA)
	Christine (P)	24	Bachelor's degree	Single/Never Married	Student; Volunteer work	With parents and brother	Student; Worker	Arthrogryposis
	Lucy (P)	30	Master's degree	Cohabitating/ not married	Paid employment	With partner	Worker; Living with partner	Osteogenesis imperfecta (also known as brittle bone disease)
	Brenda (P)	24	Bachelor's degree	Cohabitating/ not married	Self-employed/ freelance	With partner	Worker; Living with partner	Tetraplegia from trauma
	Nicole (P)	23	Upper or post-secondary school certificate	Single/Never Married	Student	With mother	Student	Tetraplegia from trauma
	Penny (P)	34	Master's degree	Single/Never Married	Paid employment; Student	Alone (with care-worker)	Worker; Student	Spinal muscular atrophy (SMA)
Sensory	Dorothy (S)	30	Lower secondary school certificate	Married	Unemployed	With father and husband	Living with husband	Deafness (congenital) – using sign language
	Megan (S)	40	Upper or post-secondary school certificate	Cohabitating/ not married	Unemployed	With partner and son	Mother; Living with partner	Deafness (since age of 1 and ½ after a disease) – using sign language
	Nancy (S)	22	Lower secondary school certificate	Single/Never Married	Volunteer work	With parents and brother	Worker	Deafness (congenital) – using sign language
	Betty (S)	24	Upper or post-secondary school certificate	Single/Never Married	Student	With parents	Student	Deafness (congenital) – speaking with cochlear implant/hearing aid
	Monica (S)	29	Master's degree	Single/Never Married	Paid employment	With mother and sister	Worker	Deafness (congenital) – speaking with cochlear implant/hearing aid

	Carol (S)	41	Upper or post-secondary school certificate	Married	Unemployed	With husband	Mother; Living with husband	Deafness (congenital) – using sign language
	Sharon (S)	44	Bachelor’s degree	Married	Unemployed	With husband and son	Mother; Living with husband	Deafness (since age of 1 and ½ after a vaccine for an infection) – using sign language
	Kylie (S)	40	Upper or post-secondary school certificate	Married	Paid employment	With husband and son	Worker; Mother; Living with husband	Deafness (since age of 10 months after taking an antibiotic) – speaking with cochlear implant/hearing aid
	Claire (S)	36	Upper or post-secondary school certificate	Single/Never Married	Paid employment	Alone	Worker	Deafness (congenital) – using sign language
	Shirley (S)	39	Upper or post-secondary school certificate	Cohabitating/ not married	Paid employment	With partner	Worker; Living with partner	Profound bilateral hearing loss (congenital) – speaking with cochlear implant/hearing aid
Mental	Sylvia (M)	24	Bachelor’s degree	Single/Never Married	Student	With parents and brothers	Student	Bulimia (at risk of psychotic disorder)
	Emily (M)	26	Upper or post-secondary school certificate	Cohabitating/ not married	Student	With parents, brother, and fiancée	Student; Living with partner	Obsessive–compulsive disorder (OCD)
	Olivia (M)	38	Upper or post-secondary school certificate	Married	Unemployed	With daughter, husband, and mother	Mother; Living with husband	Bipolar disorder (with psychosis)
	Rachel (M)	40	Upper or post-secondary school certificate	Single/Never Married	Paid employment	Alone	Worker	Undifferentiated schizophrenia/ schizoaffective disorder
	Lily (M)	29	Master’s degree	Single/Never Married	Self-employed/ freelance	With parents	Worker	Bipolar disorder (Type II) (with psychosis), binge eating disorder, hypomania
	Amelia (M)	38	Lower secondary school certificate	Separated	Self-employed/ freelance	With her 3 children, and a flatmate with her child	Worker; Mother	Recurrent Depression and Personality Disorder, emotionally unstable, crises of depression and suicide attempts, in the past hysterical pregnancy
	Mary (M)	33	Upper or post-secondary school certificate	Single/Never Married	Student	With parents	Student	Schizotypal disorder
	Susan (M)	32	Lower secondary school certificate	Cohabitating/ not married	Unemployed	With partner and flatmates	Living with partner	Schizoaffective disorder
	Jennifer (M)	44	Upper or post-secondary school certificate	Cohabitating/ not married	Paid employment	With partner	Worker; Living with partner	Personality disorder
	Elizabeth (M)	27	Upper or post-secondary school certificate	Single/Never Married	Paid employment	With parents and two sisters	Worker	Personality disorder – Borderline, with symptoms of paranoia.

4.2.1 Age

Regarding the age of participants at the time of the interview they were between 22 and 44 years old, with average age for all participants approximately 33 (standard deviation=7). Specifically, the age range and average age of participants per type of disability were:

- **mental disability:** from 24 to 44, with average age approximately 33
- **sensory disability:** from 22 to 44, with average age approximately 35, and
- **physical disability:** from 23 to 44, with average age approximately 32.

Consequently, the data collected represented a similar age distribution across and within types of disability, thus within and cross-disability comparisons based on age were feasible in this study. As already mentioned, the sample intentionally represented women, who were young adults; however, it was not intentional to have a similar age distribution across types of disability. In terms of age groups, five participants with physical disability were younger than 30 years old and the rest from 31 to 44, whereas four participants of sensory disability and four participants with mental disability were younger than 30 years old too. So distribution of participants among age groups was similar as well between types of disability; though it was not intentional during the recruitment phase of the study to select participants based on even age distribution of the sample.

4.2.2 Area of residence

All participants were living at the time of the interview in various areas within the metropolitan city of Milan, Italy. Specifically, the majority of participants with physical disability were living outside the city centre, whereas most participants with mental and sensory disability were living in or very close to the Milan city centre. Although the study was conducted in Italy, not all participants were native Italians, especially regarding the majority of participants with sensory disability and two of the participants with mental disability, whereas all participants with physical disability were Italians. Nevertheless, even participants who were not native Italians had been living in Italy for at least two years prior to the date of the interview.

4.2.3 Level of education

The highest level of education attained by the majority of participants was upper or post-secondary school certificate[24] (N=16), for five of the participants the highest level of education was master's degree, for five bachelor's degree, and for four lower secondary school certificate. According to data from the Italian National Institute of Statistics (Istat Statistics, 2018), the equivalent highest level of education[25] of the majority of women of the general population, aged 15+ and living in the region of Lombardy in 2017, was also upper or post-secondary school certificate (44%), similarly to this study, however, the data of the general population placed as second highest level of education the lower secondary school certificate (36%), whereas in this study only 4 participants reported this as their highest education level. The second most prevalent highest education level in this study was tertiary education, with 1 in 3 participants having a bachelor's or master's degree, whereas tertiary education was the level of education that was the least observed among the female total population of Lombardy. Thus, it appears that tertiary education was achieved by more participants of this study than the general population equivalent, possibly an indication that more women with disability may pursue higher educational levels compared to the women of the wider population.

Furthermore, there seemed to be a distinct contrast between participants with physical disability and participants with sensory or mental disability. In particular, the majority of respondents with physical disability (N=6) had been educated at tertiary education level (i.e. with a Bachelor's or Master's degree), whereas the majority of respondents with sensory (N=8) or mental (N=8) disability were educated to upper or post-secondary school level.

4.2.4 Marital status

Regarding marital status of participants, half of the respondents were single or never married, and almost the other half (N=14) were married or cohabitating with their partner, while one participant was separated. From those who were never married, some of them

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[24] The level of education equivalent in English from Italian degrees/levels of education was based on the Italian National Institute of Statistics categorisations in the English version of its database (Istat Statistics, 2018). In specific: 'licenza di scuola media' = 'lower secondary school certificate'; and 'diploma 2-3 anni (qualifica professionale)' or 'diploma 4-5 anni (maturità)' = 'upper or post-secondary school certificate'. For the tertiary education, I specified the degrees further as: 'laurea' = 'Bachelor's degree'; and 'post-laurea' = 'Master's degree'.

[25] Excluding from the data calculations the levels of 'primary school certificate' and 'no education', to allow comparisons with the data of this study since these levels of education did not emerge here.

had a steady relationship, with the majority of them having a male partner and only one stated that she had a female partner. Thus, it was obvious that the majority of the participants had an intimate relationship, a fact which could have been expected given that only women with a relative role of autonomy were included in the study; therefore more socially-active women were interviewed purposively. Most of the participants who were never married had a physical disability, whereas most of the married ones had a sensory disability. Of the participants with mental disability, only one was married and another one separated. None of the participants was divorced, and some of them had also one child or more. The fact that most of the women were never married, is reasonable given the fact that a bit more than 1/3 of the respondents (N=13) were 30 years old or younger, thus they were at an age that nowadays a large number of women are not married yet, and in any case, among young adults currently there is a tendency in European countries for lower number of marriages and having more children outside marriage, thus cohabitating with partners more, either due to financial reasons or ideology/beliefs against the institution of marriage. To prove that, according to Eurostat (the statistical office of the EU), the demographic data from 1970 to 2013 show that the number of marriages have decreased within the 28 countries of the EU (EU-28), while the proportion of children who are born to unmarried couples has increased (Eurostat, 2017). Specifically about Italy, the demographic evidence show that from 7.3 marriages per 1,000 persons in 1970, the rate dropped to 3.2 marriages per 1,000 persons in 2015, while 2.2% of live births were outside marriage in 1970, with this proportion increasing to 30% in 2015 (Eurostat, 2017). In other words, almost 1 in 3 born children in Italy in 2015 have been of couples who were not married. For most of the participants of this study who had an intimate relationship, their partner or husband also had the same type of disability, except for participants with physical disability, of whom the partner or husband did not have a physical disability in all cases.

4.2.5 Employment status

Participants' employment status varied significantly, with more than 1/3 of the respondents (N=11) being only in paid employment, six were university students (without having another job), six were unemployed, three were self-employed, one in voluntary work, and three participants were both working and studying (i.e. two having also a paid employment and the third one a voluntary work). If we sum up the participants who were working (i.e. in paid, voluntary, or self-employment) and those who were not working (i.e. students without another job and unemployed) it appears that there were 18 employed participants and 12 unemployed. These data closely match the data from the Italian National Institute of Statistics (Istat Statistics, 2018) on the general population, which show that in 2017 the average employment rate was 54.3% for women aged 15-44. Moreover, none of the participants with physical disability was unemployed or not studying, whereas the group of participants with sensory disability had the highest rate of unemployment among participants – possibly because according to the Italian Law 68/99 (*Legge 12 Marzo 1999, n. 68*) mentioned previously) employers of the private and public sector have the obligation to employ also a quota of persons with disability. In 2014 in the EU, the employment rate of women with disabilities was reported to be 45.7%, compared to 66.7% for women without disabilities, while the employment rate of men with disabilities was 52.3% (Grammenos, 2017). Thus, it is evident that there are gender- and disability-based differences within the European population in terms of employment. However, it was not possible to retrieve data at European level which included also a breakdown of the types of disability explored here in terms of employed and unemployed persons with disability, neither at the level of the metropolitan area of Milan, therefore cannot confirm whether the findings of this study in terms of employment status of respondents represent women with physical, sensory or mental disability living in the specific area. Nevertheless, as mentioned above, the present data are quite similar to the regional data of the wider population of women regarding employment rates. Therefore, the participants of this study did not appear to have large differences in terms of employment rate in comparison to the wider population of the same region.

4.2.6 Living arrangements

In relation to the living arrangements of respondents, no specific pattern can be discerned across types of disability. At the time of the interview, 11 participants were living with their family of origin [i.e. parent(s), brother(s) and/or sister(s)], other 11 respondents were living only with their husband or partner, with or without any child(ren), 4 were living alone, and 4 were living with both their husband/partner and/or child(ren) and member(s) of their family of origin all together in the same household. According to the data provided by the Italian National Institute of Statistics (Istat Statistics, 2018), in 2016, 57.6% of women of the wider population aged 18-34 living in Italy were single/unmarried and living in the same household with at least one of their parents. These data are not similar to the data of this study, given that here only about 1/3 of participants were living with their family of origin, without their husband/partner living together with them; however participants here were aged up to 44, not 34, thus it is possible that this dissimilarity in rates could be due to the difference of age of the population explored between the two studies.

4.2.7 Role of relative autonomy

The approximate indicator of relative autonomy was created in this study in order to identify whether respondents had a relative autonomy and at least one societal role. As it appeared, half of the total of respondents had more than one roles of relative autonomy, and two of the respondents with physical disability and one with sensory disability had three of these roles each. The most common role of relative autonomy was being a worker (N=18), followed by living with husband or partner (N=14) and/or studying (N=9), while the least common role for participants was being a mother (N=7). No significant differences appeared across types of disability for the roles of worker and living with partner/husband. However, for the social role of mother, four of the respondents with sensory disability were mothers, whereas only one with physical disability and two with mental disability were mothers too. It has to be noted here that one of the mothers with sensory disability stated that she was not living with her son, as her son was living in another country (i.e. Ukraine). For the social role of student, it was found that five of the respondents with physical disability were students with three of them also doing another job at the same time, whereas only one with sensory disability and three with mental disability were students (without working at the same time).

4.2.8 Included health issues and type of disability

As already mentioned, based on the aim of the study three types of disability were explored, including various health issues that had similar characteristics, namely: physical disability (including inability of movement of the lower limbs), sensory disability (including severe hearing difficulty with or without cochlear implant/hearing aid), and mental disability (including mental health issues of psychotic disorders). The number of participants for each type of disability was predefined; however the number of participants with specific health issues within each type of disability was not predefined, but random – apart from participants with sensory disability that were intentionally selected four speaking and six signing deaf participants. As such, there were differences within types of disability, particularly within physical and mental disability, in terms of health issues included.

Specifically, among participants with **physical disability**, three were diagnosed with spinal muscular atrophy (SMA), two with spastic tetraplegia, two with tetraplegia from trauma, and the other three with arthrogryposis, osteogenesis imperfecta, and congenital disease of muscular form. Regarding onset of the physical health issue, for the vast majority of the cases was a congenital health issue with an immediate or slow progression during life course, and two cases were health issues caused by a trauma (one by a fall on the mountains and the other one by a car accident).

Of participants with **sensory disability**, as already mentioned in the inclusion criteria of this study, all of them had deafness or profound bilateral hearing loss, and six of them were using the sign language, whereas four were speaking having cochlear implant/hearing aid. This numerical distribution among speaking and sign-language users was intentional. None of the participants was so-called 'bilingual' (both speaking and using the sign language) in order to allow clear-cut comparisons between the two dominant groups of deaf persons (i.e. those who speak and those who use the sign language), given the cultural and self-identity issues among them which had been discerned before the data collection process started. For all participants with hearing difficulty the onset of their deafness was placed at their birth or detected/diagnosed before the age of 3, and for the minority the hearing loss was caused after a vaccine or antibiotic or a disease, while for the majority was congenital.

As regards participants with **mental disability**, it was more complicated to select participants for inclusion in this study, given that psychotic disorders include a wide spectrum of mental health disorders. As a result, the psychiatrists who treated the participants were the ones who selected the cases according to their assessment of participants having a psychotic disorder, while I had no capacity (not being a psychiatrist or psychologist) to evaluate or verify participants' suitability for inclusion, regarding their diagnosis. Therefore, about the eligibility of the diagnosis of mental health participants, I relied entirely on the evaluation of the psychiatrist and the self-reported diagnosis by interviewees, using as a guide to confirm diagnoses the DSM-5 (American Psychiatric Association, 2013). Accordingly, three of the participants were diagnosed with schizophrenia or schizoaffective or schizotypal disorder, three with personality disorder, two with bipolar disorder, and the rest two cases with bulimia at risk of psychotic disorder and obsessive-compulsive disorder (OCD). Again, these participants were evaluated as eligible for this study by their psychiatrists based on their symptoms and medical history as exhibiting a psychotic disorder. The onset, duration and cause of the psychotic disorder varied greatly among participants, from adolescence to early adulthood. Lastly, all participants with mental health issues were taking medication at the time of the interview, a fact which was confirmed either directly by them during the interview or by their psychiatrist off-the-record. Thus, there were no participants in the study with mental health issues, who were not taking any medication, although it would have been interesting for the purpose of the study to interview the experiences of such cases too, based on the literature review presented above, showing that there is also criticism of biomedical approach to psychiatry and the dependence on drugs to treat mental disorders, thus less-medicalised approaches have been suggested as more beneficial for patients (Bentall, 2010).

In the next subchapters are presented the empirical findings based on the template analysis performed. As mentioned in the Methodology chapter, the initial template used both for within- and across-types of disability comparisons was based on the interview guide (list of topics/questions), including the original interview questions/topics in the form of higher-order analytical categories, and their respective sub-questions/topics as second-level lower-order analytical categories, which form a list of analytical categories representing themes. Accordingly, Figure 6 below demonstrates the initial template of the present analysis.

Figure 6. Initial template of the study.

1. **Biographical experience of disability** (time and cause of onset of disability).
2. **Coping mechanisms for disability** in everyday life.
3. **Social networks (structural aspects):** Experience about social relationships and group membership:
    - 3.1 Within family, intimate relationships, relationships with neighbours, health/social care professionals
    - 3.2 Members of organisations or volunteer groups (church, associations, sports clubs, etc.)
    - 3.3 About size of social network, about how many people they would say that they feel close to.
    - 3.4 Type of relationships, frequency of contact, and usual way of communication between them.
4. **Disability-based homophily or heterophily of social networks:** Most of the persons belonging to their social networks are persons with disability too (homophilious) or without any disability (heterophilious).
    - 4.1 If so, have they ever reached out to persons outside their usual social networks and got rejected. Or do not want to be involved with other persons since they feel that they cannot understand them.
5. **Received and provided social support:**
    - 5.1 If they receive support from others. If so, for which reason (emotional or practical support) and how often. And by what type of relationship (e.g. family members, friends, etc.)
    - 5.2 If they provide any support to other persons.

6. **Received institutional support:** from national or local authorities (e.g. or everyday tasks, or any health/social care benefits, disability benefits, etc.) or from advocacy organisations (e.g. companion for outdoor activities who are volunteers in disability associations, etc.)
7. **Change of attitudes of others due to disability:** any changes in experience of relationships with others or received support after the onset of their disorder/disease/injury.
8. **Trust:**
    - 8.1 Towards people in general.
    - 8.2 Towards institutions (such as police, justice, parliament, and the press).
9. **Political participation**:
    - 9.1 If they vote regularly.
    - 9.2 If they are members of associations or advocates for persons with disability.
    - 9.3 About their participation at a demonstration or petition regarding issues of political life in general.
10. **Perceived gender differences**. If they have observed any differences between men and women having the same health issue.
11. **Feelings of loneliness and coping mechanisms**.
12. **Daily activities** (about their routine).
13. **Leisure time activities:** preferences, hobbies, indoor or outdoor activities, with other or alone, etc.
14. **Employment issues due to health issue**: If they are not working, if they would like to find a job but they cannot due to their health condition.
15. **Opinion on specific civic norms:** If they agree or disagree with these statements [based on (Kaasa & Parts, 2008)]:
    - 15.1 Cheating on taxes if you have a chance
    - 15.2 Claiming government benefits to which you are not entitled
    - 15.3 Someone accepting a bribe in the course of their duties.
16. **Barriers for social participation** (both physical environment and social-related).
17. **Suggestions for removing barriers regarding social participation**.
18. **Barriers for independent/autonomous living**.
19. **Suggestions for removing barriers regarding independent/autonomous living**.
20. **Expectations about the future at individual level:** How they see their future in the next ten years (at personal and/or professional level).

Based on all above, below are presented the findings within each type of disability.

4.3 Findings within each type of disability

In this subchapter are presented the findings of the template analysis based on the aim of this study, along with patterns on sociodemographic characteristics at the end of each theme, and main tendencies within the Main Areas presented below.

4.3.1 Mental disability

Following the technique of Template Analysis, the initial template used for here for the analysis (Figure 6), which was based on the research questions of the study, was modified during the process of data analysis by inserting new themes and modifying existing ones, as well as removing themes which were considered redundant for the aim of the study. Accordingly, regarding data from interviews with participants with mental disability, the following changes were made to the initial template:

- Core themes were divided into two 'Main Areas' to aggregate findings based on the meaningful concepts of focus of the respective core themes. The two Main Areas were: *'The body, self and disability'*; and *'Social relationships, social participation and disability'*.
- Core themes were re-organised based on relevance between them.
- New themes and sub-themes were added which were not included in research questions, as they emerged from the interviews.
- Modified existing themes: merged themes (i.e. 'Coping mechanisms for disability' together with 'Feelings of loneliness and coping mechanisms'; 'Barriers for social participation' together with 'Suggestions for removing barriers regarding social participation'; and 'Barriers for independent/autonomous living' together with 'Suggestions for removing barriers regarding independent/autonomous living'. In addition, modified several times during the analysis the wording of themes and sub-themes while trying to create headings that would more accurately represent the meaningful concepts within all the meaningful text segments from interviews.
- Removed existing themes: two core themes were removed. First, the 'Leisure time activities' core theme was removed because it referred to activities during the day which more or less had also been mentioned by participants under the theme 'Daily activities', thus the theme was removed since it did not contribute to the knowledge of the topic of the thesis. Secondly, the core theme of 'Institutional support' was also removed as a separate theme because during analysis it

appeared as highly possible that participants might had not understood this topic correctly, since they all received institutional support from the CPS or rehabilitation centre, but many of them reported that they received no institutional support. So the results under this core theme were considered to be possibly inaccurate and were mentioned only in terms of financial support mainly, as financial support was specifically asked to participants as an example of institutional support.

Based on all above, the themes that emerged from this analysis for mental disability are presented in Table 2 below.

Table 2. Final template of themes for participants with mental disability.

MAIN AREA 1: THE BODY, SELF AND DISABILITY
CORE THEME 1. BIOGRAPHICAL EXPERIENCE OF HEALTH ISSUE
1.1 Age of onset
1.2 Cause of onset
1.2.1 Cause related to difficulties with social and/or intimate relationships
1.2.2 Cause related to family problems
1.2.3 Exhibited after an intense period of tiredness and work or within the work environment
1.2.4 Undisclosed cause of onset of mental health issue
CORE THEME 2. COPING MECHANISMS FOR DISABILITY AND FEELINGS OF LONELINESS
2.1 Going outdoors or relaxing at home and/or turning to friends or family
2.2 Relying on religious faith
2.3 Reading or writing or waiting passively for difficult moment to pass
2.4 Tackling loneliness mainly with support of friends or other distractions indoors
2.5 Loneliness as not necessarily a negative state
CORE THEME 3. PERCEIVED GENDER DIFFERENCES BASED ON HEALTH ISSUE
3.1 Never encountered man with same health issue or no perceived gender differences
3.2 Reported perceived gender differences
CORE THEME 4. EXPECTATIONS ABOUT THE FUTURE AT INDIVIDUAL LEVEL
4.1 To recover from mental health issue or remain in good health
4.2 Positive thinking about the future; without mentioning health issue
4.3 Negative thinking about the future.

MAIN AREA 2: SOCIAL RELATIONSHIPS, SOCIAL PARTICIPATION AND DISABILITY
CORE THEME 5. SOCIAL NETWORKS (STRUCTURAL ASPECTS)
5.1 About size of social network and type of relationship
5.1.1 Size of social network
5.1.2 Social network including family and/or friends and/or health professionals
5.1.3 Specifying that their social network consists of persons who know about their mental health issue
5.1.4 Specifying that they have difficulty making friends and/or are isolated from others
5.2 Frequency and way of contact with ties of social network
5.3 Membership at organisation or volunteer groups (formal social networks)
CORE THEME 6. DAILY ACTIVITIES
6.1 Meeting socially with friends, neighbours or colleagues

6.2 Not meeting socially with friends, neighbours or colleagues

CORE THEME 7. DISABILITY-BASED HOMOPHILIOUS OR HETEROPHILIOUS SOCIAL NETWORKS

7.1 Majority have heterophilious social networks

7.2 Majority conceal mental health issue thus/or have not received direct rejection from the wider social network

CORE THEME 8. CHANGE OF ATTITUDES OF SOCIAL NETWORK DUE TO DISABILITY

8.1 Received negative change of attitude from others at the beginning but later others overcame it

8.2 Received negative change of attitude from others and ended relationship or avoids social contact

8.3 Received no negative attitude; because was concealing health issue or informing others from the start

CORE THEME 9. SOCIAL SUPPORT (RECEIVED AND PROVIDED)

9.1 Received social support

9.1.1 Receiving social support

9.1.2 No social support received

9.2 Provided social support

9.2.1 Provide practical support to others

9.2.2 Provide moral support to others

9.2.3 No support provided to others

CORE THEME 10. TRUST

10.1 General trust

10.1.1 Have trust in other people in general

10.1.2 Have little or no trust in other people in general

10.2 Institutional trust

CORE THEME 11. OPINION ON SPECIFIC CIVIC NORMS

11.1 Not agreeing with tax evasion, claiming government benefit that one is not entitled to or accepting a bribe during work

11.2 Neither agree or disagree for accepting a bribe or evading taxes

CORE THEME 12. POLITICAL PARTICIPATION

12.1 Voting at elections

12.1.1 Active voters

12.1.2 Non active voters

12.2 Participation at demonstration or signed a petition

12.2.1 Never participated in demonstration nor have ever signed a petition

12.2.2 Both participated in demonstration and have signed a petition

12.2.3 Signed petition but never participated in a demonstration

CORE THEME 13. EMPLOYMENT DIFFICULTY DUE TO HEALTH ISSUE

13.1 Difficulty finding or maintaining a job due to mental health issue

13.2 Not looking for a job or could not find a job due to non-health-related reasons

CORE THEME 14. BARRIERS FOR SOCIAL PARTICIPATION AND SUGGESTIONS FOR REMOVING THEM

14.1 Prejudice, stigmatisation, and/or lack of empathy received by informal and wider social network

14.2 Discrimination and/or prejudice received by formal social network

14.3 Avoiding social participation due to mental health issue per se

14.4 Never experienced any barriers for social participation due to mental health issue

14.5 Suggestions for education, campaigns, understanding, and change of mentality of wider social networks on mental health issues

14.6 Suggestions for self-confidence, self-worth and self-acceptance of mental health issue by the person experiencing it

14.7 Suggestion for more projects for enhancement of social life of persons with mental health issues

CORE THEME 15. BARRIERS FOR INDEPENDENT/AUTONOMOUS LIVING AND SUGGESTIONS FOR REMOVING THEM

15.1 Not being allowed to have a driving licence due to mental health issue and difficulty doing housework

15.2 Not being allowed to live autonomously during institutionalisation for mental health issue and problems with benefits for children

15.3 Not being allowed by family member to live alone

15.4 Difficulty finding work due to mental health issue or for financial reasons

15.5 No barriers for living autonomously

15.6 Suggestions to change the attitude of others and themselves

15.7 Suggestions for more support from the State and in employment sector.

There is a bit this… let's say such as… the rumour that if you go to the psychiatrist you are crazy or dangerous or like that, it is still a bit diffused. (…) A bit of prejudices, this is it, this I notice it a bit. Because in fact if I am feeling like avoiding to speak also about my problem a bit it is also because in fact I know that, a bit of lack of knowledge. (…) And also because in fact in general the psychiatric phenomenon, also in TV news, it is almost always associated to something that is different, dangerous, so something to keep a distance from or take it as exact, when at least for anyone who has disorders of anxiety or depressive, depends also from the depression, however in general also not, it is no problem really. Then also others, for example someone who has eating disorders it is not of any danger for…that is no danger for the others, but also then there is maybe more inclination to accept an anorexic or a bulimic than maybe… a psychiatric ill person. Then there is also whoever has prejudice that okay whoever is depressed complains only of himself, it is he who wants to feel sorry for himself, like that. Overall as I see it anyway as a complicated thing that you cannot explain with two words like... I have cancer I feel ill, and like that, a depression you are sad, so you do something that makes you happy. It is more difficult to explain but look it is an illness due to a cause, it does not come like this, or also as OCD [obsessive compulsive disorder], so... to conclude, you see that when you are more inclined to explain these things to persons that you know that they 1) can understand you a bit, 2) persons that you trust and so to a stranger, who you maybe see already that is of narrower views and you are not there to explain them, do not say anything really to them. Maybe anyway there is still this… I see it like a thing in fact complicated, that... maybe it can create fear and all the rest, but it is difficult to explain also to others to say, there is no need to be afraid or anything like that. But in fact it still makes a little "scorched earth" around there. Therefore, we say... if there was a simple way to explain it, it is welcomed, to say look do not be afraid because… and clarify it with one word only, because, one can say that it is normal to have this problem, but it is a bit reductive. Also because then the others do not believe you a lot anymore when you say to them that it is normal or other, it is common also. Therefore… there is a bit of difficulty really to explain yourself, but also for the other person to understand. Therefore it is really a thing of incomprehension between you and the other person, so you usually bypass this problem and go ahead calmly. Emily (M).

Main Area 1: The body, self and disability

Core Theme 1. Biographical experience of health issue

1.1 Age of onset

Participants at first were asked to describe the time and cause of onset of their mental distress. Half of the participants positioned the onset of their mental health issue during the period of adolescence (in line with the clinical literature), while for the rest of the participants the onset of their health issue was placed at their young adulthood (i.e. one at the age of 21, one at the age of 22, two at the age of 25, and one at the age of 28). The onset of the mental health issue in adolescence was reported by Silvia, Rachel, Amelia, Jennifer, and Elizabeth, of whom three had personality disorder.

1.2 Cause of onset

The perception of the cause of the onset of mental health issue varied among participants. It has to be stressed that here are reported the perceptions of the participants on the age and cause of the onset of their mental health issue, although psychiatrists who follow them might have positioned a different age and cause of onset; however, here are reported only the perceptions of participants on all issues explored.

1.2.1 Cause related to difficulties with social and/or intimate relationships

For one of the participants, Sylvia, with bulimia it started due to difficulties in her social relationships with peers:

> It started, I believe, a lot of time ago. I don't remember well but I think I was a teenager (…) I don't know well why but some social difficulties especially with peers... I used to have since I was a child. Sylvia (M).

Another participant, Emily, reported that she started having aggressive thoughts towards others, which after a point could not handle anymore, had hallucinations, and when she had taken badly a relationship, she started to search about it and discovered that it was OCD (obsessive compulsive disorder). As she was enrolled in the nursing school at the university, she had to interrupt her studies due to her thoughts of aggressiveness, and now tries to enter a history school, at which nothing relevant to her issue will stress her, apart that she has a bit more stress compared to her peers, but believes she can overcome it:

> Out of the blue I had some thoughts with aggressive content. I started having images of myself that were acting harmfully against others. This was causing me a lot of anguish. In the beginning these were sporadic episodes with some disturbing contents. (…) I was attending the Nursing faculty and at some point... these thoughts became so disturbing that I was not able to.. I had to leave the Faculty because anyway... a health care worker who... is afraid to touch patients not because he is afraid of them but because he is afraid to hurt them.. it was a little bit dangerous let's say because.. (...) Let's say that I had this doubt and then an assistant of internship expressed his opinion that it was better... to interrupt the studies because it would have caused me probably more problems if I continued. Emily (M).

Regarding the causes of onset of mental health issue of participants, it was discerned that one of the main causes that triggered their mental health issues were related to difficulties with social and/or intimate relationships, for participants who were of similar age (i.e. 24 and 26), students, and living with their family.

1.2.2 Cause related to family problems

As mentioned also previously, one of the participants, Mary, with schizotypal disorder, refused to disclose during the interview any information regarding her biographical experience of her health issue because it involved serious family problems. Another participant, Amelia, with recurrent depression and personality disorder, grew up in Brazil where she first had difficulties with sleep when she was in early adolescence, and 2-3 years later when she got married, she had three miscarriages, with the third one when she was three months pregnant, so after that a sign of maternity remained within her and she started experiencing hysterical pregnancy. Then she went to various doctors in Rio and in other Brazilian cities to discover what her problem was. Later on she came to Italy for vacations and when she visited a hospital in Milan she discovered she was pregnant and in danger of losing her baby again. That is when a psychologist and a gynaecologist helped her to understand that a mother should be protective of her pregnancy thus she should become more careful during pregnancy and do not be afraid of motherhood. She said she had been afraid of motherhood due to her traumatic experiences of sexual abuse by her uncle and an employer when she was in early adolescence, which made her afraid to bring a child into this world that may suffer like she did as a child. She had also discovered from her grandmother that her mother wanted to have an abortion when she was pregnant with her and then her mother abandoned her and her little brother and this ‘blocked’ her as a child too. After all that she gave birth to three children, and as her ex-husband was not supportive of her, she was working and taking care of the three children too, she separated from him while she was expecting her third child, and went to a closed community and after she went out of there she stopped taking a lot of medicines:

> When I was a girl one morning I was talking about my life like I am doing now and it seemed that it was something that had to do with mother and child relation that I did not have, but I did not have a nice coexistence, abandonment during the pregnancy with my mum she was pregnant and she wanted to have an abortion, one day by birth, had a story from my grandma, that my mum did not want me and in fact my mum did not take care of me. My mum ran away and left me, little, with my brother and so I instead of being a child became a mum of my 11 years old brother. That thing blocked me. From that point Amelia

> started life of studying that, I asked doctor he understood that let’s do one thing is there medicine for that? He said yes, you have to get psychiatric, psychological and gynaecological treatment you have to go on nice holidays to detach from this problem and let it go. (…) But inside of me I am afraid of what I experienced in my childhood terrible, no? Because I was also abused, one of my uncles abused me he did it to me, no? And that was a trauma, and from that time at 12-16 years old the employer where I worked tried to do the same thing, that I had a big trauma, no? I mixed up a little bit everything. A day which I found out that I wanted to be mother I am afraid to bring children into the world and suffer like I did. That thing blocked Amelia that I wanted a normal life. Amelia (M).

Another participant with personality disorder, Jennifer, started having the first signs when she was a girl because she was not as happy as it would have been expected for her age (at least in her view), also maybe because she was fixated with the literature and cinema with a dramatic vein, which develop the topic of existential angst, not so common for young people, and was closed to herself, so she did not have any relationship with anyone. Later on in adolescence her performance at school started to drop and due to that she felt she lost the approval of her parents, who were professors, and this changed everything and her equilibrium started to collapse. Then she started having quarrels with her father, who was also hitting her, because she was going back home late, and she believed that she disturbed the family balance and seemed to be abnormal, as she perceived it. Later on she was institutionalised, and she described the moment that her mother left her at the institution and closed the door behind as her daughter was shouting, and five people tied her to a bed. In the institution at first she was calm, but then started to receive a stricter treatment and she was crying a lot and at a point one of the nurses stopped the others from hurting her and started feeling better as she was more in need of affection than a hard treatment. After that she had a positive experience with a doctor who asked her to help the doctor with other patients and she felt a lot better and useful to others. After that she describes how she decided to go to university and study arts and her fellow students helped her open-up and see a cheerful side of her and changed her life. When asked about her friendships she also referred to intimate relationships she created during a hospital recovery, when she was not an adult yet, with other patients who according to her perception[26] took advantage of her, and before that she had been sexually

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[26] As stated previously, the statements of participants about events which have been reported in the thesis were not examined by me if they were real or fictional, but since these events might have had an impact on the participants’ social relationships and/or social participation, were reported within the thesis. However, I did not accept that everything told by participants was true and had a critical disposition on what they reported to me.

attacked by strangers, and since then she cannot have normal relationships with men or anyone else:

> Unfortunately I started when I was young, in the sense that I do not know what happened precisely, but when I was a child I think I already had the first symptoms, because I was not very much happy for my age. (...) Because my father was always more of a closed person so at this age I could not go away from home, even if I was going to the oratory [similar to a youth centre] I was not doing anything much, but he was hitting me if I returned late [at home] because I had gone to see a volleyball game. (…) Some of them [staff of the institution] in the beginning did not understand who they had in front of them and of course a girl, even if I was a big girl, separated from her mum... I saw my mum bringing me away and closing the door behind her and I screamed, I think it was normal everyone would do the same considering that I didn't know what was happening. And they took me in five and tied me up to a bed and they wanted to stick to me a syringe, I don't know, at that time I did not know what all that stuff was. (…) because things happened to me there, I was little, underage and inside there for survival I had some relationships with patients in there, that in my opinion was not very normal, and they took advantage of me I have to say… and at the end I, for what I was, I did not… I lived this thing badly… eh… now I don't want to open a parenthesis on this thing. Anyway, the fact that I suffered from these relationships, which were not relationships that I should have had at this age, you understand? (…) and so I was disgusted of this thing here inside but also outside, before being admitted to the hospital there were some detained persons who, I don't know why, were hanging out outside the oratory and they targeted me and they harassed me in a sexual way more than once and I at that time not understanding well, was not able to protect myself. In fact one guy from the oratory in one of these occasions intervened and saved me. Anyway I don't know well what happened in these periods because I was still taking medicine at that time because I wanted to cure all my fixations and I did not see clearly things, then I had hallucinations, so I don't remember what happened exactly but at the end these problems with my body are because I am not able to have normal relationships with men and even with others at the end. Jennifer (M).

Family problems were reported by three participants who did not have any similarity in terms of sociodemographic characteristics, however two of them with personality disorder had both experiences of sexual and/or physical abuse and were institutionalised for a period.

1.2.3 Exhibited after an intense period of tiredness and work or within the work environment

For one of the participants, Olivia, with bipolar disorder her health issue first started with an incident that led her to the hospital after an intense period of tiredness, work, etc. without mentioning any further details about it. For another participant, Susan, with schizoaffective disorder her problem began in her work environment when she started having problems to follow discussions with people and it was bad for her when she realised how she changes when she is feeling ill, when confronting anxiety:

> So… to me this problem started in 2011 while I was working. I started having some problems in following other people's conversations, I could not understand everything, I would get to a point where I would be lost. Then I had problems and abandoned my job because I became aware of my change and it is... even worse when you realize it because while you are not well you do not realize it, so… it passes in a different way, but if you notice the change that you say this is not me, it is not my way of doing, of behaving, of worries, of… you see them in a way.. I don't know how to explain it well to you, but it is even worse when you realize it. Susan (M).

Both participants who reported that their mental health issue was exhibited after an intense period of tiredness and work or within the work environment were unemployed at the time of the interview.

1.2.4 Undisclosed cause of onset of mental health issue

Apart from the causes mentioned above, there were other causes reported from participants which did not form any pattern, nevertheless, were considered as important for this study, so were included under a general sub-theme.

A participant with indifferent schizophrenia, Rachel, stated that her health issue first started due to anxiety, and then after some years when she came back to Italy from Germany she was diagnosed with undifferentiated schizophrenia/schizoaffective disorder. Elizabeth, who had personality disorder with symptoms of paranoia, reported that her health issue started in adolescence with anorexia and after that psychologists and psychiatrists diagnosed her with personality disorder. Finally, a participant with bipolar disorder, Lily, reported that her first signs appeared at the age of 8 but the diagnosis was made when she was 21 years old when she did a recovery from a suicide attempt at the hospital, and now she is being treated also for an eating disorder, while in the past she had also hypomania:

> So, the first symptoms I demonstrated them when I was about 8 years old, but we know this by looking backwards to say the truth, because the diagnosis arrived when I was 21 years old. So actually, in fact… I developed a series of symptoms during my pre-adolescence and adolescence, but the diagnosis came only when I was admitted to hospital for suicide attempt at the age of 21. From that moment on I am in treatment for bipolar disorder. Plus various aspects of personality that do not find a specific diagnosis, apart from

> bipolar disorder. (…) Hypomania is a euphoric state, extremely strong, in which one has ideas of grandiosity, quite serious psychotic problems, and it happened to me to have also visual hallucinations. Once I experienced even auditory [hallucinations], usually one has strong obsessions. I, for example, was obsessed with David Bowie, I was thinking of him for weeks. I was dreaming of meeting him, eating together and things like that. One is extremely active, it is typical to sleep little, to forget to eat, to start million things, and not to finish even one. It seems that one is very productive but actually is very unproductive. But the mood is at full speed. One feels very well, one is not well but feels very well. Lily (M).

No sociodemographic similarities emerged for participants under this sub-theme.

Core Theme 2. Coping mechanisms for disability and feelings of loneliness

Participants were asked about the mechanisms they have to cope with their health issue, in other words the way in which they overcome difficult moments that occur in their everyday life due to their health issue.

2.1 Going outdoors or relaxing at home and/or turning to friends or family

One of the participants, Sylvia, stated that in difficult moments she goes running or calls a friend or goes out, but sometimes she likes to stay with the pain too. Another participant, Rachel, stated that when she has a lot of stress she stops doing anything and has some rest, or when the weather is gloomy she wears colourful clothes and put on make-up or goes out with friends or alone for a walk. One of the participants, Lily, stated that she takes medication when difficult moments occur, or seeks to interact with people to understand when she is feeling too high or when she is feeling depressed, and seeks medical help:

> Me, very simply I am taking medication, I am taking aripiprazole, I am doing psychotherapy from when I was 21 years old to date, and then I have a bunch of mechanisms more or less healthy, more or less dysfunctional, in particular this moment I am in treatment for binge eating disorder, so a disorder of eating behaviour. But I also have healthy modes to deal with this thing, for example by looking to interact with people around me to understand when I am going too high above in phase up, or to realise when I am too depressed. And so... I am running for protection, in fact going to ask help from doctors. Lily (M).

One participant, Elizabeth, stated that she relies on her father for help because many of her friends do not understand her problem so they judge her or tell her that she is crazy, creating these problems herself:

> Usually I ask help for my father, he is my reference point. Because friends, a lot of friends they do not understand these problems. Some of them judge you, maybe they tell you that “you are crazy, why you are making up all these problems? Go out and have fun”. They cannot understand. Elizabeth (M).

Those who preferred to stay at home or go out with friends or alone were not married and one of the participants who turned to her father for help was not married too.

2.2 Relying on religious faith

One of the participants, Amelia, reported that she when she is feeling tired of everything she prays to God to give her courage, takes a deep breath, drinks camomile, and rests at home not doing anything else, and relies on a nurse of the CPS who has helped her in the past:

> When I feel a mum almost every day destroyed and think about life, tired of everything, I want to escape from this world, this is what I really feel, and then I start praying because I am a woman with faith and I ask God to give me strength, give me courage because I came out of tunnel and you existed, there is the world, me, and today if I have to face anything, I have to do it for my children. Amelia (M).

Another participant, Jennifer, reported that she turned to medication and psychotherapy, but also to religious faith when difficult moments occurred, such as depression. In addition, when she was Catholic she used to have more friends compared to now that she changed her faith to Buddhism, however her new faith helps her a lot to believe in herself and that things depend on her, even in relation to her health issue:

> Now, it depends a lot on the events that happen, but my resources I must say were not only medication, psychotherapy first, but also the intervention of Faith, because before this I used to be a catholic, I had a lot of friends, now I have a little bit less friends but recently I’ve changed my Faith, but this Faith helps me a lot because I became Buddhist. I want to say this because it is a little bit particular, and this thing gave me... there is no God there, it is a faith a little bit different, you have to believe in yourself, so at the end you find yourself in front of you on this, but with help of discipline which anyway helps you. Jennifer (M).

There was a third participant, Susan, who also reported turning to religious faith when she confronted difficult moments due to her health issue.

We can notice here that these three participants chose to turn to their faith for help for overcoming difficult moments, although none of them was living alone. Also, the two participants with personality disorder appear to have another similar experience/reaction regarding coping with their mental health issue through religion.

2.3 Reading or writing or waiting passively for difficult moment to pass

One participant, Mary, said that she confronts her health issue by studying for her medical school and writing poetry. Another participant, Olivia, tackles her health issue by trying to distract herself from negative thoughts, for example by reading something. On the other hand, Emily stated that she does not fight her health issue anymore and tackles it in a passive manner, meaning that she waits for the thought of aggressiveness to pass:

> Let’s say now I let them go a little bit more, I have some mechanisms let’s say of reflection that could… oppose to this, but... instead of saying no, and becoming rigid, having some defensive thoughts like “no you would never do that, you are a good person” and so on... Normally I settle as in a passive mode, and then I let my thoughts flow a bit until they are over and then I go ahead. Maybe after that I feel a little bit more sad or afraid but I try not to oppose to it anymore. Emily (M).

No sociodemographic similarities emerged for participants under this theme.

2.4 Tackling loneliness mainly with support of friends or other distractions indoors

The majority of participants reported that when they were feeling lonely they tried to tackle loneliness by calling a friend, going outdoors for a walk with friends, their children or alone, or staying indoors and taking medication, crying, reading or watching something, listening to music, eating, or just trying to relax:

> Usually I eat and it is not very good, I am not at ease with solitude, when I am more functional usually I go out and go looking for someone. At moments in which I am less functional and I realise that I could do harm myself, sometimes I take medication and I go to bed. Lily (M).

No sociodemographic similarities emerged for participants under this theme.

2.5 Loneliness as not necessarily a negative state

The participants who confronted loneliness as not necessarily a negative state, Emily, Olivia, and Rachel, stated that sometimes they might seek solitude when they have an emotional problem, or when they feel really low try to distract themselves by reading or calling someone to share their problem, but they also simply liked doing their things on their own although they liked being in company of others, but do not mind being alone either:

> It depends because I am a type of person who, let's say, when feels bad emotionally looks for solitude, if I am feeling lonely let's say... because at that moment I am really not [alone] or maybe I feel left alone or isolated because of something, I try a bit to control it [loneliness] as I can. If I am physically lonely, I try to call someone, if I feel lonely because of a problem I try to share it, if.. I feel lonely for other reasons, I look for other solutions. In general I try a bit to control it f it is a solitude that I wasn't looking for and it bothers me or makes me suffer. Emily (M).

> I don't have moments of solitude [laughs]. I feel well in solitude. (…) Let's say that if I had to lose my parents, I would feel very lonely, that yes. But I am surrounded by a network of friends who stand by me and support me, I think... I could make it but it is important to see with time. Now I feel stronger so to some point I like solitude, I like to be with my own things, do things on my own, at times I like it and at times I would like to have some company, but I don't feel bad when I am alone. Rachel (M).

No sociodemographic similarities emerged for participants under this theme.

Core Theme 3. Perceived gender differences based on health issue

3.1 Never encountered man with same health issue or no perceived gender differences

To the topic of whether there are any differences on how women and men confront similar mental health issues, it was reported that half of the respondents met no man with a similar mental health issue, or met one but did not have the exact same problem so there was no comparison:

> Yes [I met a man with mental health issue] but he did not have the same problem as mine, we both had problems... but it is not nice to say that it seemed to me... it was a problem a little bit different. So I think the comparison is limited here. Susan (M).

No sociodemographic similarities emerged for participants under this sub-theme.

3.2 Reported perceived gender differences

The other half respondents had met a man with a similar mental health issue and they reported that they noticed that men are more embarrassed to say to friends that they are ill and to speak about their mental health issue to others and that they are more aggressive, compared to women who communicate their problems more, cry, and are more self-destructive in terms of confronting their mental health issue:

> Yes, I think that they are a lot fewer the men who have this problem, but it is what I think, I don't know it. No, I think that it is more or less the same thing, but I don't know.. I believe that it is more or less equal. Maybe in men it is a little bit more... evident, the character of shame a bit, ok. Maybe there is more shyness because for a girl... it is more normal to see a girl who is a bit shyer than a boy who is a bit shyer. Sylvia (M).

> I have noticed that females are more auto-destructive whereas men tend to be more aggressive on the outside, but this is not always true, eh.. it depends a lot on the person, and on each person's experience in conclusion. Lily (M).

Two of the respondents who reported gender differences were cohabitating with a partner who had a similar mental health issue to theirs.

Core Theme 4. Expectations about the future at individual level

As a final topic during interviews, it was asked to participants how they see themselves in the next ten years, whether at personal and/or professional level. It was considered useful to ask this to participants in order to explore indirectly any potential issues in terms of their current social relationships and/or social participation roles, or even in relation to their mental health.

4.1 To recover from mental health issue or remain in good health

Four of the participants mentioned health in their projections for the future, and the three of them referred specifically that they hope to have overcome their mental health issue, and one mentioned reducing medication and psychotherapy, along with personal and professional expectations for the future, such as getting married or having a partner, having children, and/or more stability and a job:

> I am trying to have some trust in future, so I hope to feel better because anyway I have changed a lot in these years, I have improved a lot and hope that this continues, so in few years I hope, for example, to be able to reduce a lot of medication, maybe not take them for some periods of time, or to reduce psychotherapy. I hope to find a job that allows me to live autonomously and to take care of myself without asking anything from my parents in conclusion. I hope to marry my boyfriend and to have a child. Lily (M).

No sociodemographic similarities emerged for participants under this sub-theme.

4.2 Positive thinking about the future; without mentioning health issue

Similarly, there were other participants who also had positive thoughts about their future, but did not mention their health *per se*. They mainly mentioned that in the future hope to have a child, to continue or find a new job, to have a partner, to have friends, for her children to be well and get a diploma:

> Hm... 10 years? Oh... I don’t know. We will see... Now we are expecting a child and everything changes, then... after a couple of years we will think about work, but now no, I already work enough at home to do anything else and be behind everyone and enough… but yes... let’s say that I already have my job, now a little bit because in winter they do not take care of themselves [laughs]. Olivia (M).

> I wish... ok, I will graduate I think anyway and then I will decide if I will do the doctor or no. I’ll see. But anyway I will try to find a job with the degree in medicine, and then sincerely I don’t know how I see myself... I hope to have a boyfriend and some friends. Mary (M).

No sociodemographic similarities emerged for participants under this sub-theme.

4.3 Negative thinking about the future

Contrary to the participants above who reported having a projection in the future for themselves that was positive, there was one participant, Emily, who stated having negative thoughts about her future. This participant stated that she has difficulty imagining her future for more than the next two or three years, because currently has no solid base to say what she will be doing in 10 years, so can only think of it in a negative way and prefers not to programme anything:

> I don't have solid grounds to say that in 10 years I will surely be this or that. I can think about it but in a negative way. Because in a negative way is much easier, and since I don't want to neglect myself or make thoughts of that kind, I prefer to make no plans. Emily (M).

As it emerged, Emily, who had OCD, was the deviant case under this theme, since she was the only one among participants with mental disability reporting that she has negative thoughts about her future, although she was cohabitating with her partner and her family and stated that she is coping with her mental health issue by trying to let negative thoughts pass.

Main tendencies of Main Area 1: The body, self and disability

From the biographical experiences of participants regarding the **time and cause of onset** of their health issue – as they perceived it –, it can be discerned that the majority experienced the onset during adolescence. As it has been argued elsewhere (Georgaca & Zissi, 2017), there has been increasing evidence regarding the association between childhood traumatic experiences and emergence of psychotic disorders, with traumatic experiences including abuse and neglect, as well as family disorganisation and conflict, separation from parents, and experiences of disorganized attachment, issues which were reported by some of the participants of this study too. Moreover, there have been studies showing that early childhood trauma increases the risk for positive psychotic symptoms, and there is an association between child sexual abuse and subsequent increase in rates of childhood and adult mental disorders, as well as a large association between childhood sexual abuse and psychosis, which may be a causal association, and symptoms of psychosis and schizophrenia, particularly hallucinations, are related to childhood abuse and neglect, as many other mental health problems too, while more exposure to childhood trauma in terms of physical and sexual abuse and domestic violence, has been found among a community sample of adolescents reporting psychotic experiences (Janssen, et al., 2004) (Spataro, Mullen, Burgess, Wells, & Moss, 2004) (Bebbington, et al., 2011) (Read, van Os, Morrison, & Ross, 2005) (Kelleher, et al., 2015). Another similarity noted among participants within this core theme was that both participants with schizoaffective disorder referred to experiences of anxiety, as well as the participant with OCD. It has been shown that there is an increased prevalence of anxiety disorders, including OCD, among patients with schizophrenia in comparison to the general population, with the majority of studies showing an increased rate of both obsessive-compulsive symptoms and OCD in schizophrenia (Buckley, Miller, Lehrer, & Castle, 2009). Thus, there appears to be an established connection between persons with schizophrenia, OCD and anxiety.

As it has emerged from this thesis, the most commonly reported **causes of onset** for mental disability were related to difficulties with social and/or intimate relationships, family problems, or exhibited after an intense period of tiredness and work or within the work environment. These findings are in line with a previous Italian study on persons with schizophrenia (Magliano, et al., 2009), according to which 150 out of 198 respondents perceived at least one social cause for their mental disorder, while 114 reported exclusively social causes. These social causes included family conflicts (21%), followed by traumas (20%), work and study difficulties (17%), and psychological disturbances (17%), while biological causes were more frequently reported by participants who were aware of their diagnosis of schizophrenia, whereas social causes by those who knew that they suffered from a psychosis (Magliano, et al., 2009). In addition, the same study found that difficulties in social relationships were more frequently pointed out by respondents with an earlier onset of the illness and a higher number of compulsory admissions in the past 12 months (Magliano, et al., 2009). Thus, both this evidence and the findings of this study highlight the decisive role of social relationships as perceived by persons with psychosis being the causes of their mental health issue.

Based on the findings above, participants had various **mechanisms for confronting difficult moments** due to their mental health issue. Participants were going outdoors or relaxing at home or turning to friends and family, relied on religious faith, or were reading or writing or waiting passively for the difficult moment to pass. One participant, who had personality disorder with symptoms of paranoia, stated that she turns to her father more in difficult times because many of her friends do not understand and judge her for her mental health issue, saying that she is ‘crazy’ and she is creating these problems to herself. Stigma from friends and receiving judgement has emerged also in another study, where it was noted also that persons with psychosis would not share their mental health issue with friends who would not understand them (Wood, Burke, Byrne, Pyle, Chapman, & Morrison, 2015). There was one more participant who preferred to remain calm and stay at home too, but the first thing she stated she was doing was to turn to God for help, as well as two more participants, who also turned to their faith in difficult moments. Other introvert ways to tackle their health issue were also reported by participants, who read, wrote, or preferred not to do anything and wait for the difficult moment to pass. Regarding the finding on using religion as a coping mechanism for mental health issue, it has been stated by a review of studies (Koenig, 2009), research around the world shows that religious coping is widespread, and also psychiatric patients use frequently religion for coping, probably because *"religious beliefs provide a sense of meaning and purpose during difficult life circumstances that assist with psychological integration"* (p. 285) and regarding religion's beneficial impact on persons with psychotic disorders it has been argued that *"while religious delusions may be common among people with psychotic disorders, healthy normative religious beliefs and practices appear to be stabilizing and may reduce the tremendous isolation, fear, and loss of control that those with psychosis experience."* (Koenig, 2009, p. 289).

Regarding **feelings of loneliness**, the majority of participants reported that they tackle moments of loneliness with various mechanisms, most commonly trying to distract themselves from negative thoughts by calling a friend and/or going out with friends, with their children or staying alone whether outdoors for a walk or indoors, crying, eating or reading something. There were also participants who stated that they were feeling comfortable being alone, but when it is an unwanted loneliness or have negative thoughts, then they also try reaching out to a friend or family member. It has been argued that whereas social isolation can be measured objectively, loneliness is a subjective emotional state of each person, in the sense that it might be present in persons with large social networks, and absent in persons who are isolated and have minimal social contact (Michalska da Rocha, Rhodes, Vasilopoulou, & Hutton, 2018). Therefore, we should not assume that loneliness is a negative state *per se,* since it depends on the perception of the individual experiencing it, as also found in this thesis, where some of the participants were comfortable with or seeking moments of loneliness. A recent meta-analysis of studies on loneliness in psychosis (Michalska da Rocha, Rhodes, Vasilopoulou, & Hutton, 2018) found that there is significant relationship between loneliness and symptoms of psychosis in persons with psychosis, therefore loneliness, as a common feature in psychosis, should be considered also in treatment planning. Based on the same source, some of the studies suggest that loneliness mediates the development and precedes the onset of psychotic symptoms, but on the other hand, there are other studies suggesting that loneliness might be secondary to psychotic experiences and resulting from the mental health condition (Michalska da Rocha, Rhodes, Vasilopoulou, & Hutton, 2018). Some of the participants also mentioned the fact that they seek to relax when they have negative thoughts due to loneliness, and one of them remarked that Milan is a city that everything is fast and one is continuously under stress. This is in accordance with previous findings suggesting that cities possibly foster stress, cognitive and sensory overload, along with other issues, and may change people into becoming less happy (Okulicz-Kozaryn & Mazelis, 2018).

Regarding **gender differences** based on the mental health issue, as perceived by the participants, half of the participants reported that they had never met any man with a similar health issue before, thus could not compare their experiences, while the other half of the respondents reported that they had met a man with a similar mental health issue. The perceived gender differences were mostly related to men’s feelings of embarrassment due to health issue and aggressiveness as a coping mechanism to confront health issue. A respondent also reported that it is considered more ‘normal’ to see a woman who is timid, than a man, indicating a stereotype of the man being considered as less vulnerable than women. As stated previously, there has been limited evidence up to date regarding the impact of feelings of shame and embarrassment on social relationships of persons with chronic illnesses (Soleimani, Negarandeh, Bastani, & Greysen, 2014), however, as it emerged here, there are men who hide their mental health issue because they feel embarrassed about it. This feeling of embarrassment or shame due to mental health issue could be possibly the same reason also for women hiding their health issue from their interpersonal social networks and/or employers, as it has emerged also in other themes of this thesis. This assumption is compatible with a recent literature review (Wood, Burke, Byrne, Pyle, Chapman, & Morrison, 2015), according to which, in all the included studies it was reported that service-users experienced feelings of shame and secrecy associated with psychosis. This has been confirmed in multiple themes of this thesis, showing that hiding mental health issue represents clearly a pattern and a feature of social relationships of women with psychosis, at least in reference to the participants of this study.

Based on the **expectations for the future** as reported by participants, regarding their personal and/or professional life, it appeared that the vast majority of them had positive expectations for the future, whereas only one participant, with OCD, had negative thoughts when thinking about her future, possibly due to her elevated anxiety for living on her own due to her mental health issue, as she had stated in a previous topic. Relevantly, a study comparing social functioning and quality of life of patients with schizophrenia versus patients with OCD, concluded that OCD patients had lower quality of life, possibly indicating elevated functional impairment along with deep suffering particularly for this population (Bystritsky, et al., 2001). The positive expectations of participants revolved mostly around having a child and/or getting married or cohabitating with their partner (without anyone else), and/or having a new job or changing their current one, whereas two of the participants did not mention anything about intimate relationships or having a child, with one of them stating that she does not want to have a child due to her mental health issue, although both of them were cohabitating with a partner. All participants mentioned employment among their expectations for the future, however, the participant who had negative thoughts about her future did not have any plans about work, given that due to her mental health issue she had to drop out of nursing school, as was explained in detail under a previous theme. The lack of friends also emerged for one participant, with schizotypal disorder, who hoped in the future to have friends; a desire which was not mentioned by any other participant, showing that she was possibly feeling isolated and did not have any friends, although she wanted to. Finally, only one of the participants expected for the future something which was not only personal, that Italy as a country would improve and assist more people living in it. This core theme revealed issues related to person-centered elements of recovery, which are mainly associated with the personal motivations, in the sense of hope and self-determination towards one’s own goals in life (Onken, Craig, Ridgway, Ralph, & Cook, 2007). Hope is critical for the recovery of someone having a psychiatric disability in order to move away from despair about life situations towards hoping for a better future, thus establishments of specific hopes and aspirations have been argued to be the first step in the recovery process (Onken, Craig, Ridgway, Ralph, & Cook, 2007). As participants of this study showed, the vast majority of them were hopeful for the process of their recovery and for their personal and professional life in the future, having a husband/partner, becoming a mother or have another baby, a job that fulfils them, living independently, having friends, and overcoming their mental health issue. Therefore, apart from hope, there is also evident the importance of being able to achieve goals, live among and interact with others, not being isolated from others, participate socially in the community and reintegrate in it, and in this manner one’s close social network and the wider community become important resources in the recovery process (Onken, Craig, Ridgway, Ralph, & Cook, 2007).

Main Area 2: Social relationships, social participation and disability

Core Theme 5. Social networks (structural aspects)

5.1 About size of social network and type of relationship

To the question about the persons that participants were feeling closer to (i.e. closer social network) at the time of the interview, other participants were more general in their descriptions, while others more specific, and not all of them stated a specific number, but simply the names and/or type of relationship they have with these persons or groups of persons they were feeling closed to.

5.1.1 Size of social network

The size of social network varied among participants. From those that did mention a number regarding the size of their social network, the highest network size reported was about ten people. The type of relationship also varied, some included family in their social network while others did not, and mostly referred to persons who knew about their health issue as persons who they feel close to.

Based on the responses of participants who were more specific about the number of ties included in their close social network, it emerged that the smallest size of close social network was reported by Amelia, Jennifer and Mary who had none to three social ties each; two of them with personality disorder, and one with schizotypal disorder and all three of them being older than 33. As it emerged also from another sub-theme here, the same three participants had stated that they were experiencing isolation and/or problems in socialisation, for example due to their difficulty trusting others, but expressed that they would like to have more friends. On the other hand, Lily, Emily and Rachel had the largest close social network as they mentioned having more than seven ties each; with the common sociodemographic characteristic that all three of them were never married.

5.1.2 Social network including family and/or friends and/or health professionals

There were participants who stated that the persons they were feeling closed to were family members, or colleagues from university, or friends they have made in high school, or from the neighbourhood, or that they met at the CPS, or through other friends, or health professionals:

> So I have friends from the university, and then I have… in my family we are six, so… I have relationships with them in the sense that I live with them. But especially, yes, friendships especially from the university, I would say like that (…) I have some friends from the neighbourhood, from here, maybe... I have some friends since high school, friends from neighbourhood that I see more in the evening, like that, with whom I am more like that. Sylvia (M).

No sociodemographic similarities emerged for participants under this sub-theme.

5.1.3 Specifying that their social network consists of persons who know about their mental health issue

There were also participants, Olivia, Lily and Elizabeth, who specified that the persons they were feeling closed to – again being family members, friends, colleagues, or know each other since childhood – all of them know about their health issue. Thus they mentioned only people that they were feeling closer because these people knew about their health issue, or disclosed their health issue only to the people that they were feeling closer, since, as one of the participants stated, there are people to whom you can and those you cannot disclose your health issue because they judge you:

> My mum and my daughter, but nobody else knows. (…) my friends maybe we do not meet often but we remain in touch. (…) I have one friend that I met at work, for example, she is also a beautician, etc., then the others gradually like this, acquaintances that maybe have remained through the years. Olivia (M).

> Certainly I have my family that supports me quite a lot even if it is a little bit difficult to accept all this, in particular I have my mother because my father died when I was too little, so... the husband of my mother is not very supportive, but my mother is. I have a boyfriend with whom we do not cohabitate but we have a plan to start cohabiting, he is very supportive in all that and then I have some close friends. They are few the friends who actually know about my diagnosis, they are 5 or 6, no, 6. The others, ok, I have a lot of friends but not so close friends to whom I prefer not to tell them about this thing because I keep it quite private. (…) I think including my family about 10 people. Lily (M).

No sociodemographic similarities emerged for participants under this sub-theme.

5.1.4 Specifying that they have difficulty making friends and/or are isolated from others

Some of the participants had very few friends or only God and/or stated that they have difficulty making friends, either because of the health issue or the anxiety of whether others will like her or due to lack of trust towards others or feelings of isolation:

Yes, I have some friends, I have my friends with whom I maintain social networks, quite good, in general, I find it a bit difficult to make friends, actually… I find it a lot difficult to make friends because... not so much because of introversion but... always a bit because of the OCD, that... when I have aggressive thoughts... or a bit of pathological doubts that... but they will like me or not, see they don't like me, it is better not to… and like that... relationships make me very anxious, usually I try to keep them more… the friendships that I have, and to be more difficult for me when I am making a new friendship. Emily (M).

As I have said before... no... I cannot say now that it is a lie, I am not into friendship, because trust for me was a big challenge, it [trust] is little. I am friends with God and me and that's it (…) Joanna [a nurse of the CPS] was the only person that I can say that… she is not a friend, she is a nurse but I rely on her as if she was a second mother that I did not have in my life. (…) I have one sister here, a lot of acquaintances, a lot of fellow country people, but with all that, which I have experienced, if I tell you that I have a friend it would be a lie. Amelia (M).

Yes... hmm... family members but... I have some friends as reference points maybe for example there is one friend... and some professors of the Faculty, that anyway I completed the internship, I did surgery there at the hospital, and I am still in touch with them. But anyway now, as now, I am a little bit... let's say a little bit isolated from others. (…) So this friend it is a friend that… (…) he is a talent scout, he practically found me and helped me develop in writing, and… he always helps me, so… he is a lot older than me but always helps me, there is no relationship… apart from friendship there is nothing else, I want to specify this. Mary (M).

One of the participants, Jennifer, stated she had difficulty making friends who were women and of her age or younger, because usually had older women as friends, in a way substituting the mother figure for her, so now has only her boyfriend and a woman of older age who consults her as her faith tutor:

However my peer friends they disappear, I mean those younger, I am not good at having normal relationships with a woman younger than me or of my age (…) the only relationships that I have are always with women who are much older than me and who act as if they are my mother. At the end this is a problem, I have some valuable relationships, but not with people of my age, so in the sense that with people who are as surrogate of what there should have been, but it is not a relationship... I don't have relationships

> of a certain level with girlfriends of my age (…) I would say two or three close friendships and then 10 or 20 acquaintances, and then, ok, many I know them for ok... it is not that I go out with them, I don’t know they are a bit like this... for example, also those from my work as an actress, then I also have fans. Jennifer (M).

Again, the three participants who reported having the smallest close social networks, also reported having difficulty making friends or being isolated from others, with one more participant, Emily, who reported having many ties in her close social network, however, stated here that she has difficulty making friends.

5.2 Frequency and way of contact with ties of social network

The frequency of contact with the ties of social network varied among participants, and even among friends of each participant, since they reported having more frequent contact with some of their friends while with others less often, which is a common feature of social relationships for any person. In general, the frequency of contact of participants with the persons they are feeling closer ranged from every day to once a month or less often. Regarding way of contact with ties of the social network, participant reported mostly that preferred face to face meetings, but also through mobile texting application (i.e. WhatsApp) or telephone:

> Every day, I mean I go every day. I talk to them more or less every day. (…) WhatsApp and... it depends usually face to face in the sense that we study together, we go to the lectures together, but I think it is due to the historical moment that I am living right now, I mean that I am going to university and there I meet them and do the same things. (…) More in person, but I use WhatsApp a lot. (...) Sometimes I am able to say things better on WhatsApp than in person. Sylvia (M).

> Every three days, anyway we try to meet as often as possible, once a week, or maybe twice, it depends on how things are. It is not a fixed appointment, whereas maybe we talk every two-three days on WhatsApp or on the phone. Emily (M).

One of the participants, Lily, stated that she meets her friends once a week but avoids calling them during the week because she thinks that her friends will become distant from her if she burdens them too much with her issues:

> Very little, I see my friends every Saturday evening, and apart from Saturday evening I tend to call them once a month, once every two months, regarding my problems I try not to burden on others because I have the sensation that they might distance themselves from me if I put too much burden on them. Lily (M).

No sociodemographic similarities emerged for participants under this theme.

5.3 Membership at organisation or volunteer groups (formal social networks)

Regarding membership at organised or volunteer groups, the vast majority of participants reported that they were not members of any group currently. Four participants, Sylvia, Amelia, Lily and Jennifer, reported that they were members of a group, at the time of the interview, one at a group of university students helping children with homework, one at a religious group and a political group helping someone she knows, one is a member of a political party, and another one was a member of a religious group too:

> And being also in a political party, if I like the candidate I give him a hand with his electoral campaign, but I am very sincere about this, I do not give a hand to all candidates, because I prefer to give a hand to the people that I believe in. Lily (M).

> It is called Soka Gakkai, that of my faith, I don’t know if you know it, and the group of Nichiren… how is called... there is a temple outside Milano. Jennifer (M).

The two participants who belonged to religious groups, both had personality disorder, were working, while facing various similar difficulties in terms of interpersonal relationships, such as both having only one or no friends and been victims of sexual abuse at a young age.

Core Theme 6. Daily activities

Participants were asked to state their usual daily activities, in order to explore aspects of their social participation, particularly regarding meetings with their social networks.

6.1 Meeting socially with friends, neighbours or colleagues

Four of the participants, Sylvia, Lily, Susan, and Elizabeth, mentioned that they meet socially with colleagues or friends for lunch, in the afternoon, or in the evening, while the rest of the day they are working or studying or go to hospital for recovery sessions for mental health issue, go to meeting with political party for electoral campaign, travel to see friends during weekends, go shopping, and other common activities at home such as cooking or cleaning the house:

> Ok, I wake up late because I don’t want to wake up, then I have breakfast, then it depends, now my mum has closed the kitchen with a key so I don’t do that anymore. And... I go, come here to take the medication, then I go to the university, I study, then I get a bit anxious about lunch and about with whom I will have lunch and such, I find a friend who has lunch, I don’t have lunch, but I sit with her. Then I stay at university to study or sometimes I have to go to do sports or help schoolchildren with homework, it depends, the afternoon is a bit like that. In the evening I return home and then it depends or I study in the evening or maybe I meet with my friends from the neighbourhood. If not, I stay out with a friend, it is a little bit monotonous but it is like this. Sylvia (M).

Participants who reported meeting socially with friends or colleagues, as part of their daily activities, were young (less than 32 years old) and not married.

6.2 Not meeting socially with friends, neighbours or colleagues

The rest of the participants did not mention meeting with friends socially as a routine in their daily activities, but apart from going to work or the university, they were mainly doing indoor activities alone, such as drawing, reading, studying, writing poetry, doing bureaucratic procedures, cooking, taking care of children, having a rest, watching television or surfing through the internet:

> I in my day, sometimes in the morning I go out early bring my daughter to school at 8.30, then I go and start taking the tram or bus, I go to do my work, my work starts like this, my office could be in municipality like tomorrow morning, I leave my daughter and go to the municipality to insert the paperwork of some clients that I am making their citizenship, then I leave from the municipality and go to do the police, I have to do check that they are in Italy arrived from Brazil, hospitality, I finish from there then I go to the consulate of Brazil I bring the documents for recognition, from there I stop for lunch at about 1pm or 2pm, I eat something and then I return to the [work] day. I go to one person who calls me for an interview always based on documents, always the same thing or for the residency permit that I have to fill in the kit, then I go to the post office I take the kit and I fill it in and... I go home at 5.30-6.00pm I take care of preparing supper for my children and I sit with my children during supper and then after I start working again on the phone until the midnight (…) it takes me more or less till midnight to work on that. The other days like that. Amelia (M).

> So... so... now I have to start doing again the surgery so my typical day will be completely different. Anyway now I get up, do the shopping, maybe check what is missing at home, I study and then I go to bed. (…) Basically now when I have free time I write. I write or I don't know, I go to see an art-exhibition. (…) I write poems and then I write... hm.. I have written for online magazines, so they are online, but then I write for an online magazine so I have to go to see the art-exhibition and then to write an article. And nothing, I do that, so for now I am doing that. (…) I am writing and going to art-exhibitions. Mary (M).

No sociodemographic similarities emerged for participants under this theme.

Core Theme 7. Disability-based homophilious or heterophilious social networks

7.1 Majority have heterophilious social networks

Participants were asked to whether the persons they feel closed to have a mental health issue as well, otherwise referred to as homophilious social network. Based on their responses it emerged that six of the participants did not have anyone in their closer social networks that also had a mental health issue (heterophilious social networks), although some of them suspected someone from the social network might have, or had acquaintances with a mental health issue but outside their closer social network. One of the participants, Amelia, did not have any friends so she was not asked this question, two reported that some of their friends or partner had a mental health issue too, and only one of the participants, Rachel, stated that all ties of her social network had a mental health issue as well:

> Yes, yes [all persons with whom she feels close to have a mental health issue as well]. (…) Yes, they have something, but not at my level, slightly less. Rachel (M).

> One very dear I met her when I was admitted to hospital and she has more or less the same problems as mine. (…) and another one who works with me. Elizabeth (M).

> I think no, but my friend, something that I have understood from hearing her, one she has a husband who is a little bit depressed, then also her daughter has some problems, but I don't know what they have. So anyway you can understand that there is something, that they have faced something. Maybe that time after giving birth, after giving birth. There was something, but we have never discussed it in depth, we have never specified, if one doesn't want to speak, does not… (…) no, the others [her other friends] no. Olivia (M).

Thus, as it emerged, the deviant case under this theme is Rachel, with indifferent schizophrenia/ schizoaffective disorder, who was the only participant to have reported that all the ties of her close social network had a mental health issue as well.

7.2 Majority conceal mental health issue thus/or have not received direct rejection from the wider social network

Participants were also asked if they ever received rejection when they attempted to connect with persons of their wider social network. The vast majority of the participants reported that they were never told explicitly that others did not want to be friends with them due to their health issue, or for any other reason, and some of them stated that they avoid telling other people about their health issue, since it is not visible when they meet someone:

> No [rejection from others due to health issue], this one no, if you don't mention this issue to others they don't realize, maybe they cannot understand the moments of crisis, but anyway when I have these crises I don't show myself so… It has never happened to me to be told "I don't want to go out with you anymore because you have problems". Because if I don't tell you about it, you won't figure it out. At least I hope so. Elizabeth (M).

> So I don't say it often, also because maybe it is not something visible, I mean, I imagine on others… hm.. I believe that maybe one figures it out when we go out maybe to do something, to eat, to do things, maybe one figures it out if I have... if I have difficulty…I don't believe that... but this way no, it has never happened to me that one maybe would be looking at me as if I am strange, yes, but not that would tell me "no, I don't want to be…" in my face never. Sylvia (M).

One of the participants, Amelia, stated that she had problems connecting with others, since they did not invite her to do things together with her, but did not specify if it was due to her mental health issue or for other reasons. On the other hand, another participant, Jennifer, stated that she was not aware whether others did not want to become friends with her, because she was always informing them from the beginning of a relationship about her health issue. Then, although I asked her about trying to make friendships with others, she started talking about her experiences with various past intimate relationships she had, which indicated possibly an inner need to speak to someone about these issues, or a tendency to turn discussion around these intimate issues:

> So this thing I don’t know, let’s say I don’t know if they did not want to... I don’t know that, the fact is that I had relationships in the past. Apart of having been always honest, because before starting a new relationship with anyone I have always told them about my problem, it is like they almost do not believe it [laughs], but I have always said it. Because I was afraid of it being discovered later on. And so I was always quite correct telling that I am like this and this, try to understand me, like that. Then in the past I had relationships which were a bot long with other people but I have to say that these relationships were a bit weird, because apart that artists are a separate world, I had two relationships a little bit long with two artists who changed a little bit this thing. Jennifer (M).

No sociodemographic similarities emerged for participants under this theme.

Core Theme 8. Change of attitudes of social network due to disability

It was asked from participants to state whether they have experienced any change of attitudes from their social network after they discovered about their mental health issue.

8.1 Received negative change of attitude from others at the beginning but later others overcame it

Two participants, Emily and Rachel, stated that at the beginning their social relationships had a negative attitude towards them due to their mental health issue, such as being scared, but later their social relationships overcame it.

> Let’s say that when I had this problem some of my friends got a little bit, how to say it, afraid, then later on there was a phase that they had... overcome [this problem]. Emily (M).

No sociodemographic similarities emerged for participants under this theme.

8.2 Received negative change of attitude from others and ended relationship or avoids social contact

Half of the respondents experienced a change of attitude from others regarding their health issue, which was negative and then these relationships ended. In specific, one participant, Lily, reported that her ex-partner left the country for three weeks when he found out about her health issue and then came back insulting her, while his mother was telling him to leave her because of her mental health issue, and then another ex-partner of hers had dysfunctional attitude after she experience an incident of depression and left her for another woman. Another participant, Mary, reported that she found out that some of her close friends were talking badly about her behind her back, one other participant stated that she became distant to friends who were not standing by her in difficult moments, and two participants kept distance from others on purpose, to avoid difficult moments due to their health issue:

> Yes, in the sense that it was my ex [boyfriend] who... when I was feeling bad... he ran away for three weeks, he actually went to another part of Europe in the moment while I had been admitted to hospital and then he came back insulting me a lot. The mother of this ex [boyfriend] told him to break up with me because couldn't stay with a person with this illness and then actually when I started feeling well, paradoxically he left me in the moment when I was better because he was convinced that I have changed irretrievably and didn't suit him anymore. Another ex [boyfriend] knew about my illness but probably he took it too lightly and so actually also in that case when I felt bad, this time it was a depression, I don't know, he took it in a very bad way, he started having as well very dysfunctional behaviours, he lost a lot of weight, he started using drugs, and then he left me for a girl who was more beautiful, thinner and of course healthier. Lily (M).

> Yes, and then I had... hm... I endured also meanness from people who were... some friends who were close to me that I told also here to Dr. Marvin [doctor at the CPS], real and objective things, not invented or paranoias, things like this (…) Yes, yes, the last one that I discovered then was that a person was talking about me to others and to me this person said that others were talking about me. Mary (M).

Those three that stated that they no longer have any contact with people who had a negative change of attitude towards them, due to their mental health issue, were all living with their family and had never been married.

8.3 Received no negative attitude; because was concealing health issue or informing others from the start

Two of the participants, Jennifer and Olivia, stated that they received no negative attitude because they either concealed their mental health issue from the people close to them, or the opposite, always said to others from the start that they have a mental health issue.

> No... but because I've never explained anything to anyone, so it would be impossible to encounter something like that. But yes, it could happen that they [other people] would become distant, I think yes, it could be because people are stupid. And ignorant more than anything else. Olivia (M).

> In my case it is more difficult because it is not that they did not know it in advance, etc. I started like this and it has developed like this, but I have to say that in my case it was always a source of richness and not only of disadvantage, because maybe I am a kind of person who is disadvantaged but intelligent, no doubt about it, so I have never allowed others to marginalize this, in the sense that... because I think it is important how you deal with this and not only how others deal with this (…) I must say that I had the balls anyway to... from a certain point and on to accept it, so anyway to say that this thing should not disturb me a lot anymore, I am like this and that's it. So or no or yes or that, I am like this and I cannot change immediately so at the end I didn't even know that it was possible to recover a little bit from it, so I decided to accept this situation. So those who stayed, fine, those who didn't stay... Jennifer (M).

The two respondents who reported never having experienced any change of attitude from others towards them due to their mental health issue were older than 38 (i.e. 38 and 44) and living with their partner or husband.

Core Theme 9. Social support (received and provided)

9.1 Received social support

9.1.1 Receiving social support

When participants were asked if and from whom they were receiving social support regarding their mental health issue, the majority of them responded that they receive support from health professionals or care worker, especially in difficult times, and for less serious issues from friends or their partner:

> Yes, I have the psychiatrist and my psychologist more than anyone. With friends maybe I have to do it [to rely for support on them] more with regard to relationships, I have problems with my boyfriend, I have problems with this other friend, I have some problems with my mum or my father, but of the kind of not serious ones, related to misunderstandings, I try to not put burden on them too much with my emotional problems, it can happen... but I try to avoid it. Emily (M).

> I have to say this, I am... this thing that in the beginning yes a lot... in the sense that I had a lot of support from this ASL [azienda sanitaria locale – local health service]. Really a lot a lot a lot because when I wasn't well or I was going almost every day to one educator who supported me mentally a lot, even more she taught me to work, she did to me courses, so if I hadn't have this person, even with all the psychiatrists in the world I wouldn't have made it. (…) So my boyfriend is a little bit my caregiver, in the sense that I have always been a little bit sly. (…) So I have to organize myself better because I did not cook at first, so now I am… learning to do things, it is difficult for me but we are both organising things a little bit, so also there, there was a step from me on this thing. Jennifer (M).

One participant, Elizabeth, said that she mainly receives support from her parents, mainly her father and her mother in terms of housework. In addition, two participants, Olivia and Amelia, mentioned that they try to tackle difficult moments alone. As alternative they ask help from health professionals, or else one of them turns to her mother, while the other one asks help from a flatmate who takes care with her of her children:

I try to help myself in a sense to cheer up by myself because I cannot explain everything to everyone. Enough. (…) Only my mum, only my mum [for support] or I tell her something or I run here [at the CPS]. If I really feel in a lower mood without exaggerating. Olivia (M).

In this moment I do everything by myself with strength from God, really that's why I said that sometimes I feel tired of work, I feel tired of everything, I wish I could escape from this world and get some rest, I take a deep breath and go back home, for this reason. The only person who helps me is this girl called Janis with her daughter, no? Who with me takes care of my children, brings them to school (…) she gives me a hand but on the other side there is no support from anyone. Amelia (M).

Moreover, four of the participants, Rachel, Amelia, Jennifer, and Susan, stated that they receive disability benefit (in Italian *'pensione di invalidità civile'*) or from social assistants in terms of support from the State:

Yes, the disability benefit, because I have a legal disability of 100%. Rachel (M).

Financial yes, from the social workers they give me 200 euros. (…) They wanted me to apply for disability benefit but I've never done it because of… [making a gesture above her head as a label and asked her if it is a label she means] (…) eh… [lifts her shoulders and nods her head to show agreement] (…) I understand it now after years have passed, I understand that it does not change anything, if I make it [the disability benefit] or not. Susan (M).

The two participants, Amelia and Olivia, who stated that they first try to resolve issues on their own, both face depression, are both mothers, of exactly the same age (i.e. 38), and one of them is married but not relying on her husband for support and the other one is separated from her husband due to lack of his support with their children, financially, etc. The participants who stated that they received disability benefit due to their mental health issue were older than 32, two of them having personality disorder and the other two schizoaffective disorder.

9.1.2 No social support received

Lastly, only one of the participants, Mary, stated that she does not receive any kind of social support, while six participants received no financial support from the State, with two of them, Emily and Lily, being more elaborative in their answers, stating that although they knew that they deserve institutional support, such as disability benefit and exemption from paying fully for medication for their health issue, they chose not to receive this support because they did not need it since the price of their medication was quite low, or because they were afraid that acknowledging officially their mental disability might create for them a problem with finding employment or losing their driving licence:

> I don't think I need it. I don't know, once my psychiatrist at [name of Milan hospital] told me that... if I wanted I could ask a... something for medication, I don't know if it was a small disability benefit, a recognition that as I am taking medication every day, but in reality my medication cost barely 2 euros, it is not I need who knows what. The only support that I actually have it is at the level of the psychologist and psychiatrist, institutional [support] I have never asked for anything. (…) I didn't ask for it [financial support], I could have done, but I did not ask for it because... (…) I could have, but... (…) Because really they are only two euros for medication, it does not seem to me to be right let's say. Emily (M).

> No, zero, I've never wanted to be explicit about my illness asking for disability [benefit] or the 104 [referring to Law 104 (Legge 104/92) on assistance and social integration of persons with disabilities] or the direct exemption, I did not even ask that, because I was afraid that it could create me some problems with the driving licence or rather with work, so I preferred to let it go. Lily (M).

No sociodemographic similarities emerged for participants under this sub-theme.

9.2 Provided social support

Apart from the social support that participants received from others, they were also asked whether they provide any social support.

9.2.1 Provide practical support to others

Some of the participants stated that they provide practical support to others, through their paid employment or volunteer work, such as assisting in housework other family members, or making packages or cakes for people in need, and giving money to beggars:

> Yes once a month we all meet in a group in a meeting and make package to give to persons who have difficulties, no? help for people who are in the middle of the street or people who are part of the church group, friends who you see that they have difficulties, basically a package to give to persons who are in need, this thing helps me also physically because I like this, helping other people. Amelia (M).

No sociodemographic similarities emerged for participants under this sub-theme.

9.2.2 Provide moral support to others

There were also participants, who reported that they provide moral support to others during employment to clients as beautician, or in terms of reciprocity within interpersonal relationships, such as through social media, or when someone has a problem, for example assisting a partner who has a mental health issue too or others:

> As a beautician it happens very often and willingly [providing support to others], at least it used to happen when I was at work, because a beautician is almost like a psychologist, like a priest, people come to tell you everything, if they trust you they come and tell you everything, so yes, I have to say that very often and willingly it happens, more than anything to cheer them up because maybe I... even if… with all the problems that I have, at work I always laugh, smile and cheer up everyone, we are never sad, that is why sometimes people come for that. Olivia (M).

> Yes I try to be very supportive with other people. Probably because I see myself as less supported, so I prefer to give a hand when I can, I do it mainly via Facebook groups, things like that. But actually even in real life when I know that someone is not well I run [to them]. Lily (M).

Of those who provided moral support to others, two had personality disorder, two had bipolar disorder, and one had OCD.

9.2.3 No support provided to others

Only one of the participants, Susan, reported that she provides no social support to anyone, although she would like to.

The case of Susan, who stated that she were not providing any kind of support towards others, was the deviant case under this theme, given that all other participants had stated that they had provided support to others.

Core Theme 10. Trust

10.1 General trust

General trust refers to whether participants have trust towards people in general in their community, a question often asked as an indicator of the cognitive dimension of social capital relevant to the degree of reciprocity within a community (Kaasa & Parts, 2008).

10.1.1 Have trust in other people in general

Four of the respondents, Olivia, Rachel, Mary and Jennifer, reported having trust towards other people in general, with one of them reporting having a lot of trust, Olivia, whereas another participant, Jennifer, stated that she has trust even more than the average, although others have betrayed her trust when she lent them money but they never returned it to her:

> So… I think yes, a little bit more than the norm, because... I always trusted others, more than what some people invest. But I cannot say that I got only scams, in the sense that actually this spirit of optimism on some things made me that… even worse persons, how to say, would think about whether something is right before doing me wrong. Jennifer (M).

All four respondents who stated that they have trust in other people in general were older than 33.

10.1.2 Have little or no trust in other people in general

The other six respondents reported having little or no trust towards others, mainly due to negative experiences they had in their past that made them have more difficulty trusting people, such as Emily having received bullying or Lily having received many ‘blows’ from others, or Amelia had two suicide attempts because of her lack of trust towards others and because before she had trust in people she ended up institutionalised and social services questioned her capacity to raise her children, while another participant, Sylvia, reported that she is always a bit afraid that others might betray her trust:

> Not really. (...) In part because people cause me anxiety, in part because in the past... I suffered a lot from bullying and so this... has remained… this mistrust, that’s it, to let myself really go in the moment. In general I overcome it, but at first... on the impact with strangers or other people near... I find it difficult. That is also the reason why I have difficulty in making relationships, I am very distrustful let’s say. Emily (M).

> Very little, I always say that, because this word to me... later it is not nice for me that I am a person with little patience to wait, trust is the strongest word, it was what everyone should have trust to go ahead, I am a woman with little trust because what I experienced and continue to experience in words, in what I hear, the behaviour of a person, I do not trust. Amelia (M).

No sociodemographic similarities emerged for participants under this sub-theme.

10.2 Institutional trust

Participants were asked to state if they had trust in specific institutions, such as police, justice, parliament and the press.

Half of the respondents reported having trust in the police, while less than half of the respondents had trust in justice and parliament, with some reporting of having had personal negative experiences themselves or heard from their friends/partners with the police and/or justice, and only one, Mary, stated that she had trust in the press, whereas the rest of them said that it depends or have little or no trust in the press:

> Hm... [laughs] it depends, let’s say yes, the police yes, trust in institutions, in politics not that much. Sylvia (M).

> [trust in justice] very little, because actually I was involved in it for too much time for stupidities, for a long time, I even found a lawyer who asked me to be paid under the table if… he reported me for defamation when I told to the association of lawyers about it and at the end he won. So actually... ok… overall I trust little in justice because I had hands on experience that they are not very fair. Lily (M).

> [trust in the press] I am a little bit partial because having worked in the world of television, some things, not of the press exactly, but I know how to manipulated news, in the sense that I know a little bit how it works, but at the level of TV news I don’t know. But I see a lot that negative news are on the first page to make cash and I never see a counterpart, I don’t believe that in the world there is only negativity and this thing I never see it being in the first line. If you give 10 negative news you should also give 10 positive news, I think. You cannot lead people with negativity. I sometimes turn it off [the TV] because it is impossible, it does not exist in a normal world I think. There is too much negativity. Jennifer (M).

Two of the respondents, Rachel and Elizabeth, who demonstrated very low institutional trust were both workers in paid employment.

Core Theme 11. Opinion on specific civic norms

According to Kaasa and Parts (2008), as mentioned previously, in the cognitive dimension of social capital are included also civic norms, apart from general and institutional trust, as an indicator of trustworthiness too. Thus, participants were asked to state whether they agree or not with civic norms as an indicator of the degree of trustworthiness within their community. The specific statements used as civic norms were based on the ones used by Kaasa and Parts (2008).

11.1 Not agreeing with tax evasion, claiming government benefit that one is not entitled to or accepting a bribe during work

The vast majority of participants replied that they disagree with anyone avoiding paying taxes, claiming government benefit that one is not entitled to, or accepting a bribe during one's duties, showing a shared opinion on civic norms and trustworthiness within their society.

> I don't agree that people do not have to pay taxes because everything in life has a price, if you go live [somewhere] you must pay for what you live. Our social life is based on taxes, you do not just live your life and thank you. In the God who made the world and made thanks-giving. Today we live and pay for this reason, why the government have to say, you are in the world thank you? Everything has to be paid. It is right. Amelia (M).

No sociodemographic similarities emerged for participants under this theme.

11.2 Neither agree or disagree for accepting a bribe or evading taxes

However, one participant, Emily, said for accepting a bribe that it depends if the person receiving it is in need, and another participant, Susan, said that it depends about someone not paying the taxes in full:

> [to accept a bribe] it depends from whom, there are some people who the poor ones have salaries of hunger that maybe... accept something that maybe they do it because by need, it depends a little bit, so I do not accept it but maybe I can understand whoever is in this situation. But in general whoever is fine and accepts bribes, like that no. As there have been cases of someone who has been in these situations and accepted [a bribe] because of financial problems so... I can understand them even if I don't approve the choice that they made, that's it. Emily (M)

The similar characteristic that these two participants had was that both of them were cohabitating with their partner, so these were the deviant cases under this sub-theme.

Core Theme 12. Political participation

12.1 Voting at elections

12.1.1 Active voters

Participants were asked whether they vote or not as indicators of political participation. Seven of the participants stated that they are active voters:

> Yes I am quite active politically, I vote, I try to be very much aware of things, I read programmes and follow various politicians, what they say and all that. Lily (M).

No sociodemographic similarities emerged for participants under this sub-theme.

12.1.2 Non active voters

On the other hand, three of the participants, Rachel, Elizabeth and Amelia, stated that they are not active voters, with one of them, Amelia, because she does not have the right to vote in Italy yet, and the other two by choice:

> No, because I don't believe in anyone anymore, sincerely I don't… I don't feel represented by anyone in the government, because every time someone gets elected and goes to power, they eat our money. Rachel (M).

The three participants who were not active voters were all working and had personality disorder or undifferentiated schizophrenia.

12.2 Participation at demonstration or signed a petition

12.2.1 Never participated in demonstration nor have ever signed a petition

It was also asked from respondents to state whether they have participated at demonstrations or signed petitions, as indicators of active political participation too.

Half of the respondents reported that they have never participated at any demonstration and have never signed a petition:

> No I don’t like participating in these [demonstrations], even when I was a child, I think that this is not the way to be heard, I believe a lot more in the strike, in quotation marks, that it is a more legal thing, in quotation marks. The manifests I don’t read them if they are made by others, but I... I don’t like it because first of all, I am also afraid to go to a demonstration especially lately because they get assaulted, they thrown you down. So these things I don’t understand them. (...) [to sign petitions] no, I don’t like that much either because they don’t... they ask also on the internet if you want to sign it but as I don’t know well in these legal things where to sign, I have a little bit of fear of these things and maybe I do not do it, but not because I don’t share the value of this thing. Jennifer (M).

No sociodemographic similarities emerged for participants under this sub-theme.

12.2.2 Both participated in demonstration and have signed a petition

On the other hand, three of the respondents, Elizabeth, Mary and Lily, reported that they have both participated at demonstrations and signed petitions. The topics of the demonstrations they have participated were relevant to reform of education, biomedical research, in remembrance of World War II, whereas the petitions they signed were relevant to social themes, and other topics that they do not remember:

> Yes I’ve participated in many demonstrations for the things I believed in, and... I started when I was 20 years old with the school reform because in my opinion the reform of Gelmini was wrong, then I participated in a lot of demonstrations in the period in which research was underestimated or there were hindrances placed especially in the field of biomedical research, because I’ve done a lot of biomedical research in the past and so I feel it close to me. Generally when there is something in the society that I don’t like I practically try to change it. (…) Yes, yes sometimes I do it [to sign petitions] usually on social topics. Lily (M).

The participants who had both participated at demonstrations and signed petitions were never married and living with their parents.

12.2.3 Signed petition but never participated in a demonstration

There were also two participants, Emily and Susan, who stated that they signed petitions but never participated in a demonstration. The petitions they had signed were relevant to environment, animals, the rights of persons at international level, the rights of women, or children with health problems due to war, or persons who become evicted, or employment in general:

> I sign every now and then, now there are also the petitions online every now and then. (…) Environment and animals, and also rights of people, maybe more on human rights on the international level, maybe the rights of women or children with health problems due to the problems of the war or... let's say socio-environmental. And then it depends, then I think about it a bit. Usually I sign everything on animals, because it is almost always violence against animals, so there is not much to assess. Emily (M).

Both of the participants who had signed petitions but had never participated at demonstrations were cohabitating with their partner and were not married.

Core Theme 13. Employment difficulty due to health issue

The participants who did not have full-time employment in their field were asked whether they wanted to find a job, but could not find a job due to their mental health issue.

13.1 Difficulty finding or maintaining a job due to mental health issue

Three of the participants who were not employed, Emily, Lily and Susan, reported that they had some kind of difficulty finding or maintaining a job due to mental health issue. Emily had been rejected by colleagues during her nursing internship because of thoughts of aggressiveness due to her mental health issue. Lily had difficulty finding a job in her field of studies since she had to attend recovery sessions for her mental health issue, and the fact that she finished studying late she does not have a job yet and cannot say to her potential employers that she has bipolar disorder. Lastly, Susan said that she would like to find a job too, but is worried about having a panic attack at work due to her mental health issue and finding herself well within the context:

> Only during the internship I was told that my problem could... that my disorder could have been a problem. In general at school I've never felt discriminated, when I was attending the Nursing faculty. I felt it very much when I was doing my internship. (…) For the rest, now soon I want to try again to find a job, a little bit less demanding. (…) but I think that anyway I will not tell them that I have an obsessive compulsive disorder. Because firstly, it is not a big deal, and secondly, I don't want to scare my potential employer. So in the sense that if I present it as a problem, it is a problem. (…) So I try not to live it too much as a problem, to leave it to be something... If it comes out for any reason I will explain to them that it is not, that it is nothing, as it is. If not, I will try to keep it to myself, which maybe is better, I don't have to tell anyone about it and prefer to keep it to myself. (…) Also because I have seen that people get scared a bit when you talk about a psychiatrist, then maybe they get to know you and they calm down, but in general they ask you

> also a lot of questions, when you basically apart from the disorder, are feeling fine. So if I run the risk to be considered ill because... when on the other hand you are not or you don't feel it, I prefer to stay silent, that's it. Emily (M).

> Because at the moment I am facing this rehabilitation in day-hospital, in which I am since about September every day. I graduated in December, so till the end of December I was studying, from December to this hospitalization I decided to not work in order to dedicate myself only to my health (…) My illness made me delay a lot in my studies, I didn't find much collaboration from the part of professors to help me with university studies, even when maybe I was asking for example another appeal because I was not feeling well or things like that, so now I am almost 29 years old and have just finished my studies and I do not have a job. And I know that I cannot say to my employers that I am bipolar, because that would compromise me everything. I am trying to reach the level of doing a job with responsibilities because I want to work in the pharmaceutical companies of regulatory affairs and naturally I will not be able to say that I have this illness. Lily (M).

All three participants were never married, although two of them were cohabitating with their partner and others.

13.2 Not looking for a job or could not find a job due to non-health-related reasons

On the other hand, there were also participants, Olivia, Sylvia and Mary, who did not want to find a job, or have left a job due to pregnancy, or wanted to find a job but could not because of non-health-related reasons, such as not having enough experience yet in their field:

> Currently... I do not work because I have decided to get pregnant and thus I wouldn't be able to deal with this well and everything, so... but to find a job now, as right now, will not be possible as the child is coming and it is a bit... maybe occasionally, but occasionally once a week I already do it, so at the end I work anyway, I like it more almost as a freelancer but… to open a store costs and... it is not the time now. Olivia (M).

All these three participants were living with both their parents or only their mother and husband and child; so they had family members to rely on for financial help.

Core Theme 14. Barriers for social participation and suggestions for removing them

Participants were asked to state whether they had ever faced any physical environment or social-related barriers in terms of social participation due to their mental health issue.

14.1 Prejudice, stigmatisation, and/or lack of empathy received by informal and wider social network

Two of the participants, Emily and Lily, reported that they faced discrimination and/or prejudice towards them by their friends or partner, but also members of the wider social network, such as family members of their partners or other acquaintances or the mass media.

In specific, Emily participant reported that when someone goes to the psychiatrist is considered as 'crazy' or 'dangerous' by others – including the mass media – so she tries to explain the complicated nature of her mental disorder only to those that can understand it and she trusts them, because others cannot understand her issue. The lack of understanding by other people was also noted by Lily, to whom others suggested to go to an all-you-can-eat restaurant while she had an eating disorder, so the participant perceived it as a social barrier for her, indicating lack of empathy from her social network. The same participant also said that she felt stigmatised by the families of her previous partners, who did not want her to be with their family member due to her mental health issue:

> There is a bit this… let's say such as… the rumour that if you go to the psychiatrist you are crazy or dangerous or like that, it is still a bit diffused. (…) A bit of prejudices, this is it, this I notice it a bit. (…) Overall as I see it anyway as a complicated thing that you cannot explain with two words like... I have cancer I feel ill, and like that, a depression you are sad, so you do something that makes you happy. It is more difficult to explain but look it is an illness due to a cause, it does not come like this, or also as OCD, so... to conclude, you see that when you are more inclined to explain these things to persons that you know that they 1) can understand you a bit, 2) persons that you trust and so to a stranger, who you maybe see already that is of narrower views and you are not there to explain them, do not say anything really to them. (…) Therefore… there is a bit of difficulty really to explain yourself, but also for the other person to understand. Therefore it is really a thing of incomprehension between you and the other person, so you usually bypass this problem and go ahead calmly. Emily (M).

> It happened especially with the eating disorder, to tell the truth... because... it happened that others do not understand that it was the moment to take me to an all-you-can-eat place, things like that... but it has also happened in other things... for example I had been very much stigmatised by the families of my exes [boyfriends] due to the health problems I had... It happened naturally during hospitalisations that I couldn't even go out to take a coffee, so to conclude I would say there were some quite important restrictions. Lily (M).

As it emerged, the respondents who experienced prejudice, stigmatisation and/or lack of empathy from their informal and wider social network were of similar age (i.e. 26 and 29) and never married.

14.2 Discrimination and/or prejudice received by formal social network

Another two participants, Amelia and Jennifer, stated that they experienced discrimination within employment settings, a religious group, and school settings; all of them considered as formal social networks. In particular, Amelia reported having faced discrimination during recruitment phase for employment when she went to a legal office for a job interview, where she told them that she is under psychiatric treatment and the potential employers looked at her like crazy and ill and did not give her the job. Moreover, Jennifer reported that she experienced discrimination by leading members of a religious group that she was part of, when they refused to give her a symbolic scroll[27], although the rest of her religious group received it, because, as she stated, someone from the group suggested that she should not get it because she is 'crazy', thus perceived it as a discrimination against her. The same participant also experienced prejudice at school when she told about her mental health issue to a schoolmate and that schoolmate told others behind her back and the school did not support her since she was not yet a protected category, so she had to leave school:

> I went to work at an old legal office I had some difficulties, this makes part, no? (…) I had some difficulties because if I say that I am under psychiatric treatment, they look at my face as if I was crazy and ill and they could not give me a job, it is not true because if I am doing the treatment, I am able to work for 4 hours as I have told you, so in the morning when I work for 4 hours I feel tired and I have to go home, but that does not mean that I cannot work. I manage well my life and I am able to really understand that I am feeling unwell I am always feeling unwell. Amelia (M).

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[27] The scroll of Sōka Gakkai, a lay Buddhist movement, refers to a printed scroll copy of a character mandala (Gohonzon) originally inscribed by Nichiren to be the fundamental means for attainment of enlightenment. Acceptance of the Gohonzon scroll marks initiation and official membership to Sōka Gakkai (Gebert, 2016).

> Now I have to tell you one unpleasant thing that this faith… I had to take a symbolic scroll (parchment), of this faith here and they did not give it to me with the excuse that because I had a legal guardian, that I could not... they invented this absurd thing, and at the end I got angry about it but I endured it because the rest of this faith is nice. Bus I... I remained very upset with this attitude (...) it is not that there are merits to have it, everyone has it, only for me they found this obstacle to give it to me as if there was someone who put the bug that 'she is crazy, don't give it to her'. Do you understand? I experienced this thing personally. (…) Once I was very upset with a school that they did not know about my illness (…) I had a colleague that did not like me much, I did not understand it, I confided to her and from one day to another she did... I don't know what she went and told behind my back and I saw that they… from one moment to another they left me at home because of that encounter there. Jennifer (M).

The two respondents who experienced discrimination and/or prejudice by a formal social network both had personality disorder and were working.

14.3 Avoiding social participation due to mental health issue per se

Two more participants, Sylvia and Susan, reported that they avoided social participation due to their mental health issue and the consequences that it had had on their health meeting with others socially, so they preferred to retreat from such situations. Sylvia said that she has faced barriers in terms of social relationships due to her mental health issue, such as when she went to a dinner or camping, where she had difficulty coping with the situation and others realised that, so it was a decision both from her and others for her to withdraw from that situation. Susan reported that she avoided social participation due to her mental health issue because being among other people, when she was not feeling well, would make her feel even worse, as it occurred to her not being able to enter a supermarket and speak about a simple thing:

> Ok, yes in social relationships, or in... even simply at a dinner in company of other people, this yes, for sure, or… now nothing comes to my mind, but yes, I went camping and it was difficult, I mean, to do things, so yes, in this sense yes. (…) I cannot deal with things and the others notice it. (…) So it bothers me and I pull back. (...) So a kind of a double 'ta ta ta' [doing movement with hands in front of chest indicating reciprocal behaviour] like this. Sylvia (M).

> No, if I had tried I would have had some problems, but by avoiding it [social participation], I did not have any, but if I had tried to participate, when I wasn't well at all, to participate at certain activities, I would have felt bad for sure. (…) now no, but before yes, because of my feeling unwell I wasn't around people, I wasn't participating in activities, I wasn't talking, I was keeping everything inside. (…) because I was

> afraid of feeling even worse. (...) no, I dealt with them in a different way because for me it was a barrier even entering a supermarket, so I did not need activities *per se*, for me it was a barrier to enter a supermarket, talk about a simple thing, for me it became an impossible thing, if I say it in a wrong way, if I don't know how to talk, if I don't know... it was a huge thing. So I overcame them like this. Susan (M).

The two participants, who avoided social participation due to their mental health issue, both were never married.

14.4 Never experienced any barriers for social participation due to mental health issue

On the other hand, there were also participants, Olivia, Rachel, Mary and Elizabeth, who stated that they had never experienced any barriers in terms of social participation, maybe because as two of them said, Olivia and Elizabeth, they had not disclosed their mental health issue to others, so they would not know about it:

> No I've never had problems like this. I mean my problem is only human, at a human and psychological level but not on the institutional level of this kind. I've never had problems like this. Mary (M).

> It never happened to me, but if it ever happened I would not agree. For example, if I wanted to be a volunteer and I was told that I couldn't do that because you have... you have this problem, maybe you are dangerous, I would not accept it. (…) no, because if I don't tell them, they cannot investigate my medical history, thus they cannot know it. Elizabeth (M).

The participants who never experienced any barriers of social participation were older than 27 and their highest education degree was upper or post-secondary school certificate.

14.5 Suggestions for education, campaigns, understanding, and change of mentality of wider social networks on mental health issues

The participants who reported having experienced barriers for social participation were also asked about how they suggest that these barriers could be removed.

Three of the participants, Emily, Sylvia and Lily, who had experienced barriers for social participation, suggested that these barriers could be overcome with various ways. One of these ways was education at schools, although Sylvia pointed out that then it might be risky to speak to students about mental health issues because they might get an idea, nonetheless she suggested that there should be education on these issues too. Campaigns and education to teach people about the origin of mental health issues was suggested by another participant as well. In particular, Emily mentioned that many people think that mental health illness is intentional, while it is not intentional for her to stay at home and have difficulty to socialise with others, because in fact she wants to socialise, so in order for her to overcome this, she suggested that people should try to become closer to others, have more empathy, and understand that her mental disorder is a disorder like all other health disorders. She also stated that persons with depression disorders or anxiety are usually shy so they attract bullies, and teachers could be taught how they can help children more, who have elevated anxiety, for example. Similarly, Lily reported that above all it is a matter of mentality and should be made understood that people with mental health issues are not dangerous and should not be stigmatised, but they simply have an illness like all the rest of illnesses. On this change of mentality the participant suggested that could contribute campaigns on otherness, in order to remove the existent stigma of ‘crazy’ for persons with mental health issues, and is important to make people understand that these are illnesses and the nature of these illness:

> No, I don’t know, I would say... that if I have any suggestion, I would say... that it varies from person to person, meaning that if some people are able to understand more, or others less, I wouldn’t generalise it, so... everyone does a bit whatever she/he wants, I believe, then… (…) It would be nice if everyone understood everyone but then everyone is free, no? (…) I believe some education on these things, so maybe schools or... even if I don’t know if that would be risky, but... maybe yes. I don’t know if that would be risky for some people to hear talking about these things from childhood, I don’t know (…) because maybe then you get an idea (…) At schools some education like that on these problems here should exist. Sylvia (M).

> A lot of campaigns, but maybe also explain... do some... educate people a little bit, as in the beginning anorexia and bulimia were not known, it could be also explained like that why one has OCD or anxiety disorder. Maybe... seeing that anyway it makes you close yourself at home, stop doing anything like this... People think that maybe it is a voluntary thing. It is voluntary to close yourself inside, but there is no will in staying locked up, or in not wanting to eat or even in… trying to avoid people. I, for example, have a lot of difficulty with... who I keep at a distance because I cannot socialize, but actually I want maybe to stay with a person like this. (…) Like a misanthrope, maybe actually it is because the misanthrope who stays alone really maybe just has problems to communicate, to tell you something. Maybe if they can do… some steps towards that, to teach a little bit. And then I think that everyone experiences anxiety, and at everyone it could be explained, everyone could identify with the person and know what she/he thinks, if it can be done this thing with empathy, maybe it can be one step ahead, if it can be done, it does not require a lot overall.

> (…) but also just to educate people a little bit, even only the teachers to recognise an anxious child, like that... that could help a little bit more. Emily (M).

> I think that more than anything else it is a matter of mentality, there is need to make understandable that mental disorders are not dangerous, are not to be stigmatized, but they are simply illnesses like all the rest and the person behind them can be good or bad regardless of her/his illness. (…) But maybe also through informative campaigns on otherness. In my opinion that would be important because many people do not understand yet the various pathologies, they don't know them, plus there is still the social stigma of the crazy person. In my opinion, to intervene on these issues to say that crazy people do not exist, but exist people with illnesses and these illnesses are created like this, this and that, I think that would be important. Lily (M).

The three participants, who made public-oriented suggestions relevant to education and campaigns mainly, were students or recently graduated, never married and living with their parents.

14.6 Suggestions for self-confidence, self-worth and self-acceptance of mental health issue by the person experiencing it

Two more participants who had experienced barriers for social participation, Susan and Jennifer, suggested that for removing these barriers the person suffering from a mental health illness should have more self-confidence and self-worth, but also to accept their mental health issue and not hide it from others because sooner or later it will appear. Jennifer also pointed out that she made her mental health issue become an asset for her, not a 'handicap' (as she mentioned) and show others that she is better, but without pietism:

> In my opinion to feel a little bit more self-confident, as if looking to the mirror saying, but I am worth [laughs]. This is a suggestion. I wish I looked more often into the mirror and told me oh it is not me. Susan (M).

> In my opinion the first thing as I was saying before is... we, starting from ourselves, because if one does not accept the illness, the others won't accept it for sure (…) And speaking about it first of all in a congruous manner. In the sense that I always did it in a way that I let the people know about it, those people who had to know, because… eh... if you hide it, say half truth, and make all this puppet theatre people then say oh but you did not tell me, oh you did not did that to me, and already starts going on tilt and all situations. (…) not only to trust others but also receive trust because anyway if you have a defect it is not that you can hide it for long, sooner or later it come out, it is like I don't know, as if a person limping says 'I am not limping,

> I am going to do 100 metres', it does not make sense, you understand? I know it, I have always known that I am this way, unfortunately, so for me I turned it into richness, in the sense that I did not see it as a handicap anymore. I said I am different from others? I will be better, full stop'. (...) It is important to accept yourself, as what Zanardi [an Italian racing driver with prosthetic limbs] did who with prosthetic limbs went to do these... because he went beyond, otherwise he would have been still in bed. I mean, in the sense that we need to do more to show that we are better, in quotation marks, and then trust others, in the sense to say 'I am like his' but without pietism, but to say 'I am like this, if you want to accept me we can go ahead together, if not... did you understand? Because if not, we don't go ahead. Jennifer (M).

Both participants were cohabitating with their partner and relied to religious faith for support – which might have some connection with the fact that they mentioned aspects of self-perception here.

14.7 Suggestion for more projects for enhancement of social life of persons with mental health issues

Lastly, there was one participant, Amelia, who experienced barriers in terms of discrimination in employment due to her mental health issue, that she stated that in order to overcome such problems by a national project which will help persons with difficulties to have a social life:

> Let's make an example, right now there are a lot of foreign people in Italy that have difficulties, that have this kind of barriers, don't have opportunity speak like I am speaking today, there should be a project to help people who have difficulty in having a social life because they want to do things, but they are not able to, I think so, because if they had more opportunities to help people who have difficulties, it seems a project to help many. Amelia (M).

Core Theme 15. Barriers for independent/autonomous living and suggestions for removing them

In terms of barriers for autonomy, further issues emerged which were mainly practical in nature that did not allow the majority of participants to live autonomously, whereas others faced no barrier for living autonomously.

15.1 Not being allowed to have a driving licence due to mental health issue and difficulty doing housework

One participant, Jennifer, perceived as barrier for autonomy the fact that she has difficulty doing the role of the housewife and cleaning her house, so she did not have independence in terms of housework. She also saw as a barrier for her autonomy the distinction that she could not have a driving licence due to her mental health issue:

> For me the most difficult thing right now is to do housework, because the work I have handled it quite well, but I despise having the role of the women, meaning really be a housewife. (…) So I was always more or less economically independent, but what I did not have was independence at home, I was really an idiot. (…) I cannot drive, not even if... I don't care about it anymore because there have been many years that I don't care, but maybe in the first years of my life… to accept it when you are 18 years old for example, when I was 20 it was hard, because it is the time when everyone takes a driving license and I have to explain every time that I don't have it because this and that, it was a bit of a it was a little bit pain in the ass because I could not even get it, so it would have been money thrown away, so at the end it was a hard thing to say at my age. (…) You stood out but not for good, but for bad. Jennifer (M)

15.2 Not being allowed to live autonomously during institutionalisation for mental health issue and problems with benefits for children

Another participant, Amelia, perceived as barrier for autonomous living the fact that she could not go out and live alone with her children while she was institutionalised, despite the fact that she was working, as well as the fact that she does not deserve lunch meal for her children at school so she has to go to school to bring them lunch, which was considered also as a barrier from her:

> Yes I had some barriers/obstacles, I've just spoken about the community [institutionalisation], I've asked many times to move out and start an independent life and they told me that it was not easy to leave a mother alone around with three children because they were seeing me as an ill mum, that was a real barrier. I used to say yes, I told to the community that I could manage dealing with my duties, as a mum, I have 4 hours that I can work as I am working, doing my duties, bringing food to my children, and for this they see me as a capable woman, but to go away to take care of my children you see me as ill? To manage the things inside here, to bring food to other mums, to help the community, and you see me as ill and as a bad barrier like that? No, I felt it as a really bad barrier and I did not think twice before leaving that community. Amelia (M).

15.3 Not being allowed by family member to live alone

Another young participant (age 24), Sylvia, who was a university student, was not living autonomously because her mother did not agree with that, without the participant disclosing the reason:

> For now as in right now I don't think so [to live autonomously], in fact, yesterday I was talking to my mum if I could move to the house of my grandparents that is empty, to live there, and she said to me no, because... I believe no. Sylvia (M)

15.4 Difficulty finding work due to mental health issue or for financial reasons

Four of the participants, Emily, Lily, Mary and Elizabeth, stated that did not live autonomously because they could not find employment, either due to their health issue, as stated by Emily and Lily, due to added anxiety during a job interview or difficulty in relationship with colleagues or because of recent relapse or delay in concluding studies, or irrelevantly to the mental health issue, as stated by Mary, while Elizabeth said she could not afford financially to live autonomously due to the expensive rents in Milan, despite the fact that she had a full-time employment:

> Maybe I still have some problems in being independent because... on my own maybe, I don't have a lot of trust yet... I am still very afraid to trust myself. Because if what I see comes again from out of the blue, everything will come back again... all the psychic collapse that I had at the onset [of the mental health issue], that I had last year, that I had to be hospitalised, to count on now only and completely on myself, I am very afraid to say ok now I take it and I am independent. Emily (M).

> Yes, if I make some sacrifices, yes (...) because I should save, make sacrifices. (…) for two years I was living in London and was feeling better on my own, so... but unfortunately the rents, also in London are very expensive, but in Milan they are expensive and so it is not easy to go and live on your own, maybe if you could share an apartment with your boyfriend, if you have one or with a friend, then it can be different. Elizabeth (M)

Both participants who stated that they could not find a job due to their mental health issue were never married, but had a partner, and were living with their parents too.

15.5 No barriers for living autonomously

However, there were also three participants, Olivia, Rachel, and Susan, who stated that they did not face any barrier for living autonomously:

> No, I've never had them [barriers]… I have always worked, I was always independent, now I depend a little bit on my husband but also because I decided to... do so, I decided to rely on somebody and it was difficult but… a bit let's say for financial reasons because as I am not working... Olivia (M).

These three participants who faced no barriers for living autonomously were older than 32 and living with their husband, child and mother or alone or with their partner and flatmates, so they had indeed independence from their family of origin.

15.6 Suggestions to change the attitude of others and themselves

The participants, who reported that they had experienced barriers for living autonomously, were also asked to suggest ways to remove these barriers, based on their personal experiences.

Emily suggested that in order to remove barriers for autonomy there should be more openness from people in order for her to live a more autonomous life, in the way that if she saw openness, kindness and understanding from others towards any person in general, then she would also become more open about her mental health issue and not hide it, and this would help her overcome the shyness due to her mental health issue. Regarding her personal autonomy, she suggested that she has to just try living alone with her partner to see if she can handle it and all young persons have worries for living autonomously, so she characterised it as normal to have this kind of concerns:

> It would be nice to see in all people openness, yes, but you cannot demand it, also because if one like me chooses to keep... prefers to keep hidden the... hidden, keeping to herself her problem because exactly it is nobody's business, I cannot demand that the other is open maybe in front of my problem, at me being closed because of my disorder. (…) It is the only way maybe to break the barrier from the other side, if one said you don't be so pedant, don't insist, don't be aggressive things like that, that I think should be the basic, the natural, but… (…) Then as I told you maybe it is only a thing that lies on the surface, because if you wait a little bit then... it goes beyond mistrust and shyness and it is possible to have a normal conversation. But there are some certain attitudes that on the other hand... exacerbate OCD or anxiety like that, and so... maybe this is the only thing. The only barrier that could be controlled is this, people can try to

> be more open... more open in the sense of comprehension and openness, exactly. Accept a person with all... all her/his facets, yes, that is the only thing. Emily (M).

Another participant, Jennifer, suggested that in order to remove barriers for autonomy, people should find alternative solutions, for example, in her case that she perceived as a barrier not being allowed to have a driving licence due to her mental health issue, because she wanted to feel like all the other people, she tried to see the positive side of it and overcame that by using the public transportation of Milan and the effort to get to her work every day gave her more benefits than having a car.

> Yes, look to find alternative solutions because in the beginning, for example, this problem with the driving license I experienced it a lot [often], that was a thing that I did not feel that... I wanted this driving licence a lot in order to drive but to feel like everyone else, no? Instead of this... when I understood that it is wasn't so important in my life because public transportation in Milan work well and I have always travelled the world using public transportation (…) So at the end to use a car was not… would not have been so damn useful to me. At the end I accepted it and turned it into an asset for me... like that. Jennifer (M).

No sociodemographic similarities emerged for participants under this theme.

15.7 Suggestions for more support from the State and in employment sector

A participant, Lily, stated that, although she did not receive the disability benefit, being afraid that recognising her mental health issue might hinder her from finding a job in her field as mentioned previously, even if she decided to get the disability benefit, the amount of money of the benefit are not enough to allow someone to live an autonomous life, and although there are laws against discrimination at work, she reported that these laws are not implemented in reality, and she knows people who belong to protected categories – vulnerable groups – who others take advantage of them.

> Hm... I don't know, I think that it does not concern me because I don't get a disability benefit, but I know many people who have disability benefit and it is 290 euros per month, which is very little and does not allow you to live an autonomous life, it would be nice if the benefits allowed you to live overall. The laws on what concerns me, so the fact of not being discriminated because of the illness exist, but the truth is that they do not become applied, so maybe it would be needed to give a hand a bit to the workers in this sense. But I know that it is very difficult because I have heard people who belong to the protected categories [vulnerable groups], who are exploited very much, so I don't know, it is a difficult field. Lily (M).

Finally, Amelia suggested that for removing barriers for autonomy there should be done what the law promises and the State institutions and there is lack of safety, communication, and projects – for people in need – in Italy.

> Me in my life, like everyone says, we hope for better things, the things that are promised by the law, lawyers, the police, the government, it seems to me that security is missing, more communication, more projects in Italy, I think so. Amelia (M).

No sociodemographic similarities emerged for participants under this theme.

Main tendencies of Main Area 2: Social relationships, social participation and disability

Regarding **size of social network**, it varied among participants from none to about 10 persons. In terms of **types of social relationships**, it varied greatly too, with almost all participants including at least one friend, and then some also a family member or more, and partner, health professionals, neighbours, a faith tutor, and one participant mentioned God as her only friend. As shown by the themes that emerged, some of the participants specified that the persons they were feeling close to were aware of their mental health issue, and others reported to have difficulty making friends or feeling isolated. Relevantly, according to a study comparing quantity and quality of social networks of young persons with early psychosis and young persons without any mental illness, found that persons with psychosis had fewer friends and fewer persons to turn to in a time of crisis, and a higher likelihood to have healthcare service providers among their contacts, compared to persons without mental health issues (Macdonald, Hayes, & Baglioni Jr., 2000).

The **frequency and way of contact** with social relationships again varied greatly, with the vast majority of them having a face-to-face contact or via texting or telephone at least once a week with their closest ties of their social network, while other participants reported to having less frequent contact even with closest friends. In specific about Italy, a recent study on the relationship of health and an aspect of the structural dimension of social capital (i.e. frequency of meeting with friends), found that individual structural social capital improves health condition, with persons in Italy who meet friends every day or more times per week to be about 11-16% more likely to report good health (Fiorillo &

Sabatini, 2015). Regarding the use of social media as the medium of contact with social network, which was reported by participants here too (i.e. via WhatsApp or Facebook mostly), another recent study found a negative association between the numbers of hours spent on social media and happiness for persons who reported feeling disconnected from their social contacts and lonely, thus it seems that social media cannot substitute the benefits of real-life personal contact (Arampatzi, Burger, & Novik, 2018). However, the use of social media, such as Facebook, or mobile applications, such as WhatsApp, is a very common way of communication between young people in general nowadays and in Italy as well. Furthermore, based on a systematic literature review of studies focusing on social networks or social support of persons with psychosis (Gayer-Anderson & Morgan, 2013), there is evidence that persons with a first episode of psychosis have fewer contacts, and are less satisfied with the ties of their social networks, plus they are three times more likely, compared to control sample, to have a low frequency of contact with persons belonging in their social network. On the other hand, there have been also findings that there is no association between psychotic symptoms and size of social network or frequency of contact (Gayer-Anderson & Morgan, 2013). Nevertheless, most studies indicate that persons with a first episode of psychosis have reduced size of social network, in terms of friends and confidants – not family –, and less satisfactory access to social support compared to others (Gayer-Anderson & Morgan, 2013). These findings have been confirmed in this study too since there were participants who reported a rather small size of social network, consisting mainly of ties who know about their mental health issue, and reporting difficulty making friends and/or being isolated from others.

As mentioned above, the vast majority of participants were **not members of any group**, such as organised or voluntary ones, and those who were members of a group, again the two participants with personality disorder both belonged to different religious groups, and one of them belonged also to a political party, similarly to another participant. According to Kawachi and Berkman (2001), human relations, apart from intimate and close social network ties, also consist of ‘weak ties’ formed within involvement in community, voluntary, and religious organizations, in which participation is not – necessarily – consisting of intense interactions between people, however, participation in them provides a sense of belonging and general social identity, which have been argued as relevant for promoting psychological well-being (Kawachi & Berkman, 2001). Still, the finding of this study that the majority of participants were not members of any organised group, is in accordance with previous research on general population, which has shown that *“women* *tend to have significantly lower levels of overall civic participation in formal networks"* (Kaasa & Parts, 2008, p. 148). Therefore, it is possibly related to gender the fact that participants here had relevantly low levels of participation in formal social networks, and was unrelated to their mental health issue. Regarding religion and personality disorders in specific, a review of the literature has discerned a pattern in findings of studies in the area of personality disorders, that for individuals displaying schizotypal and borderline personality traits, religious and spiritual well-being remained high, although their overall well-being was low (Bennett, Shepherd, & Janca, 2013). This finding is confirmed also by the results of this thesis, since the two participants who belonged to religious groups, both had personality disorder, while facing various issues regarding interpersonal and intimate relationships and overall well-being, such as having only one or no friends. Finally, evidence has shown that, in general, religiosity has positive impact on both formal and informal social networks, as well as norms and institutional trust (Kaasa & Parts, 2008).

Most of the participants reported that they are doing **daily activities** which do not involve meeting with friends or colleagues socially, and these activities are mostly done indoors and by themselves, such as reading, watching television, drawing, and studying. Thus, most participants seemed to lack informal social network engagement, and only some of them had formal social network engagement with colleagues at work, but not outside working hours. Persons with persistent mental illness, who spend a large amount of time in all activity categories (i.e. work/studies, self-care/self-maintenance, and play/leisure), have been found to have better perceived health, quality of life, and social interaction, compared to those who devote less time to these activities (Leufstadius & Eklund, 2008). In particular, persons with psychosis have been found to spend less total time in activities compared to persons with non-psychotic mental illnesses (Leufstadius & Eklund, 2008). To improve experiences of persons with mental disorders, it has been suggested that self-help skills are very important, because only a minority of them might seek professional help, and such self-help skills can include *"seeking support from family and friends, engaging in pleasurable activities, and taking up new activities and physical exercise"* (Jorm, 2000, p. 397), thus persons with psychotic disorders could benefit from the development of their self-help skills by engaging in more pleasurable activities, including physical exercise, and seek more support from family and friends. Another issue discerned in the data here is that one participant, who was 26 and university student, reported that the medication she is taking for her mental health issue make her sleepy a lot, thus in the afternoon she is usually feeling tired and sleeps for a couple of hours, which implies that medication could potentially lower social participation due to side-effects for persons with mental health issues. Similarly, as it has been argued elsewhere, studies show that persons with persistent mental illness often have difficulties initiating activities, structuring their time, and they sleep a lot during a 24-hour period, with younger people spending more time asleep (Leufstadius & Eklund, 2008), which is confirmed here too. The reason for the finding that participants who reported meeting socially with friends or colleagues as part of their daily activities were 32 years old or younger and unmarried, might be that younger women have more free time for themselves or more interest in meeting socially with others, compared to older women or women with children. This is in line with a study showing that time spent with friends across life span constantly declines until middle age, when adults tend to spend less than 10% of their time with their friends (Hartup & Stevens, 1999). So as it emerged from this study, the majority of daily activities reported by participants, apart from going to work or university, were indoor activities, confirming previous evidence of a systematic review and meta-analysis that persons with psychosis spend about 11 hours of their waking day being sedentary, considered as a very high level of sedentary behaviour (Stubbs, Williams, Gaughran, & Craig, 2016). On the other hand, it has been found elsewhere that psychosis does not stop most participants from wanting to engage in social and leisure activities, which are common to their peers and typical of activities enjoyed by their friends (MacDonald, Sauer, Howie, & Albiston, 2005). One participant, pointed out also the fact that when she has a day-off from work – which she deserves as one of her rights as a person with disability based on the abovementioned Law 104 (Legge 104/92) –, she goes to visit her partner who lives in a residence at a nearby city. This Italian law guarantees the right for assistance for persons with disability by the employer in the working environment, for example, regarding entitlement to three days-off per month or reduced hours per day respectively. However, not all of the participants who were working had an official recognition of their mental disability by the State, although they could, as mentioned previously, thus they were missing out benefits, such as days off from work, that could allow them more free time and potentially in turn enhance their social participation.

As mentioned previously, both bonding social capital (referring to forms of inward-looking and homogenous groups) and bridging social capital (referring to outward-looking and heterogeneous groups) can have positive social effects, since bonding social capital can be beneficial for motivating reciprocity and solidarity, while bridging social capital indicates networks which can facilitate connection with external assets and diffusion of information (Putnam, 2000). Based on the findings here it appears that the vast majority of participants with mental disability had **heterophilious social networks**, in terms of disability, in other words that their social networks were mainly heterogeneous since they were not composed primarily by persons with a mental health issue as well, thus demonstrating stronger bridging social capital and weaker bonding social capital (Putnam, 2000). The topic of concealing a mental health issue from social networks emerged in this theme as well, and the majority of participants did not experience any direct rejection when they attempted to connect to members of the wider social network – probably because they avoided disclosing their mental health issue to others. This finding is compatible with a recent literature review (Wood, Burke, Byrne, Pyle, Chapman, & Morrison, 2015), according to which, participants have been found to show secrecy associated with psychosis, within all the studies included in the review.

As it appeared from the responses of participants on whether others had a change of attitude when they learned about the participants’ mental health issue, the majority of them reported that they received **negative change of attitude from others** and therefore ended the relationship with them or avoided social contact due to their health issue or their difficulty with social relationships. Moreover, two participants reported that at the beginning, their social network had a negative change of attitude, such as fear, due to their mental health issue, but with time or by getting to know them better, their social network overcame this negative attitude towards them. Finally, one participant had not received any negative change of attitude because she was straightforward with her relationships from the start about her health issue, whereas on the contrary, another participant stated that she did not receive any negative attitude because she was hiding from others her mental health issue. There is evidence reported elsewhere, that persons with early psychosis might feel misunderstood by their friends and prefer to spend time with those that they feel they can understand them, and specifically regarding previous friends, it has been found that they would not understand their experience of psychosis (MacDonald, Sauer, Howie, & Albiston, 2005). This closely resembles the experiences of the majority of the participants of this study, who received negative change of attitude by previous social network ties, due to their mental health issue. Additionally, persons with early psychosis try to make sense of their own and others' reaction towards their health condition and the impact this has on their social interactions (MacDonald, Sauer, Howie, & Albiston, 2005). Thus, it can be expected that persons with psychotic disorders, especially at a young age, might be more cautious disclosing their mental health issue to others until they understand more how they should handle potential negative reactions from others, due to their mental health issue, in order to protect themselves also from any potential offensiveness by their intimate or social relationships, as it happened for some of the participants of this study.

As it emerged from the present findings, the vast majority of participants reported that they **received social support** from health and care professionals, such as from the CPS, psychiatrists, psychologists, and care worker, with two other participants seeking first to resolve any difficult moments on their own, and receiving support from family member or flatmate and health professionals. Only two of the participants mentioned family as a source of provision of social support, and one participant stated that she does not receive any social support from anyone. Regarding the fact that a small minority of the participants mentioned their family among their sources of social support, there has been evidence suggesting that the support of family may be more important than support from friends or other non-kin persons in reducing use of hospitalisation, and given that assessment of social support can predict the treatment outcome, increasing social support could improve potentially the outcome of psychotic disorders (Norman, Malla, Manchanda, Harricharan, Takhar, & Northcott, 2005). Thus participants could have benefited from more family support too. Moreover, social functioning and social support levels have been found to be associated with general functioning and well-being in persons who are at risk or have already experienced their first episode of psychosis, and in particular, lower level of social support has been associated with poorer general functioning, and poorer social functioning has been associated with poorer overall quality of life (Robustelli, Newberry, Whisman, & Mittal, 2017). As mentioned also previously, from a study comparing young adults' experiences on social networks and social support with a sample of persons with early psychosis and persons without any mental health issue, there were no differences found within the two groups of the sample regarding the amount of perceived social support and reciprocal relationships, however, the sample with early psychosis had fewer friends and fewer persons to turn to in difficult moments (Macdonald, Hayes, & Baglioni Jr., 2000), which has been confirmed also in this study given that there were also participants who did not have any friend to turn to in moments of crisis, but mainly healthcare professionals, also matching another finding of the same study (Macdonald, Hayes, & Baglioni Jr., 2000). Thus, it has been suggested that health professionals should be aware of how persons with early psychosis experience social relationships during their first recovery (Macdonald, Hayes, & Baglioni Jr., 2000), clearly not focusing only on the biomedical model of health.

In terms of financial support received from the State, four participants were receiving disability benefit or financial support from social assistants, however six of them did not receive any financial support, such as disability benefit or exemption from medication payment, for fear they might lose their driving licence or have difficulty finding a job, or because the price of medication is quite low, or for other undisclosed reasons. One participant received a type of financial support from social assistants, but not disability benefit, without stating clearly why, although during the interview she made a gesture to show that it was due to being labelled with her mental health issue. This kind of 'label avoidance' is maybe the most significant way that stigma hinders care seeking by persons who are entitled to it (Corrigan P. , 2004). This evidence is compatible with the findings of this study that participants had often hidden their mental health issue from their social networks and avoided institutional support, although they deserved it, due to their lateral concerns, such as regarding employment and driving licence.

In terms of **provided social support** by the participants to other people, it appeared that most of them provided volunteer moral (to clients during employment as beautician, or in terms of reciprocity within interpersonal relationships) and/or practical support to others (through their paid employment or volunteer work, such as assisting in housework other family members, or making packages or cakes for people in need, and giving money to beggars), and only one participant stated that had never provided any support to others. Consequently, almost all participants provided or wanted to provide support to others and had an elevated sense of empathy, despite the fact they had psychotic disorders, which often have as symptoms detachment from reality and lack of empathy – as mentioned also previously. The value of helping others, and the aspiration to do so, has emerged in an earlier relevant study with participants with psychosis (Lal, Ungar, Leggo, Malla, Frankish, & Suto, 2013), thus the findings here are in line with this study too. This tendency and willingness of participants to help others, confirms the argument of another study as well that persons with disabilities make significant contributions to society, in terms of voluntary work and support to others, but these actions remain invisible and unrecorded, thus are not attributed to them (Chenoweth & Stehlik, 2004), although they should. It has to be noted here also that women tend to provide more frequent social support compared to men (Kawachi & Berkman, 2001), a phenomenon which may be more evident in southern European countries, and at least for Italy, it is quite evident the role of women as caregivers – based on my personal observations during previous work as researcher and my doctoral studies. Moreover, a systematic review and meta-analysis has found that regarding mental health, volunteering can have a favourable effect on depression, life satisfaction and wellbeing, nevertheless, causal mechanisms are not yet clear and there is also evidence that although persons tend to volunteer for altruistic reasons, if there is no experience of reciprocity, then there is no positive impact of volunteering on the quality of life of the volunteer (Jenkinson, et al., 2013). To conclude, it has been stated that having supportive relationships with family, intimate partners, and friends is crucial for recovery, along with engagement in socially valued roles and activities, as well as having a sense of belonging to communities, as recovery does not only take place in the mental health service system, but mainly in the person's interpersonal and social networks and everyday life, for example through self-care strategies (Georgaca & Zissi, 2017).

Six of the respondents reported having little or no **trust towards other people** in general within their community, and four that they do trust others, however, only one of them reported having a lot of trust in other people, thus could be assumed that participants reported a moderate to low overall level of trust towards others in general. Various past negative experiences of participants were the cause for their lack of trust, for example, being a victim of bullying at school or having shown trust to husband and health/social care professionals, who then put the participant into an institution questioning her ability to take care of her children. Hospital readmission rates for persons with psychoses have been found by a study being higher for people living in areas with high perceived community safety, thus high level of general trust, while the authors of that study presumed that this finding occurred due to low community tolerance to deviant behaviour (McKenzie, Whitley, & Weich, 2002). On the other hand, a systematic review of relevant studies has shown that there is strong evidence of inverse association between cognitive social capital (i.e. feelings of trust and reciprocity) at individual level, and common mental disorders, with higher levels of social capital being associated with lower risk of mental illness (De Silva, McKenzie, Harpham, & Huttly, 2005). Another study reporting on a trust game of real time social interactions between persons with psychosis, their relatives, and healthy controls, found lower basic trust in participants with psychosis and their first-degree relatives, compared to healthy controls, suggesting an underlying influence by family (Fett, et al., 2012). Persons with psychosis were found to have made the lower investments among the study groups and were the least successful in adapting their decisions to their partners' trustworthy behaviour (Fett, et al., 2012). In any case, one cannot develop any hypothesis with certainty regarding causation between social capital – of which trust is a main component – and mental health (McKenzie, Whitley, & Weich, 2002). Moreover, psychotic illness has been also associated with negative social experiences, which may strengthen distrusting behaviour, thus in order to clarify the role of trust and reciprocity in the onset and maintenance of specific symptoms, one should examine whether these behavioural alterations are present at the onset of the illness or are associated with a prolonged illness duration and symptom fluctuation (Fett, et al., 2012). Accordingly, the lower or higher level of individual trust reported by the participants of this study, towards their community, can be due to symptoms of social dysfunction of psychosis or due to their perception of their community as unsafe environment or experiences of betrayal or bullying by others, which were reported here, and naturally result in hesitation for any person in terms of trusting others.

Regarding **trust towards institutions**, it emerged that participants had moderate to low overall level of institutional trust, with most of them reporting trust in the police whereas only one trusting the press. The findings that police was the institution mostly trusted by participants and parliament one of the least trusted, confirms previous evidence from a study across 15 European countries, which found that persons with depression have more trust in the police and less trust in the parliament and politicians (Zoppei, et al., 2014). Two of the respondents stated that they had no trust in any of the four institutions mentioned (i.e. police, justice, parliament, and the press), with one of them saying only about the press that it depends on the situation whether it was trustworthy or not for her. Two of the respondents that demonstrated very low institutional trust were both workers in paid employment, however this finding is not in line with previous evidence that there appears to be more institutional trust in cases of higher income (Kaasa & Parts, 2008), although income of respondents here was not assessed, however there were unemployed participants to compare them to. Moreover, self-rated health has been associated with trust in institutions (Poortinga, 2012) and trust in government has been strongly related to good general and mental health (Goryakin, Suhrcke, Rocco, Roberts, & McKee, 2014). Similarly, the findings here that the majority of participants had moderate to lower levels of institutional trust, confirms partly this previous evidence, in terms that persons with poorer mental health are more likely to have lower trust in institutions. One of the respondents also had experience in the past of being caught by the police for a careless action during her hypomanic state and she had problems for years with this case with the police and justice, thus she did not have trust in these institutions from a personal experience. Relevantly, it has been argued that persons exhibiting symptoms and signs of serious mental illness are more likely than others to be arrested by the police and be incarcerated for longer time compared to others without a mental health issue (Corrigan P. , 2004).

Participants were found to have **similar opinion on civic norms**, apart from two participants who stated that for two of the civic norms it would depend from the circumstances whether they would agree with them or not. In any case, as it has been stated elsewhere, there is possibility that not all of the participants were honest about their opinion on civic norms since *"one has to bear in mind that claimed norms can noticeably differ from actual behaviour"* and participants may be *"reluctant to admit to bad behaviour"* (Kaasa & Parts, 2008, p. 151) irrelevantly if someone has a mental health issue or not. However, given the great homogeneity of responses here, and considering the fact that all participants were living in the same metropolitan area, could be assumed that there was high sense of reciprocity in terms of social norms among members of this community – irrelevantly if they have a disability or not.

The majority of participants were **active voters** and three were not. Two of the latter ones had never also signed a petition or participated at a demonstration, while the third one although she had done both, she did not remember the reason behind them and stated that she was not interested in politics. Half of the participants had never signed a petition or participated at a demonstration. Thus, the majority of respondents had active political participation in terms of voting, but **not signing petitions or participating at demonstrations**. In Italy, in 1967, persons placed in psychiatric hospitals and persons with capacity limitations were deprived of their right to vote with a law[28], a deprivation which was removed in 1978 with the so-called 'Basaglia Law'[29], thus now all persons with mental health issues and intellectual disabilities can vote in Italy (European Union Agency for Fundamental Rights, 2013). Moreover, it has been argued that mental health is connected to social capital, and in turn social capital is connected to political participation, thus it is important to explore the relationship between political participation and mental health (Couture & Breux, 2017). According to the same source, mental health has a greater effect on local electoral participation than on national electoral participation, and persons with mental health issues are more likely to sign online petitions than others; possibly because persons with poorer mental health might be more socially isolated and online petition signing is less 'costly' for them as a political act (Couture & Breux, 2017).

Six participants did not have a job in their field, and three of them faced difficulties due to their mental health issue **during their employment or for finding employment**, while the rest of participants, who did not have a job in their field, were not looking for a job (for example due to pregnancy) or could not find a job due to non-health-related reasons, and only four of the participants had a full-time job. One of the participants who faced difficulty during employment, Emily, experienced rejection by her colleagues when she was doing an internship as a nurse and was told that her mental health issue can be a problem while she is working. Therefore, she decided that when she tries to find a job again in the future she will not disclose her mental health issue to her potential employer for fear the employer might be scared of her having a mental health issue, and people get scared when they hear about psychiatry as she stated, which also indicates that she has received prejudice also apart from rejection within working environment. Similarly, two other participants, Lily and Susan, who did not have a job in their field and would like to find one, stated that they already have hidden or will hide their mental health issue from potential employers, thus the issue of hiding the mental health issue emerged again in this study, while Lily delayed to finish her studies and decided not to look for a job because she had to attend her recovery sessions at the hospital due to her mental health issues. This confirms also findings of a previous study, which argued that young people who experience a mental disorder experience also interrupted opportunities to achieve their

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[28] Art. 2 (1) and Art. 3 of the Presidential Decree no. 223/1967 (20.03.1967).

[29] Article 11 Law 180/1978.

vocational goals and make career choices, due to hospitalisation and recovery from their mental health issue, and there are a number of barriers which have an impact on their ability to achieve their goal of employment, such as related to personal losses, low self-esteem, lack of direction, and the experience of being unwell (Bassett, Lloyd, & Bassett, 2001). According to another study, negative employer and community attitudes towards mental illness are a significant barrier to employment, not only for finding employment, but also for opportunities for advancement within the job and having a risk of losing their job in case of economic difficulties of the company, even more for employees who hide their mental health issue from their employer, a fact which adds to the stress and possibility of the illness recurring (Bassett, Lloyd, & Bassett, 2001). Moreover, it has been found that persons with psychoses spend less time in work/education compared to persons with non-psychotic conditions (Leufstadius & Eklund, 2008). In specific about the context of this study, based on a recent Italian nationally representative study (Starace, Mungai, Sarti, & Addabbo, 2017), economic crisis has had a negative impact on society as a whole in Italy in terms of psychological distress, and young persons are more likely to be unemployed – regardless of having or not mental health issues – while among those with mental health issues, men and persons with low education level are more likely to be unemployed. However, this was not entirely confirmed in this study since two of the participants who did not have a full-time job in their field were educated to bachelor or master degree level, but the fact that there are high rates of unemployment for young persons in Italy was confirmed in this study too, with half of the participants having no job at all.

According to the findings on **barriers for social participation**, four of the participants never experienced any discrimination due to their mental health issue, whereas the remaining six participants experienced prejudice, discrimination, stigmatisation, and/or lack of empathy towards them from others, on the basis of their mental health issue, within their informal and formal networks, but also from the wider social network, and there were also participants that it was their choice to avoid social participation due to the nature of their mental health issue. These findings are in line with a study on a sample from the population of England, showing that the vast majority of persons with severe mental illness (88.2%) have reported experiencing discrimination in at least one domain of their lives (Webber, et al., 2014). A thematic synthesis of qualitative studies on stigma associated with psychosis, found that persons with psychosis perceive stigma *“as a* *systemic problem driven by several underlying processes"* (Wood, Burke, Byrne, Pyle, Chapman, & Morrison, 2015, p. 11). In particular, the stigma system refers to the fact that stigma originates from many aspects of a person's social environment, thus is socially embedded, and the way to overcome it is through both individual and systemic change, possibly with the use of large-scale anti-stigma initiatives (Wood, Burke, Byrne, Pyle, Chapman, & Morrison, 2015), such as campaigns or education of the public – as participants of this thesis suggested. It has been suggested elsewhere as well, that one way for diminishing public stigma is to protest, for example, against inaccurate representations of mental illness both to the mass media and the public who believe these inaccuracies (Corrigan P. , 2004). Because as one of the participants mentioned here, mass media present mental illness as something 'dangerous' and according to previous research, confirming that mass media inform the public about mental illness regularly and their presentations are both inaccurate and unfavourable for persons with mental illness (Wahl, 1992).

The **suggestions on removing barriers for social participation** as reported by participants, based on their personal experiences, were mostly public-oriented suggestions, such as education, campaigns, understanding, and change of mentality of wider social networks on mental health issues, as well as implementation of more projects for enhancement of social life of persons with mental health issues, but also individual-oriented suggestions, such as self-confidence, self-worth and self-acceptance of mental health issue by the person experiencing it. From the suggestions underpinned by participants there appeared to be various issues that persons with mental health issues face in relation to social participation, such as lack of information or ignorance of the wider social network about the nature and origins of mental health issues and discrimination also among various pathologies of mental health, the common perception by others that it is an intentional illness, the social stigmatisation towards them as being 'dangerous' or 'crazy', experiencing bullying from peers, having low self-confidence and difficulty accepting their mental health issue as well as communicating it to others, along with lack of social life and assistance through projects for persons with mental health issues. Persons with severe mental issues have also been found elsewhere to reduce their social contact when they experience discrimination, thus interventions for persons with severe mental illnesses aiming to increase social capital, should also consider both reducing discrimination, as well as supporting people to finding employment where possible (Webber, et al., 2014). In addition, similarly to the findings of this study, there is evidence that family and friends may represent sources of discrimination for persons with depression and other severe mental illnesses, thus psycho-education with persons' close social networks may help reduce discrimination against them and prevent any loss in their access to social capital, as well as working on a wider level, in order to promote changes in society, in the way in which communities will include, support and relate to persons with severe mental illnesses (Webber, et al., 2014) (Zoppei, et al., 2014). To this plays an important role also mental health literacy of the public, since the lack of understanding and awareness of mental disorders emerged in this study too. Accordingly, it has been found that the public have difficulty dealing with mental disorders because they do not have sufficient knowledge, have fear of making mistakes, and do not know how to behave to persons with mental health issues (Jorm, 2000). One of the participants, Emily, argued that her mental health disorder is a disorder like all the rest, however, this relates to campaigns' message that 'mental illness is an illness like any other' which has been argued that it follows the biomedical model, which in turn has been proven by studies to increase fear and social distance (Wood, Burke, Byrne, Pyle, Chapman, & Morrison, 2015). Thus, it has been proposed that psychosocial approaches in campaigns are more beneficial for tackling stigma and making the public understand mental health, with messages *"which encourage acceptance of difference, which dispel myths about dangerousness, and which portray mental health on continuum"* (Wood, Burke, Byrne, Pyle, Chapman, & Morrison, 2015, p. 12). Nevertheless, it has been suggested by studies that the public indeed discriminate among psychiatric groups in terms of stigma, thus persons with psychosis receive more judgement compared to depression or anxiety disorders, for example (Corrigan P. , 2004). The same participant also referred to another important issue having an impact on mental health, which is being a victim of bullying from peers, relating it to persons with depression or an anxiety disorder, who are usually more shy as persons, thus attract bullies. Concerning to this issue – and not only – a study has shown that adolescents with psychotic symptoms are significantly more likely to be identified as bullies or victims of bullying, as well as having been physically abused in childhood and exposed to domestic violence, compared to their peers without psychotic symptoms (Kelleher, Harley, Lynch, Arseneault, Fitzpatrick, & Cannon, 2008). It was also mentioned here by two participants, Susan and Jennifer, the importance of self-esteem and self-worth for them for overcoming barriers of social participation. This finding is in line with previous evidence, that people with mental illness often internalise any stigmatising ideas that exist within their society and believe that they are less valued because of their mental health issue, and this kind of self-prejudice and self-discrimination has a negative impact on a person's quality of life and life goals (Corrigan P. , 2004). Similarly, the issue of decreased self-confidence and self-worth has emerged in another study too on young people with psychosis, where it was argued that *"experiencing psychosis during the period of young adulthood has a significant impact on the young person's vocational, social and educational goals and plans"* (Bassett, Lloyd, & Bassett, 2001, p. 69).

The findings presented above on **barriers for living autonomously/independently**, three participants reported no barrier for living autonomously, while four other participants could live autonomously if they had a job or financially were able to sustain their expenses independently. Two of them had difficulty finding a job due to their mental health issue, the first one because she had difficulty in social relationships including work relationships and even to endure a job interview, given that she has a lot of anxiety, while the second one because she delayed to finish her degree due to her mental health issue and now she does not have a job in her field. The other three participants did not have homogeneity in their responses regarding barriers for autonomous living, with each one having a different reason that did not allow them at the time of the interview or in the past to have an autonomous life. These barriers were related to their mental health issue, such as being institutionalised or lack of right to have a driving licence, or due to other reasons, such as bureaucratic difficulty for having meal for children at school being a foreigner or disliking doing housework or not being allowed to live alone yet by a family member. As it emerged, overall participants experienced barriers of autonomy due to lack of a job in their field or adequate financial resources, and they expressed or hinted that they would prefer living autonomously without their family of origin, but were not certain if they would be able to do that due to their mental health issue or for other reasons. In another study as well was found that persons with psychosis wanted to decrease dependency on their families and work towards living independently (MacDonald, Sauer, Howie, & Albiston, 2005), thus this study compliments these findings. It also emerged here that participants had difficulties finding a job due to the symptoms and progress of their mental health issue, but as suggested by a previous study, this could be overcome if they try to believe in themselves more, and present their strengths and skills to potential employers and continue job search despite any rejection (Bassett, Lloyd, & Bassett, 2001). During interviews, two participants mentioned the fact that they were not allowed to possess a driving licence due to their mental health issue, and that is one of the reasons that one of them had not recognised her mental health issue officially – not receiving disability benefit – because she did not want to lose her driving licence. Indeed, in Italy persons with mental disorders are not allowed to have a driving licence according to the Italian State's law[30], specifically mentioning also about persons suffering from psychosis or personality disorders or taking any psychotropic medication, which may affect their driving.

Relevantly to participants' tendency of concealment of mental health issue and avoidance to acknowledge formally their mental health issue, there has been evidence that public identification as 'mentally ill' may cause significant harm, thus persons with concealable stigmas (such as persons with mental health issues) avoid this harm *"by hiding their stigma and staying in the closet"* (Corrigan P. , 2004, p. 616), or avoid the stigma all together by denying their group status and not seeking institutions that mark them, such as mental health care (Corrigan P. , 2004).

About **suggestions on removing barriers for autonomous/independent living** by participants, two of them who had experienced barriers for living autonomously suggested that these barriers could be removed by change of attitude of others towards them, such as with more openness and understanding by others, but also with a change of attitude of themselves regarding circumstances in their own lives, such as overcoming fear to live alone or finding alternative solutions to barriers. There have been three approaches suggested elsewhere (Corrigan P. , 2004) for diminishing aspects of the public stigma perceived by persons with mental illness: protest, education, and contact. Protest aims to diminish negative attitudes, but may cause rebound of the stigmatising attitude of the public due to reactance thus negative attitudes worsen (Corrigan P. , 2004). Education provides information to the public and studies on participation in educational programs on mental health have suggested that they do improve attitudes of the public, but may not endure over time (Corrigan P. , 2004). Lastly, stigma can be diminished if the public have contact with persons with mental illness who have a job and live as good as their neighbours in the community (Corrigan P. , 2004). Therefore from the above it can be

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[30] Decreto Del Presidente Della Repubblica 10 luglio 2017, n. 139. Regolamento recante modifica all'Appendice II al Titolo IV - Articolo 320 del decreto del Presidente della Repubblica 16 dicembre 1992, n. 495, in materia di idoneita' psicofisica per il conseguimento e la conferma di validita' della patente di guida da parte di persone affette da malattie del sangue. (17G00152) (GU Serie Generale n.221 del 21-09-2017). Note: Entrata in vigore del provvedimento: 06/10/2017. Gazzetta Ufficiale della Repubblica Italiana. Available at: http://www.gazzettaufficiale.it/eli/id/2017/09/21/17G00152/sg [Accessed 19 July 2018].

concluded that diminishing stigma does not only depend on change of mentality or attitude from the public *per se* through their education or better information, but also through change of outlook of persons with mental health issues themselves who should have more social participation and active roles in the community to prove to others their capabilities and thus change prejudice, and try to turn around barriers to their benefit by finding the positive alternative to them, such as one of the participants here suggested. The other two participants who faced barriers for living autonomously suggested that these barriers could be removed by more support from the State in terms of the amount of the disability benefit and the protection of the rights of vulnerable groups in practice within the employment sector where she knows persons belonging to vulnerable groups that are being exploited, since in practice the laws are not being implemented, a remark that also another participant made, who also suggested more safety, communication, and projects should be put into force by the Italian State for vulnerable groups. These two participants were both self-employed and one of them had also recurrent depression and the other one bipolar disorder. Regarding the issue of exploitation of vulnerable groups, it has been stressed by the UN Convention on the Rights of Persons with Disabilities (CRPD) 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, p. 2). Thus special attention should be given to banning incidents of exploitation particularly of women and girls with disabilities, also within employment and public sectors – which here emerged as important for overcoming barriers for independent living for population with psychosis.

To conclude, as it has been stated in previous parts of this thesis, there is need for mental health practice, as well, to move away from the old paradigm of 'fixing' individuals or correcting their deficits, towards trying to remove their barriers and create access for them through promotion of health and well-being, and therefore recovery in mental health should not be assessed anymore by the quantity of tasks someone can perform, but by the quality of life one has with support (Onken, Craig, Ridgway, Ralph, & Cook, 2007). In other words, it is vital to acknowledge that disability is an interaction between a person's characteristics and aspects of her/his social environment – among cultural, natural and built environments too – , thus understanding and support in terms of social participation and enhancement of social relationships can be important for overcoming also one's mental health issue.

4.3.2 Physical disability

In order to allow comparisons across types of disability, the Main Areas and Core themes included in the final template for persons with mental disability – which was the first one to be analysed – were also included in the other two types of disability (i.e. physical and sensory) explored in this study. However, themes and sub-themes were modified according to the aim of the study and the data reported by participants with physical disability, independently – meaning without any influence on the selection of themes between types of disability. The final template of the themes identified for participants with physical disability are presented in Table 3 below.

Table 3. Final template of themes for participants with physical disability.

MAIN AREA 1: THE BODY, SELF AND DISABILITY
CORE THEME 1. BIOGRAPHICAL EXPERIENCE OF HEALTH ISSUE
1.1 Age of onset
1.2 Cause of onset
1.2.1 Genetic disorder or pregnancy/birth complications
1.2.2 Traumatic injury
CORE THEME 2. COPING MECHANISMS FOR DISABILITY AND FEELINGS OF LONELINESS
2.1 Have help throughout the day to perform personal and civic life tasks due to health issue
2.2 Stay in their home when feeling lonely
2.3 Turn to friends or go out when feeling lonely
CORE THEME 3. PERCEIVED GENDER DIFFERENCES BASED ON HEALTH ISSUE
3.1 Gender differences relevant to physical functions and intimate relationships
3.2 Gender differences in a wider sense (not necessarily disability-related)
3.3 No major gender differences or no differences at all
3.4 Differences depend only on personality traits and not on gender or disability
CORE THEME 4. EXPECTATIONS ABOUT THE FUTURE AT INDIVIDUAL LEVEL
4.1 Positive thinking about the future in personal and/or professional life
4.2 Fear of thinking about the future due to health issue.

MAIN AREA 2: SOCIAL RELATIONSHIPS, SOCIAL PARTICIPATION AND DISABILITY
CORE THEME 5. SOCIAL NETWORKS (STRUCTURAL ASPECTS)
5.1 About size of social network and type of relationship
5.1.1 Size of social network
5.1.2 Family/partner and/or friends from childhood, school, university, or work
5.1.3 Friends through rehabilitation centre or sports
5.2 Frequency and way of contact with ties of social network
5.3 Membership at organisation or volunteer groups (formal social networks)
5.3.1 Association of persons with disability and/or sports group
5.3.2 Political group or trade union
5.3.3 Do not belong to any group currently
CORE THEME 6. DAILY ACTIVITIES
6.1 Commonly going out socially
6.2 Not regularly going out socially
CORE THEME 7. DISABILITY-BASED HOMOPHILIOUS OR HETEROPHILIOUS SOCIAL NETWORKS
7.1 Social network with both friends with and without disability
7.2 Social network including only one or no friend with disability

CORE THEME 8. CHANGE OF ATTITUDES OF SOCIAL NETWORK DUE TO DISABILITY
8.1 Experienced no change of attitude or negative attitudes from others
8.2 Experienced negative attitudes or negative change in attitude of others
CORE THEME 9. SOCIAL SUPPORT (RECEIVED AND PROVIDED)
9.1 Received social support
9.1.1 Mainly support from family/partner and/or friends (informal support)
9.1.2 Mainly support from care assistants and/or health professionals or others (formal support)
9.2 Provided social support
9.2.1 Support through associations/organisations of persons with disability and/or political activity
9.2.2 Psychological support and encouragement
CORE THEME 10. TRUST
10.1 General trust
10.1.1 Trust other people in general
10.1.2 Do not trust others at all, or not always, or it depends from time to time
10.2 Institutional trust
CORE THEME 11. OPINION ON SPECIFIC CIVIC NORMS
11.1 Disagree with tax evasion, claiming government benefit that one is not entitled to or accepting a bribe during work
11.2 Agree with claiming benefits one is not entitled to or it depends on the motive about tax evasion
CORE THEME 12. POLITICAL PARTICIPATION
12.1 Voting at elections
12.2 Participation at demonstration or signed a petition
CORE THEME 13. EMPLOYMENT DIFFICULTY DUE TO HEALTH ISSUE
13.1 Employment barriers due to inaccessible workplace
CORE THEME 14. BARRIERS FOR SOCIAL PARTICIPATION AND SUGGESTIONS FOR REMOVING THEM
14.1 Barriers related to physical environment and accessibility issues
14.2 Barriers related to social environment
14.3 Suggestions for implementation of existing laws on accessibility and denouncement of accessibility problems to institutions
14.4 Suggestions for change of mentality of the public, more public visibility of and communication about persons with disability, education of the public, and life projects for persons with disability
CORE THEME 15. BARRIERS FOR INDEPENDENT/AUTONOMOUS LIVING AND SUGGESTIONS FOR REMOVING THEM
15.1 Major dependency from parents and/or partner and/or need of more financial support
15.2 Physical environment / accessibility barriers
15.3 Lack of a common law, cultural and bureaucratic barriers
15.4 Suggestions of changing mentality of the wider society on persons with disability and/or removing architectural barriers
15.5 Suggestions to provide financial support, employment opportunities and advanced education to persons with disability
15.6 Suggestions to denounce barriers to institutions and provide institutional support at municipality level
15.7 Suggestions towards self-empowerment, finding the resources to reach autonomy and not focusing on disability.

Then there are the mental barriers, there are prejudices and in my opinion those hurt the most. From my own direct experience I have not received in particular any prejudices, but I know people who... and I hear about people who are subjected to them [prejudices] and those really hurt at heart, because we are persons with disability, we are neither handicapped or... we are only persons who have a little problem or a big problem, but from a physical point of view, but we are equal to everyone else. We also have brain, we also have the capacity to think, so the most dangerous barriers are mental barriers, in my opinion, because when you have a mental barrier or when you do not consider the person in question or anyway you think about the person as a poor one, as someone who is not able. In contrast, we are all able in some ways to... to say that we exist, maybe with different instruments, because maybe one who does not speak, maybe communicates by drawing… or with sounds, but everyone communicates and everyone has the right to be treated as a human being. (…) And so it is not right that society discriminates these persons. Rather, that

> society discriminates us, I put myself among them, I am also a part of persons with disability. Fortunately I have never been discriminated, but there people that unfortunately… they know it and they suffer because of this and in my opinion this is something unfair and shameful, in my opinion. Amy (P).

Main Area 1: The body, self and disability

Core Theme 1. Biographical experience of health issue

1.1 Age of onset

Participants were asked to state the age of onset of their physical health issue. The vast majority of them (N=8) had a congenital condition, whereas two suffered traumatic injury (an acquired condition) due to accident, one of them at the age of 11 and the other at the age of 18. Of those who had a congenital condition, some of them had never been able to walk, such as Diana and Penny, whereas others were able to walk at first but gradually stopped walking due to the progression of their health issue or an accident, which occurred in the cases of Brenda and Nicole, with the oldest age reported among participants for having stopped walking being 18; by Phoebe and Nicole. Thus, all participants were unable to walk by the time they reached adulthood. In addition, some of the participants with genetic conditions had the diagnosis of their health issue once they were born while others few months or years later, such as Rebecca who was diagnosis in birth, and Janet whose diagnosis was made when she was about one year old, or for other participants, when parents noticed that their child could not walk properly or had pain and fractured bones, such as in the cases of Phoebe and Lucy, respectively, and, thus initially considered it as a developmental delay of the child and not a physical health issue:

> I was born with disability, because my disability has been due to a birth trauma. I have perinatal spastic tetraparesis, so I got to know disability from the start, because I have never walked. I was lucky to have a normal inclusion, because I went to school normally, elementary, middle school, I did not have any problems in dealing with others. Diana (P)

> I have a type-3 spinal muscular atrophy (SMA) that was diagnosed when I was 3 years old. They noticed it, actually my mum noticed it because I was walking badly in comparison to other children, they saw that my mobility, my walking was a little bit different, I was walking a bit like ducks. So, ok, they did to me various exams, in the beginning it looked only like a developmental delay, but then in [a hospital] in Genoa I was diagnosed with SMA-3. Then from that moment on, let’s say that I did not have big problems until my first years, because my SMA develops mainly in the age of adolescence, so let’s say that up to 6-7 years old I

was a normal girl, then of course I had some difficulty in walking, but not serious. Then in the elementary school I started getting worse a little bit, I also started using a manual wheelchair, and then in high school I continued anyway using manual wheelchair, but while in the elementary I was still walking a bit, in high school I was practically almost always in a wheelchair. Till the age of 17-18, when I lost all my autonomy, because until that age I was able to go to the bathroom on my own, get up from the chair, but then from that age onwards I was not able to do that anymore, so from that moment I have needed someone to help me. Phoebe (P)

So, the osteogenesis imperfecta (brittle bone disease) is genetic, so I have it since my birth. The first years actually, in comparison with more severe forms, mine is a moderate form anyway, when I was born there were not so strong evidence, because I was born with caesarean section and I did not have any fractures during delivery, so nobody could imagine this thing. (…) But then fortunately they [her parents] started visiting different paediatricians, one doctor told them ‘look in my opinion the type of X-ray that I see, the composition of the bone that I see, it could be this pathology, and he directed us to go to Brescia where there was the first orthopaedist at the time, who was working on this pathology, now there are others, and he directed us to the prognosis and the various interventions to be done, etc., etc. So then when I was about 2 years old I had the surgeries where they put nails on the shinbones and from that I gained a bit of autonomy, because anyway I could move more without always fracturing substantially any bones. Lucy (P)

So, it was an accident on 17th August of 2005, I was on the mountains with friends, I had an accident on the mountains. Brenda (P)

Mine is a pathology that starts from birth, so I have never walked. I was born in a very little town of the Piedmont region where I was the only one ever been seen around in a wheelchair, and fortunately I had a very good social network also in terms of family but also of friends whom I met. I grew up in a wheelchair, I started studying, after compulsory education to a nearby town, where then I moved to live on my own after my first degree. Penny (P)

No sociodemographic similarities emerged for participants under this theme.

1.2 Cause of onset

1.2.1 Genetic disorder or pregnancy/birth complications

Three of the participants were diagnosed with spinal muscular atrophy (SMA), two with spastic tetraplegia, one with arthrogryposis, one with osteogenesis imperfecta – which is also called brittle bone disease and it is a rare pathology –, and one participant with congenital disease of muscular form. Thus, the majority of participants had a congenital and genetic physical health issue, related to neuromuscular, muscular or bone disorders, with no specific cause mentioned, since their condition belonged to genetic disorders, however, two of them stated a possible cause for their health issue. In particular, one of the participants with spastic tetraplegia, Amy, stated that she was born prematurely due to an unexpected respiratory failure, and another participant, Christine, that she was diagnosed with arthrogryposis but after many exams that she has done it was concluded that her health issue is not degenerative nor genetic nor hereditary, possibly caused by a virus during the last month of the pregnancy, but they do not know – to the date of the interview – the exact diagnosis and cause of her health issue:

> So I was born at 6 months, I was born prematurely, due to an insufficiency, I had an unexpected respiratory insufficiency, and then with my condition I was always fine also with relations with others, I have never experienced discrimination of any kind, neither have I never been maltreated, on the contrary I was always involved in any experience that I have lived from a social point of view, starting from elementary school until the university, and also in other settings non-related to school I have always been integrated very well, I have not had any, how to say it, I have not had any problems in relating to others. Amy (P)

> Actually it is still not clear what I have, because the name ‘arthrogryposis’ is name that defines a group of pathologies, each one has its own characteristics, each one is with specific, so the exact name is not known, neither exactly where it originated, and the exact origins, it is thought that it was originated from a virus in the last month of pregnancy. Because from what my mum told me, from the tests that were done it resulted that when she was in the last months of pregnancy, so in the months of development, I developed normally, and I was also moving. In the last month [of pregnancy] incurred this virus, which depends on the peripheral zone of brain, and it is of neurological nature. My brain gives order to my legs to move, but the nerves of my legs do not follow this order, so it is as if they were asleep. So it is a problem of this kind, everything is covered by fog. (…) Then they did more in-depth examinations and saw that it wasn’t SMA, and among other things we discovered that my pathology is neither degenerative, nor genetic and hereditary. Christine (P)

No sociodemographic similarities emerged for participants under this sub-theme.

1.2.2 Traumatic injury

Two participants did not have a congenital or genetically-related condition, suffering from tetraplegia due to an accident that occurred early in their lives. One of them, Brenda, when she was 11 years old she was injured by a 10-metre fall while she was on the mountains with friends, and the other one, Nicole, when she was 18 years old in a car with friends they had a car accident from which she was the only survivor:

> So, it was an accident on 17th August of 2005, I was on the mountains with friends, I had an accident on the mountains and fell down from 10 meters, and I had the injury. So from then on I had the injury. Since then have passed 12 years, first I was brought to the hospital of Geneva because I was in France at the time, at the time of the fall, and they agreed that the most appropriate place to bring me was the hospital of Geneva, then after one month I was brought to the spinal unit of [hospital in Milan] where I stayed from 5th September until 1st April 2006. Brenda (P)

> When I was 18 years old I had a car accident, I was in a car with friends and I was the only person to come out of the car with an injury and then I spent one year in the hospital doing physiotherapy and recovering after the accident. When I got out of the hospital I went back to school, actually I continued also the story during the year in the hospital and when I was out then I took the high school final exams and I started the university. Nicole (P)

Both participants with traumatic injury were never married, had a similar age (i.e. 23 and 24), were among the youngest participants with physical disability, while one of them was an undergraduate student and the other one had just finished her undergraduate studies.

Core Theme 2. Coping mechanisms for disability and feelings of loneliness

Participants reported various ways for coping with their physical disability and for tackling feelings of loneliness.

2.1 Have help throughout the day to perform personal and civic life tasks due to health issue

All participants with physical disability required assistance with everyday tasks, mainly regarding their personal hygiene and using the bathroom, as well as moving to and from work or around the city in general. Some of them reported having a family member or partner as an informal caregiver, who was helping them for free, or care assistants or co-workers who were helping them on payment, in order to perform daily tasks in or outside their home. Participants also mentioned making adaptations in their own houses or car in order to meet their needs and make them more usable for them. Most participants who received external help (not from a family member) mentioned that they were paying people to help them through their own pocket money, whereas one participant mentioned receiving funding through a project of the Lombardy region for people with severe disability that she was part of. Also some of the participants stated that they were living independently from their parents, only with the help from their partner/husband and/or care assistants:

I always need help because, in the sense that... I've been working for 15 years part-time at the municipality (…) but I need someone to bring me to work and to come and take me from work, because I do not drive. I just have a specially adapted car with a platform for a wheelchair, but someone has to drive it for me and I go accompanied [by someone]. I always need help from someone. (…) it is a person to whom... I pay a contribution and gives me a hand (…) It is a little bit like this for everything, because let's say there are very few thing for free, apart from volunteering. I manage to put all the pieces together. Diana (P)

I have had a very capable family, very good that helped me build up a good profession, that gives me a great income, and so basically I manage to pay for having the assistance that I need. I am working, I am a freelancer and have persons who help me with daily activities that I cannot do on my own. Maybe a fundamental thing that allowed me to reach the point of being completely independent, even with help, is having a high level of education, and thus to be able to have a profession that allows me to pay for the help that I need. Janet (P)

There is personnel that works in general services here that take care of the receptions to whom it was done a training to be able to help [someone] go to the toilet. Because the big problem when you are around is the toilet. For this reason there are two people who work here normally, and who in addition get some extra money because once or twice a day I call them for the toilet, so I have two persons in the morning and two in the evening. They are not my employees, they are doing their own job, but if needed they come down and give me a hand, and this happens a couple of times per day. Whilst at home there are still my parents, but they are getting older, there is my husband but he is working, but at home I can move around better, because the house is more adapted to my needs, at least for now, then we will see about the future. Rebecca (P)

Concretely since I became an adult I have started using this fund for assistance of independent living, by which I have personnel paid by me, who are my legs and my arms, they help me with everything, to conduct my personal tasks but also with transports, and with everything that is included in my daily tasks and this allows me to have that level of autonomy that does not depend on my family, even if my parents are absolutely alive and present but I got detached from the nucleus [of family] and started my independent life thanks really to the personal assistance, which allows me the quality of my life. Penny (P)

2.2 Stay in their home when feeling lonely

The majority of participants reported that they usually stayed at home when they were feeling lonely, without mentioning any contact with others. They stated that they mainly prefer listening to music, watching a film, writing, or drawing:

> When I was younger I used to stay on the internet a lot. Now I do not have much time, when I feel a little bit lonely, so maybe I listen to the music, that yes, or watch a movie, but most of all I listen to the music. This yes. Phoebe (P)

> I write on the blog or I write on Facebook and I share it in the way… I like a lot using irony, so also when I am a little bit sad I write in an amusing way in a way that people would want to laugh together with you, and to exchange opinions but in a calmer way. Rebecca (P)

> I have always had passion in writing, so my therapeutic way to deal with and to analyse things is to write, then for the rest I listen to the music, and for the rest I think of a way to manage to get out of that situation and I am positive, I stay positive because it is a thing that I do not want to do and I try not to feel down for a long time into the vortex of depression, even if as everyone I have my moments of discouragement, but I try staying positive and cling on hope because I think that if one does not have hope, cannot manage to live. If I did not have this conviction that maybe it is a little bit idealist, a little bit illusory, that things can go well, that something will go well or better, if I don't have this hope I wouldn't manage to deal with every day, this is the hope in order to deal with my moments of loneliness. Christine (P)

> Like all other people, I am a person that sometimes feels lonely even if I have a lot of friendships, and how do I deal with it? Hmm I have found a beautiful I believe, very efficient: to go to this centre Activity Place [a rehabilitation centre], and to engage in their activities, mainly I am telling you about painting. While I am painting I let off steam, I put on the canvas all my anger, all my delusion, all my happiness, I mean any emotion that I am feeling in that moment I throw on canvas and it takes a form, a picture which then expresses who I am in that moment. So painting has helped me a lot, let's say as an instrument to express my dissatisfaction or my fear, or my happiness. Painting helped me a lot, also working with clay helps me, but painting let's say that is the instrument that until today I prefer for expressing myself truly when I am not able to do that with words, it is the instrument that I prefer. Amy (P)

No sociodemographic similarities emerged for participants under this theme.

2.3 Turn to friends or go out when feeling lonely

Only four of the participants, Diana, Nicole, Lucy, and Janet, mentioned speaking to friends or going out in moments of loneliness, either to a bar or for dancing or to go shopping to feel better. One of them, Janet, reported that she would actually prefer to have more time to herself, but as she needs help from others to perform daily tasks, it is difficult to find some time alone to herself:

> To deal with it [loneliness], I need to let off steam with someone, mainly need to let off steam with someone, it can be a female friend or male friend, but I always need to let off steam usually. Nicole (P)

> A bit to look for others, that famous sentimental circle, to say I feel lonely and to seek their comfort. Actually I do not suffer a lot from loneliness because by nature I am quite… I actually like being alone every now and then, if we can say it is the opposite, a person who has an issue with non-self-sufficiency, at least me, every now and then I suffer from the opposite thing, so to have the need of other people to be able to do many things makes you stay for very small amount of time on your own. And I sometimes would like to be able to do stuff for myself, because I am quite independent and autonomous by nature, I don't like… I like every now and then having… eh whoever needs help for practical things, unfortunately does not have solitude. Janet (P)

The four participants who reported that they turn to friends when they are feeling lonely or go out were never married, but one of them was cohabitating with her partner.

Core Theme 3. Perceived gender differences based on health issue

Participants were asked whether they have ever met a man with the same health issue as theirs and if so, if they have noticed any differences between men and women with this health issue.

3.1 Gender differences relevant to physical functions and intimate relationships

Three of the participants, Christine, Brenda and Phoebe, referred to gender differences in terms of behaviour in intimate and sexual relationships, one of them stating that men with the same type of disability tend to have more difficulty finding a partner compared to women with disability, another one said that she has friends with the same type of disability who have more difficulty in having a steady and long-lasting intimate relationship, and the other one stated that there is a different approach between men and women with disability in terms of sexuality. By two of the participants, Phoebe and Amy, it was noted that there are differences also regarding basic physical functions, such as toileting, for which men might find it easier to do their need than women:

Yes, certainly there are differences mostly at physical aspects, in dealing with personal matters and maybe in my specific case, being a man can bring more difficulties in social approaches, not so much in friendships but in the intimate relationships, there could be more difficulties. I have friends who have had more difficulty or relationships that lasted for less time or that changed more often. Of course to say that this was due to their character or their disability, only they would know this. Brenda (P)

In my opinion, also at the level of, ok, how one goes to the toilet, because for a man for example if he is around has less difficulty because anyway he does not have to actually go to the toilet, whereas for us, women, it comes a bit more difficult, so when you are around and you want to go to the bathroom it's not that you pull out the 'parrot' and you go to the bathroom, the thing is more complicated. Then also certainly at the level of sexuality, it is anyway a different approach the disability of a person who is male from a female person. Phoebe (P)

We have the same problems and obviously we live them [the problems] maybe in a different way, but the problems are the same. Maybe there are male persons... who maybe have problems that I don't have, they have a tool to solve them that I do not know. Also from the physical point of view, maybe people who do… I don't know, for example catheterizations, but I do not do that, to say that this is a different problem, but in general we are all treated equally, so I do not notice any differences, maybe only at physical level for the problems that one can have. Amy (P)

No sociodemographic similarities emerged for participants under this theme.

3.2 Gender differences in a wider sense (not necessarily disability-related)

There were participants who stated that they have noticed gender differences based on physical disability, however these differences are possibly irrelevant of disability and similar for any man and woman depending on their character, such as, reported by Lucy, men being attached to their mothers for too long and do not live on their own, or when a participant goes to work even when she has back pain and a fracture in her hand, but men make a tragedy and suggest to relax and not do anything. Another participant, Janet, pointed out that women have insecurities about their body and being attractive, so she stated that women with disability have even more insecurities, and they also discuss with their female friends about any intimate details, so women are not ashamed to talk about problems of intimacy and being fragile, whereas she does not know if men have this kind of relationship with their male friends too, and she has experience being in a profession dominated by men (i.e. lawyer) so she has faced also difficulties related to gender within her profession too:

> Then there is always the issue that maybe males make things tragic, if I think also about a very dear friend, who tells me you should stop, you should rest, not exaggerate and I on the opposite if I have to do something, even if I have a backache, if I have one broken rib or a minor fracture in my hand like last week, it is not that I do not go to work or do not do what I have to do. So I do not know how much it is related to character or to gender. Lucy (P)

> There is a difference that goes beyond disability, which is a difference that I think exists between a man and a woman. It is clear that some issues of fragility, of insecurity related to the body, being attractive, all the insecurities that we [women] all have, when you have a disability they get amplified a lot. And this is the hard part. We women are a little bit more insecure by nature, if we add to this disability, then insecurity increases. But I think that a positive side, at least in my experience, I with my female friends have very intimate relationship of sharing which I do not know if it is the same in the friendly relationship among men, you know you have to be good-looking and that in my opinion is a facilitation. Anyway with my [female] friends I have always found a possibility to tell them about difficulties, even if I am very discrete, I find it quite difficult to open myself on my personal issues, but female friendships are actually a little bit different, and this I think... I have never felt ashamed to show my fragility to my female friends, I don’t know if it is the same in friendships among men. Janet (P)

Both participants who reported gender differences in a wider sense, not related necessarily to physical health issues had a master’s degree, never been married, and were working in paid employment.

3.3 No major gender differences or no differences at all

Three of the participants, Rebecca, Nicole and Diana, reported that they had not noticed any particular gender differences, with one of them stating that she has noticed that men with physical disability receive more help from their male friends compared to the help women receive from their female friends. One of the participants, Diana, mentioned that she knows other men with physical disability but did not say in detail if she sees any gender differences:

> No, actually no [gender differences discerned]. (...) If it is about disability maybe men are able to help each other more, while us women help each other less, I have noticed that. (…) I see that my male friends in wheelchair maybe have more help from their male friends, while I with my female friends… they help me less. Nicole (P)

All three participants were living with their mother or both parents.

3.4 Differences depend only on personality traits and not on gender or disability

One of the participants, Penny, expressed the opinion that any difference depends on the development of the person and the person's characteristics, which are different between a man and a woman, but these characteristics, experience and personality influence how the person experiences her/his pathology more than the person's gender:

> I start from the premise that the first difference depends on the person, so certainly this is the first difference despite gender. Then I believe that rightly also male and female, that inside a man or a woman who developed in a different way have some characteristics, so it is obvious that these characteristics influence the way in which a person lives also his pathology. But even before the gender difference I believe that the individual makes the difference, his experience, personality, what she/he has built. Penny (P)

Core Theme 4. Expectations about the future at individual level

Participants were asked what their expectations were about their personal and professional life in the next 10 years.

4.1 Positive thinking about the future in personal and/or professional life

The majority of respondents stated that they make positive thoughts about the future regarding their existing own family or getting married and starting their own family, to travel, or regarding professional life, to continue working in their field or having a stable job, and two participants mentioned expectations also in a more general sense, such as to be in a world that is more inclusive not only of disability but any kind of diversity, and being involved in politics on persons with disability and make steps forward:

> I am always a little bit positive about these things because at the end the luck of having a family gives me strength. But for my daughter I hope that she lives in a more righteous world, more equal, more inclusive, in terms of disability as well as for other diversities, because there are diversities but everyone is in their own way different and equal. More respectful the world, less mean and less selfish, and nothing, I hope that institutions really will come to us and even those who have a say in speaking to society like that, will change a bit this style, will come a little bit closer to persons in comparison to economic interests and anything else. Phoebe (P)

> I hope to continue to be involved in politics which is a thing that I like, I hope to be able to continue doing my profession that I am doing and I like. Let's say, if it continues like this, I am happy. Janet (P)

> I hope to have a steady job. I would like to create a family. I am ambitious and so I already see myself with a family, but to have a stable situation also from a sentimental point of view, and maybe to have a house that is mine, shared with my partner and to manage to take a driving licence, and so to have a car to be able to move, and then I hope for more engagement from the part of political forces on the issues of disability, so I hope that in 10 years they would have made at least some small steps forward. Christine (P)

No sociodemographic similarities emerged for participants under this theme.

4.2 Fear of thinking about the future due to health issue

Three of the participants, Diana, Rebecca and Amy, did not have a positive outlook regarding their future. Diana stated that it terrifies her to think of this question because she does not know if she will have any help in the future. Amy said that she is afraid to think about the future, but hoping she will be able to live on her own and having an assistant and a worthy quality of life. Lastly, Rebecca was more pessimistic about the future, stating that she prefers not to think about the future as well, and live day by day, because due to her health issue she might not even be around anymore in ten years' time:

> In this moment I don't ask myself this question [regarding expectations about the future] because it terrifies me, because there no predisposition for help. It is a big unknown and it scares me. I am honest. Diana (P)

> So my future? In 10 years from now... If you even ask me what I will do tomorrow, I will respond to you that I don't know, I mean that... so I am afraid to talk about my future, but my future in 10 years from now, like now... so I would like to still see myself in this house, maybe to live on my own with some help let's say from assistants, but I say that I would like to see myself because I already know that it will be very difficult to have that because... if these are the premises, I am already fighting to have it and it is already difficult now… imagine in the future. But I told you that I am a very positive person, so I say that in my opinion I hope to have a worthy future... of my quality of life. Amy (M)

> I think of not thinking about the future, mostly because in theory I should have died when I was 18 years old, therefore I have learned a lot to live day by day. It does not mean that I do not do things for my career or to increase my level of culture or knowledge. But I try not to ask myself how it will be in ten years,

> because it might be that in ten years I will not exist, like everyone else, I am just a little bit more aware of it. Rebecca (P)

The three participants who stated that they were afraid to think about their future were older than 30, living with their mother or both parents, and had a congenital health issue.

Main tendencies of Main Area 1: The body, self and disability

According to the findings, all participants had lost their ability to walk before the **age** of 18. Eight participants had a congenital condition and the other two, who were also among the youngest participants, had an acquired condition due to traumatic injury. As mentioned by participants, some received the diagnosis of their condition very early in their life while others later on, since their parents at the beginning thought that their child had a developmental delay and not a physical health issue. In addition, there were participants who had a progressive condition being able to walk with difficulty at first, while others were never able to walk. As mentioned above, regarding the **cause** of their physical health issue, the majority of participants had a congenital and genetic physical health issue, related to neuromuscular, muscular or bone disorders, with no specific cause mentioned; however, two of them stated a possible cause for their health issue, such as premature birth due to unexpected respiratory failure, and possibility of a virus infection during the last month of the pregnancy. The two participants who had suffered a traumatic injury one had an accident falling on a mountain and the other one had a car accident. Based on a previous study by DeLoach & Greer (1981) [as cited in Antle (2004)], children growing up with physical disabilities are more likely to have a positive sense of themselves compared to their peers with an acquired disability, because the first ones' physical differences are 'normal' for them, however later on in their life they might experience disability-related stress too when they are able to perceive negative views about living with a disability. This was partly confirmed by a later on study (Antle, 2004), which on a sample of persons with physical disability younger than 23 found a significant inverse correlation between sense of self-worth and age, with older age groups being associated with lower self-worth scores, as well as that young people born with physical disabilities do not have a negative sense of self until they are older and able to perceive and internalise stigma. Relevant to differences in age of onset of disability and in terms of socialisation, as it has been stated in a previous chapter of this thesis, according to Goffman (1963), the different patterns of the phases of socialisation of a stigmatised person include: a) those who were born with a stigma and become socialised without having realised yet fully the consequences of their situation; b) those with congenital stigma who learn to see themselves in their early life as similar to everyone else – however later in life they will have a ‘stigma learning’ experience which cannot be protected from; c) those who become stigmatised later on in their life, or learn later that they had a stigma, but had 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 be their real and valid identity. Given the variety of onset age and progression of disability of the participants of this study, all these patterns of socialisation could be represented by the participants, however they all seemed to be fully aware of the consequences of their situation, thus the first pattern was probably not confirmed here, plus, it is not certain whether any of the participants were initially socialised within a confined community or not.

In terms of **coping mechanisms for disability** reported by participants, all participants required practical assistance to cope with the physical limitations of their health issue in order to perform daily tasks, such as going to and returning from work, having a bath or going to the bathroom, and moving around the city in general. Persons helping participants were family members/partner, co-workers, or other persons under payment, such as care assistants. One of the participants mentioned also having made adjustment to her house to meet her needs; however it can be speculated that other participants have done the same but omitted to mention it. About **coping mechanisms for feelings of loneliness**, most participants preferred staying at home listening to music, watching a film, writing or drawing without mentioning any contact with others, while only four participants mentioned speaking with friends and/or going out with them when feeling lonely, and one participant mentioned that she would like to have more time alone to herself, but as she needs care assistants it is difficult. A study on loneliness and physical disability concluded that physical disability affects the quality of loneliness, in the sense that persons with physical disabilities will experience more “self-alienation” and attempt *“to dissociate from the agony and to dull the pain (of their illness as well as their loneliness)”* more, compared to persons without physical disability (Rokach, Lechcier-Kimel, & Safarov, 2006, p. 695).

In terms of **gender differences based on physical disability**, some participants mentioned that they had noticed gender differences on the basis of sexual behaviour and intimate relationships, with men having more difficulty finding a partner and a steady relationship compared to women with physical disability, and have a different approach on sexuality. As it has been found elsewhere, persons with severe physical disabilities had mutual sexual activity significantly less frequently, compared to persons without disability, and women with physical disability were found to have significantly more positive feelings of their sexuality and significantly more frequent mutual sexual experiences compared to the male participants (McCabe & Taleporos, 2003). Thus the findings of present study confirm the difficulties participants presented here in terms of approach on sexuality and frequency of sexual relationships. Apart from gender differences based on sexual behaviour, two participants mentioned that it is easier for men to perform their toileting needs compared to women, due to the physiological differences between the male and female body.

There were also participants who reported that they had noticed differences between women and men with physical disability, but not necessarily related to physical aspects but related more general behaviour patterns. For example, men being more attached to their mothers and not living on their own, or women being more insecure about their body image compared to men, women talking more openly about their intimate relationships and feelings compared to men, and experience of male domination within a profession (i.e. lawyers) by a woman professional. The issue of self-perception of body image has already been mentioned in a previous chapter of this thesis, in respect to the 'looking-glass self' by Cooley (1922), a self-idea 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. As the participant, Janet, here mentioned on this topic, some issues related to fragility and insecurity of the body, being attractive, and insecurities that all women have, become more amplified when a woman also has a physical disability. Thus the 'looking-glass self' of women with physical disability includes added insecurity of their body image compared to women without disabilities. This assumption is in accordance with the findings of a previous study (Moin, Duvdevany, & Mazor, 2009), which concluded that although women with physical disability had the same sexual needs and desires as women without disability, their body image, sexual self-esteem, sexual satisfaction and life satisfaction were significantly lower compared to women without disability, and these differences were stronger among young adult women; similarly to the age of the participants of this thesis too. Lastly, there were also participants who stated that they had never noticed any differences between men and women with physical disability, with one of them mentioning that maybe men receive more assistance from their male friends compared to the help women with physical disability receive from their female friends.

The majority of participants reported making positive thoughts in terms of **expectations about their future** within the next ten years, such as making a family, having a stable employment, and travelling. Nevertheless, there were also participants who did not have a positive outlook about their future, and were afraid to think about it, due to fear of what will happen in case their informal caregivers, such as parents, will not be able to help them anymore, or due to having a health issue which may not allow them to live through the next ten years, thus having a more pessimistic outlook about their future. Due to the finding that the three participants who stated that they were afraid to think about their future were older than 30, could be possibly assumed that older participants were more pessimistic about their future, whereas younger participants more optimistic, however, that is probably a supposition applicable not only for participants of this study but the general population too. Indeed, similar findings have been reported by a recent study on optimism and pessimism in a general population sample of 9,711 participants (Hinz, et al., 2017), showing that in terms of age, the older age groups reported less optimism compared to the younger ones. There were also participants who had expectations related to a more global level, for example, that the world will be more inclusive of any kind of diversity, not only disability, and aspirations that they would be able to help others through politics on persons with disability for improving the future for them.

Main Area 2: Social relationships, social participation and disability

Core Theme 5. Social networks (structural aspects)

5.1 About size of social network and type of relationship

5.1.1 Size of social network

Regarding the size of the social network, not all of the participants mentioned an exact number. However, from the persons they mentioned belonging to their close social network, the smallest number of ties within the social network of participants with physical disability was about 5 people and the largest about 20 persons, with the majority of them mentioning about 10 people in their close social network.

In specific, Janet reported the largest close social network including about 20 persons in it, followed by Diana, Brenda and Lucy who included about 10 persons each. All four of them were working and never been married. From those who mentioned an exact number, the smallest close social network was reported by Phoebe who mentioned 5 persons, and Nicole 6 persons within their close social network; who did not have any sociodemographic similarities.

5.1.2 Family/partner and/or friends from childhood, school, university, or work

About the type of relationship with the persons that participants mentioned as part of their close social network, all of them mentioned family and friends, except from one of the participants, Penny, who did not mention her family, only friends and colleagues being her family. The majority of participants mentioned having friends since high school, university studies and/or work, some of them mentioned friends from elementary school, and fewer mentioned friends known through other friends or an ex-partner, while one of them, Brenda, mentioned friends from nursery school, and another one, Janet, mentioned also friends from her political life:

> Of course, for sure my family, my husband, then obviously my colleagues, because while working far from home all day long the colleagues become almost ‘family’, in quotation marks. While lately as I do various presentations for the book there are different contacts deriving from Facebook, but for promotional

campaigns for the book, so people contact you for events and similar stuff, saying that… and because many of them maybe have similar difficulties, then… Let's say that I have never hanged out a lot with the disabled, not because of racism, but because I have never attended institutions for disabled, except when I was very little and I was doing physiotherapy. Lately on the other hand because of the book I have contacts with various associations, that I did not have before, and from there were born new friendships, new acquaintances. Rebecca (P)

I would say family members and friends, they are principally my network of reference. (...) But quite mixed, I was lucky to have had a course of studies that was very normal, I attended all public schools, so I have old friends, some from lyceum [equivalent of high school], some from university, some from work, some friends from my political life that I participate in. To sum up, different life experiences, each one carrying a piece of sociality. (…) about 20 [people in social network]. Janet (P)

Let's say that I have good relationship with my family, my parents, so for sure the most fundamental part is my family. I am not a very social person as a character, in the sense that I prefer having few friends but good friends. So my close circle of friends. But if I have to participate in a conversation or keep some relations, I manage to do so with any person, I mean if I have to speak, I speak. (…) mainly more connections from lyceum [equivalent to high school], two or three friends from lyceum and some friends even from elementary school or the kindergarten, so from childhood, and my parents (…) important persons, important are about 10. Brenda (P)

Thus, Penny here is the deviant case since she did not include any family member in her close social network.

5.1.3 Friends through rehabilitation centre or sports

Three of the participants, Phoebe, Lucy and Nicole, mentioned having friends through sports, such as hockey team, and one participant, Amy, mentioned having friends from a rehabilitation centre, where she had the chance to engage socially with other persons with disability as well:

So I have a very nice family, I speak about my mum and my dad who always supported me in all my choices, but also a lot of friends who fortunately care for me and support me, so I have a quite full social life, especially from last year when in February I started attending this centre that I talked to you about, it is called Activity Place [pseudonym for a rehabilitation centre] that allowed me to get to know other persons with disabilities like mine or more or less like mine, because I have always had friends '*normododate*', so without any type of disability, and let's say that I have never known profoundly persons with disability, except when I was little that I had one friend but then she moved to Sicily, where her mum is originally from. And so by attending this centre I also had a way to get to know better the world of disability and the abilities I can have, but above all to get to know better other people who like me live in the same condition as mine. Amy (P)

Look, the real friends could be counted on one hand. (…) But in general I know really a lot of people, because I have done a lot of things, I used to play hockey, that is a game for persons with disability, also Travis used to play it, and it is a sport that for example at social level has helped a lot whoever like my pathology needs to be integrated. In the sense that for example sport is a mechanism, is a way which really bring people closer, because for example when I used to go to do sports and then I was seeing that spectators were coming, also people who were not in a wheelchair, they were not seeing anymore the disability but they could see the competition. Actually I met my husband like this, he was a volunteer of one team and we met in the sports' fields, actually I think that doing sports is an incredible way to bring people closer, so in general, doing sports, being also involved in the association, I have been involved for years in the association, my pathology, and doing many things, I know a lot of people, so in this moment right now I cannot tell you a number. Phoebe (P)

For sure my mother was very close to me from the day of the accident, so most of all it is her who gives me a lot of strength and energy. Then I was lucky to have friends who have always been close to me, so actually the friends that I have today are the same that I had before the accident, so old friends. I have always maintained relationships with persons who I have known for a lifetime, and new friendships that I have made and all of them are people I have met in the hospital context such as my physiotherapist or sports mates. So both old friendships with persons I have known before the accident and social relations with persons I have met after the accident always in the hospital or thanks to sports. (…) so the closest for sure are four persons, but persons that I consider as my family, besides my mother, five friends who I consider part of me. Nicole (P)

No sociodemographic similarities emerged for participants under this sub-theme.

5.2 Frequency and way of contact with ties of social network

Participants were asked how often they speak with their social network ties and which way of contact they commonly use. Most participants spoke with their closest friends at least once a week, but were meeting them in person less often, most of them about once a month. Those who were feeling close to colleagues were seeing them every day. The most common way of contact used by participants was WhatsApp, and then less often they also used phone calls and Facebook, and the least often face-to-face contact:

Yes, with the new means of communication, let's say that I feel almost closer. I have a very dear friend who lives in Rome, but I don't see her often, but as a character, lifestyle, ideology, and so on I feel her quite close. Then obviously there are friends more connected to the city context than… But I live in a very small town, I don't have a lot of social contacts in the town, while I have more in Milan where I spend the bigger part of my daytime. Because when I return home in the evening it is already very late, I have not developed much in my town also because I go there to sleep basically. Rebecca (P)

Look at my age now I go out with certain amount of friends and when we meet we meet in the evening, when we do not work. I do not do sports anymore because I cannot make it between time and family, I cannot make it anymore, but I had done sports for ten years, from 19 till 30 years old more or less, so a little bit more than ten years. Social media I have used them a lot, they have been a great way to socialize, but the problem with social media, the fact that you don't see each other is always a little bit like this… a double-edged sword. (…) Now I am using it but for different things, I am using it a lot also for promoting things that I am interested in, the music, the passions that I have. But at a social level, I tell you, in this moment of my life because I have a family and everything, I have friends who we see according to the time we have. Phoebe (P)

With people who are closer we talk to each other every week, with some various times a week. Then of course there are other situations, colleagues from work who certainly are not the first persons, it is difficult for me to even consider them as friends, I mean that you do not share with them whatever, but you see them every day so also with them there is a nice relationship, my people at least once a week, yes, definitely. (…) with some who live closer we have the possibility to meet so we do what is possible, maybe once a month, and with respect to everyone's needs. With the other persons who live further it is clear that WhatsApp or Facebook are becoming fundamental, mainly for those who are abroad and to keep in touch you have to do so. Lucy (P)

On average, excluding my parents, with my friends on average once per week, at least for a 'hello, how are you, everything is ok'. (…) it may happen once or twice, whether messages on WhatsApp, or Facebook or calls, indifferent; whatever is more convenient in that given moment. Brenda (P)

No sociodemographic similarities emerged for participants under this theme.

5.3 Membership at organisation or volunteer groups (formal social networks)

Participants were also asked whether they belonged to any organisation or volunteer group or association.

5.3.1 Association of persons with disability and/or sports group

Half of the participants, Diana, Lucy, Penny, Amy and Phoebe, stated that they have been members of associations for persons with disability in general, or for a specific pathology, such as spinal muscular atrophy, and/or part of sports groups, such as hockey team, or mutual-help groups with persons with disability and their families at a rehabilitation centre:

> So on Sundays I do not have to go to the Activity Place, but on Saturdays, for quite some time, Saturday morning I go to the swimming pool at [hospital in Milan], it is connected to the Activity Place centre, I go to the swimming pool to do gymnastics in the water, actually it is a course for learning to swim, meaning to swim on my own, but I also do a lot of exercises which helps my muscles, to train my muscles. (…) And then on Saturday afternoon, in the afternoon, one Saturday yes and one Saturday no, we usually have a group, always in the Activity Place, a self-help group where parents, relatives, girlfriends/boyfriends of persons with disabilities together with us persons with disabilities discuss on different topics, and it is very nice because there is an actual comparison between two worlds, and two generations, and it is very interesting apart from very stimulating. Amy (P)

> So in general by doing sports, experiencing also the association, I have been for years in the association, my pathology and doing many things I meet a lot of people. Phoebe (P)

All five participants who reported belonging to associations of persons with disability and/or sports group were of similar age (i.e. 30-36 years old).

5.3.2 Political group or trade union

Two of the participants, Rebecca and Janet, mentioned being part of political-focused groups. In specific, one of them was secretary of the trade union (meaning the union of workers/employees) of the university she was working at, and the other one was active member of a political party:

> I am a union secretary, so I take care of employees registered in the trade union here [at the university where she is working]. (…) No, it is actually a trade union, trade union, I have contacts also with associations of disabled people but I have never had an active role in associations for disabled people. Rebecca (P)

> I am registered to the Democratic party [political party]. Proudly registered to the Democratic party. Janet (P)

Both of these participants were the oldest among the participants with physical disability (i.e. 42 and 44 respectively), and both had a university degree and were in paid employment.

5.3.3 Do not belong to any group currently

Three of the participants, Brenda, Nicole and Christine, stated that they currently do not belong to any kind of organised or volunteer group; although during other parts of the interview they mentioned being active members of association or sports group. One of them, Christine, mentioned that she used to be part of an association for leisure time of persons with different types of disability, but saw it negatively because the point of the association was to spend time together, however she could not communicate with people with diverse disabilities also intellectual and different age, so preferred to belong to more spontaneous relationships with friends who share the same interests:

> So, sports no. Regarding associations, I have a specific position, I mean an opinion of my own, I have always thought that these associations tend to create a gap between educators, volunteers and persons with disability. I prefer going out with my group of friends which has some guys with disability and guys without disability. And we go out in a completely normal way, I mean what connects us is a spontaneous friendship without any correlation to the associations. I have never attended associations, I have attended only one association for a certain period of time and then I did not have any positive reply and I stopped attending it. (…) It was an association for leisure time, in Milan, for people with disability that united persons of various ages and with various disabilities. This thing personally I think it was a little bit negative, in the sense that persons with different disabilities also intellectual ones cannot manage to communicate and so the goal of association that was to hang out together I was seeing it with some scepticism because I was saying to myself 'how could I make it to communicate and interact with persons, it is not nice to say, but different than me also in terms of age. I prefer spontaneous relationships also from sharing passions and interests in common. Christine (P)

The three participants who stated that they did not belong to any group were 23-24 years old and never been married. However, one of them, Christine, stated in other parts of the interview that she was writing articles for a group of women with disability within an association for persons with muscular dystrophy, so clearly belonged to a group or association.

Core Theme 6. Daily activities

Participants were invited to describe a typical day they have and talk about their hobbies and what they like doing in their free time. All participants mentioned doing many activities during the day and the majority of them were quite busy, given also that 8 out of the 10 interviewees with physical disability were working; whether in paid employment, self-employed or in volunteer work. A common hobby all participants mentioned was watching a series or a film on television or at the cinema, whereas activities such as shopping and housework, were commonly not done by participants but their mother, partner, or care assistant; however there were two participants who mentioned doing housework themselves, Brenda who said she was cleaning the house and taking care of the pets each morning, and Rebecca who said that she prepares something quick to eat before going to bed. Apart from going to work or university and going out socially or not participants mentioned doing also many other activities during the week, such as going to concerts, exhibitions or museums, being occupied with trade union, writing articles on a personal blog or for association of women with disability, drawing, knitting, reading, listening to music, checking Facebook or internet in general, doing sports for rehabilitation or pleasure, and one participant, Penny, mentioned also meditation. The main difference among participants is that some mentioned going out socially as part of their daily activities, whereas others did not mention that.

6.1 Commonly going out socially

Six of the respondents reported that they are usually going out socially outside work or university, with friends or their husband/partner at cinema, or a pub, for 'aperitivo'[31] or dinner:

When I am on holidays I like very much to travel, I go abroad a lot especially to countries that are more accessible. I do not go to countries that are slightly accessible. Let's say that at least once a week I go to the cinema, because I love cinema, at least once or twice a week I go out, maybe I go to a pub or for dinner. Rebecca (P)

There are days that I come here in the municipality for meetings, for activities that I am carrying out, go for lunch, usually if I do not go out for lunch with a friend I have my lunch in the office because like many of my colleagues working in the centre of Milan we would spend a fortune. In the evening if I return home I usually eat, watch a movie, I love cinema, I am quite addicted to cinema, and I go to sleep. If I go out I have quite a lot of responsibilities related to politics in the evening, because I am registered with the Democratic party, so we have round table meetings, etc. I go out or sometimes have commitments with male friends or female friends, in this case I go for dinner or to the cinema, I go often to the cinema because it is my

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[31] The 'aperitivo' is similar to the 'happy hour' discount period offered by local bars/pubs, but including a light meal (as a buffet) together with a drink/cocktail, starting usually at the end of working hours; a very common activity for young people in Milan.

> favourite hobby. In the weekend generally I wake up a little bit later, if I do not have to work I do the things that I am not able to do during the week, such as hairdresser, waxing, shopping… the shopping I do it a lot online, but maybe I go... I am not into night bars, I am more into cinema, dinner with friends, sometimes theatre or less than that. Normal. Janet (P)

> In my free time I write as a volunteer to this online journal, I am always writing articles for the group of women [of an Italian association for muscular dystrophy], I listen to music, watch TV series, and then when I can especially in the weekend I go out with my friends. Christine (P)

No sociodemographic similarities emerged for participants under this theme.

6.2 Not regularly going out socially

Four of the respondents, Amy, Diana, Phoebe and Brenda, reported that they usually do not go out socially outside work, university, classes, or rehabilitation activities, because they do not have the time due to a new-born baby or prefer to stay at home in their own environment, or they simply did not mention going out socially as their regular activity:

> As I was telling you, TV series at home, music concerts, but now with a baby girl everything will be a little bit different, I think my hobbies will change based on her. So everything will be new, but I would like to keep something, going out with friends, yes, before maybe I was involved… there was a period in which I was a bit engaged politically, now I do not have time anymore and hobbies, well, at this point I watch movies and listen to music. Phoebe (P)

> I like taking photos but mainly I prefer staying at home, to invite my friends, to have dinner, things like that but I prefer staying in my environment. Or I like to travel but only with my boyfriend, not with other people, because we have our own times and we know how to manage them, we travel smoothly without hitches and without anything. Brenda (P)

The four respondents who stated that they do not go out regularly socially as part of their daily activities were all of them never married, however, two of them were living with their partner and were quite active in general, working, having a baby, doing sports, rehabilitation activities, and/or studying. No other similarity was discerned among them.

Core Theme 7. Disability-based homophilious or heterophilious social networks

Participants were asked whether the persons belonging in their close social networks have a disability or not, for exploring whether they had homophilious or heterophilious social networks based on disability.

7.1 Social network with both friends with and without disability

Six respondents stated that they had both friends with and without disability within their social networks. One of them, Rebecca, mentioned that some of her friends have disability, but most of them do not, however, both have an open mentality towards rights of inclusion, gay persons, and immigrants and are activists. Another participant, Lucy, mentioned that she finds it easier to share with her friends with the same pathology doubts she has regarding their common health issue, whereas it is difficult for her friends without disability to enter this perception:

> Some yes [have disability] and some no. (…) also other [health issues]. I believe that the difference exists also in the type of relationship. For example, whoever has the same pathology maybe it is easier to share doubts or difficulties related to the pathology, discomfort, emotional states that arise from that, and the same thing also with persons with other disabilities, in the sense that it becomes a comparison. And at times this kind of topics with people who are close to me are not difficult to deal with, because even if they can't feel it on their own skin, they have lived so many of them with me that they put themselves in my shoes or at least can do it. Not anyone without disability is able to get into that perspective, so there are topics that maybe need to be introduced in this sense. Lucy (P)

> Both, I have attended sports for disabled that allowed me to get closer also to persons without disability, like my husband, and I have disabled friends and non-disabled friends, a little bit of everything. Phoebe (P)

The participants who stated that they had in their social network both friends with and without disability were all working

7.2 Social network including only one or no friend with disability

Four of the respondents, Brenda, Janet, Nicole and Penny, stated that they had no friends in their close social network with a disability, while one of them, Brenda, mentioned that she had recently made a friend with a similar disability, but she was the only friend with disability that she had:

> Only one person [with disability] that I met recently, but who soon entered my heart. (…) she had myelitis, but our condition is quite similar. Brenda (P)

> My old friends that I still have from elementary school, absolutely no [disability], obviously my colleagues that I told you about, absolutely no, but those that I mentioned who are part of the association [for spinal muscular atrophy], obviously yes, but my friends with whom I have the closest relationships, no. Penny (P)

No sociodemographic similarities emerged for participants under this theme.

Core Theme 8. Change of attitudes of social network due to disability

Participants were asked whether they had ever experienced any negative change of attitude from others when they knew or saw their physical disability.

8.1 Experienced no change of attitude or negative attitudes from others

There were participants who stated that they had not experienced any change of attitude from others due to their health issue. One of the participants, Rebecca, when she was little she could not participate in more active games, but when she was older her parents were giving her their car for her friends to drive it and allowed her to being her friends over at home to sleep, which helped her socialisation. Another participant, Phoebe, stated that she did not see any change of attitude because when her health issue started being developed she was very young, and that there are people who are afraid of disability or do not know how to behave, this is a limitation of these people and she does not hang out with them. Then there was also another participant, Janet, who said that fortunately she has a visible disability so she had never experienced any negative prejudice towards her from others, on the contrary, sometimes there was a positive prejudice, in the sense that since you are a person with disability you are nice and intelligent. But she had faced practical difficulties, such as to check the working place if there are any barriers of the physical environment and organising her everyday life at work, so has to explain these practical issues to others who do not understand them:

> When I was younger, I mean when you are little maybe it happens that, I don't know, there were organised some very active games and you would stay a little bit apart. Let's say that from the moment that all of your friends start having a car and can bring you with them. I had a car but I could not drive, they knew how to drive but did not have a car, from then on the social life went a lot better, because then I had parents who were very open, so if I invited persons to sleep at my home, or if I went away they would give me the car without any problems and so on. That helped a lot the socialisation. Rebecca (P)

> So, I was lucky, obviously I have a disability that is visible straight away. It has never occurred to me perceiving negative prejudice, on the contrary, if we want sometimes it is a positive prejudice, there is also the opposite risk, no? That one thinks that since you are a disabled person you are nice, you are intelligent, you are good, and every one of us is different from the other. Since public kindergarten, I have always assessed myself in normal contexts and I have not encountered any negative episodes, so I can't tell you that I have had negative experiences. Janet (P)

No sociodemographic similarities emerged for participants under this theme.

8.2 Experienced negative attitudes or negative change in attitude of others

Four of the participants, Lucy, Brenda, Nicole and Penny, reported that they had experienced negative change of attitude from others. One of the participants, Lucy, said that when was going to a psychologist she was using crutches, so people thought she had a temporary health issue, but they saw her wheelchair changed their attitude towards her. Another participant, Brenda, said she has received negative changes of attitude, for example, when she gets presented to a group of people so some of them do not know how to act because of her disability, some people cause problems while others not, mainly older adults have an attitude of pietism towards her or envy from younger people, but did not have any experience particularly negative. Nicole also stated that she had experienced change of attitude and had difficulty making friends and people approaching her at university, because physically she could not enter the lecture room and sit next to her companions. There was also a participant, Penny, who experienced change of attitude from others, although she is not hiding her physical health issue, she has photos of her on social media that show that she is in a wheelchair, so maybe someone had not understood that from the beginning and then became distant, but nobody told her explicitly that they do not want to be friends with her due to her health issue:

> Yes, I have had this kind of experiences that are similar or differ a little bit between them, for example, people that when I get presented to a group they do not know how to behave towards me, maybe they say 'hello' or they do not speak or they ask you how it happened, more outgoing persons, persons who make more problems and persons who don't. Obviously mainly from older people there is a form of pity or 'poor you', but to sum up there are differences of mentality, between young people or indifference or some jealousy but childish things, that you feel bad at the moment but then when you grow up you understand. Let's say that I have never had experiences that marked me particularly in a negative way. Brenda (P)

> Ok, certainly, maybe at university in the beginning I did not manage to have any friendships, because it is not possible for me physically to access the classroom on time and maybe to sit close to my fellow students and so yes at university I did not feel very well because the others do not approach me immediately. Nicole (P)

The only sociodemographic characteristic similar for the four participants who had experienced negative attitudes from others was that they were never married, while almost the same ones – apart from Lucy – had stated that they have none or only one friend with disability in their close social network.

Core Theme 9. Social support (received and provided)

9.1 Received social support

Participants were asked whether they received any social support for everyday tasks, or in terms of psychological or institutional support.

9.1.1 Mainly support from family/partner and/or friends (informal support)

Six of the respondents stated that they mainly receive support for performing everyday tasks from their family, particularly their mother, or partner, and some of them also from their friends, for example when they were going out or whenever they asked them for help. Some of them also mentioned that they face financial difficulties and would prefer to have had more help from the State or municipality to be able to pay a care assistant to do outdoor activities more autonomously, as Amy suggested, or have a person living with them 24 hours per day in case their parents will not be able to care for them anymore, as Diana pointed out, or in case Phoebe's husband would not had been able to return earlier from work every day to help her and their baby:

Actually I do not have any assistance because I would have to pay for it and I can't afford it in this moment, and my mum does all daily tasks I mean. (…) She does everything, she manages everything. (…) I have the disability benefit that is around... now I don't remember the amount. (...) Anyway I take the disability benefit, yes. Amy (P)

Psychological help… up to date I have never needed it. The most part of things are done by my family. When I was at university there was a service for disabled and they would accompany me to the lectures, to meetings with professors, or to get some books from the library for my thesis, etc. etc. or also help with eating, for example to heat things up, because for example there are things on the shelves which I cannot reach them, so they help me in this sense. Or assistance to the toilet. Then regarding friends sometimes yes [receives support], when we go out and we have to go to some places with a car they help me get in and out from the car. They help me if I have to take off my jacket, yes, they do. (…) The disability benefit and carer's allowance[32], yes. Christine (P)

No sociodemographic similarities emerged for participants under this sub-theme.

9.1.2 Mainly support from care assistants and/or health professionals or others (formal support)

The rest of the participants were more independent, at least financially, given that they were in full-time employment so most of them, apart from Penny, did not receive the disability benefit, but a carer's allowance. Janet did not receive any financial assistance from the State and was paying for care assistants privately to help her with everyday tasks. Rebecca receives help from persons at work and a care assistant for her housework under payment, Lucy pays someone living in her same building that helps her with housework and used to have also psychological support in the past after an intimate relationship had ended, and Penny has a live-in care assistant who helps her with all everyday tasks and attends a psychotherapy course:

By having a good job I went beyond the required threshold of income [for disability benefit]. I would never allow myself to ask help of that type [financial] because there are people who need it a lot more than I do. (…) yes I have two persons who help me: one person lives with me, I mean who sleeps there and helps me in the evening and in the morning, and then one person who has a driving license and who helps me during the day driving my car, because I have to go to work, have to go to other places, with the car. And it is a

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[32] Translated from Italian: "indennità di accompagnamento". It is a benefit provided to persons living in Italy with physical or mental disability, who need help from a carer/escort in order to move around or complete daily tasks. For more info: https://www.inps.it/nuovoportaleinps/default.aspx?itemdir=50194 [Accessed 24 March 2019].

person who then helps me to do housework, clean the house. Two persons who alternate. (…) No, I pay them privately. Janet (P)

So I have this lady at home who lives in my building too, who comes to give me a hand with handling house tasks, to clean, to iron, which clearly are difficult for me to do. (…) yes I pay her. While from the emotional point of view, in this moment no [support received], but there was a moment a year, a year and a half ago that I needed it and so I referred to a psychologist, because my previous affair was this… the only relationship that was so important, because it lasted for quite some time, finished in a turbulent way, and even being both disabled with the same pathology and so I believed that this would not be a problem, in the moment that we broke up this became for him the reason for which he did not want to stay with me. Lucy (P)

Having a personal assistant and he helps me a little bit with daily tasks, sometimes some things I do them autonomously. I have an electronic wheelchair that allows me to be autonomous in moving around and doing some things. Yes, besides carer's allowance, obviously like all disabled, and the disability benefit, since I became an adult I have been also receiving money from this fund for independent life that in Piedmont region it is €20,000 euros per year that I use for paying the personal assistant. Penny (P)

In addition, the participants mainly receiving formal support were older than 30, working in paid employment, and educated to bachelor or master's degree level. Thus, indicating that they were able to be more independent, at least financially.

9.2 Provided social support

The majority of participants reported that they provide social support to others.

9.2.1 Support through associations/organisations of persons with disability and/or political activity

Some of the participants stated that they provided support to others with their contributions through formal networks, such as associations of persons with disability, or through political activity to promote issues on accessibility at municipality level, or national and international events of sports group:

I support with my professional activity a foundation that established a rehabilitation centre for children with severe neurological disorders and I support them from their birth, helping them with all the legal part and giving annually a financial contribution. Then ok a little support to associations not related to disability but to environmental care, causes that for me are important, and then ok I am involved in this pro bono activity in municipality that is a little bit my way to contribute to an issue such as accessibility and accessibility policies, trying to bring this topic internally to the administration of the municipality of Milan. Janet (P)

I feel like telling you that yes [provides support], I mean for a long time I had taken actively part in the association of my pathology, on the executive board, organising things, etc. Even now I try to give them a hand even if I am not on the executive board anymore because of issues related to work and time, I was not able anymore to follow them as before, but it seems to me that even being able to respond to some questions posted on Facebook can be of help. And then on the other side in the world of hockey I am still very present at Italian and international level, so thinking to organize manifestations or give possibility also to young people with various pathologies to travel, I see it as an important thing. And in daily life of the team it is clear that I feel very lucky because not having a neuromuscular pathology I have the possibility to do a lot, and so when we are going around, instead of staying on the bus it is obvious that helping others for me is something that comes naturally, help with eating, dressing them, to put on a jacket or the cap on them, it is something that comes naturally to do, then I believe it can be read as help. Lucy (P)

No sociodemographic similarities emerged for participants under this sub-theme.

9.2.2 Psychological support and encouragement

There were also participants, Christine, Brenda, Nicole and Penny, who reported that they provided support at more informal level, as psychological support to others and encouragement, for example, in terms of mutual support by giving advice to others with the same pathology, particularly young people, giving a talk to a hospital about their own case, or chatting with patients at the hospital with the same pathology, or bringing counselling which is part of work also in every day interactions:

They have asked me more than once for children who are at [a hospital in Milan], because I have had an experience when I was a child, how to deal with it and I simply told my experience nothing more not less, I do not feel I am a guru. Brenda (M)

When I am at the hospital I try to psychologically support other people who have had an accident, when I am at the hospital once a month for medical visits, I am trying to see patients who are still hospitalised to talk about my case, how I dealt with my life after the accident, some people I try to support them psychologically. Nicole (P)

In this sub-theme it emerged that the same three participants who had experienced negative attitudes from others and had stated that they have none or only one friend with disability in their close social network, also stated here that they provided psychological support to others and encouragement.

Core Theme 10. Trust

The main components of the cognitive dimension of social networks is trustworthiness, thus participants were asked whether they trust other persons in their community and institutions.

10.1 General trust

10.1.1 Trust other people in general

Seven participants stated that they trust others, with three of them – Amy, Janet, and Penny – saying that they trust others a lot. Rebecca mentioned that when she asks help from others, even if they do not know how to provide it, if she explains it to them then they all help her. Christine mentioned that she has trust in others and in diversity of people that can be enriching for one's personal development. Lucy also shows trust to others, maybe too much, but prefers to give the benefit of doubt to others:

> Yes, no I, hm... Because I am studying psychology I would say yes [trust people in general], but I mean that if you explain to people what you need and if you explain to them the way they can respond to your need, it has never happened to me that someone would not want to help me. There is maybe from the part of some disabled the difficulty in asking, but people sometimes feel inadequate because they do not know if they are able to help you, but when you explain to them exactly how they can help you, it has never happened to me that someone would tell me "no, I am not helping you", that's it. Rebecca (P)

> Yes, quite, to the extent that everyone trusts these days, so I am not someone who confides in others. I start from the presumption that a person in front of me is in good faith, but if I don't know this person I am quite discrete and careful. Janet (P)

> A lot, otherwise I could not have been doing this work, I trust a lot in people, in society, and in the change of people of the society, the evolution, otherwise I could not have been doing what I do. Penny (P)

The three participants who reported trusting others a lot were above 30 years old (i.e. 30, 34, and 44) and never married.

10.1.2 Do not trust others at all, or not always, or it depends from time to time

Only one of the participants, Brenda, stated that she had no trust at all towards other people in general and that she is quite pessimistic, so she does not see our society improving. Another participant, Diana, said that she does not always have trust in others because there are people who might take advantage of another person's need for help, while Phoebe stated that sometimes she trusts others, but sometimes she sees that she did wrong trusting them, but if one does not trust society then starts seeing everything wrong, so for Phoebe it depends from the moment whether she trusts others or not:

> I am quite pessimist, I do not see our society moving towards what is better, so for this reason I do not trust [others in general], no. Brenda (P)

> No, not always, not always. Because you have to... I have learned that it is important to protect your own self. Because then you recognise who does it because of her/his interest, who does it because really wants to help you. So… you have to also be able to regardless of the help to distinguish between help and taking advantage. I do not always trust anyone. Because there are people who take advantage of the needs you have. (…) I have not had a specific experience, but I think that before being able to trust a person completely you have to know this person, to learn to live together, before saying "ok, I can trust this person". But I think that this happens with any person, even more when there is the issue of needing help. That's what I meant. Diana (P)

All three respondents who had the lowest level of trust among participants with physical disability were working, without any other similarity discerned among them.

10.2 Institutional trust

Participants' responses on whether they trust specific institutions (i.e. police, justice, parliament, and the press) varied greatly.

Overall, the participants trusted the most the police, whereas the least the parliament, while for justice and the press they seemed more divided about having trust in them:

> [press] Yes and no, we have some journalists that I respect a lot and unfortunately there are newspapers that unfortunately worsened a lot and that play, for example, with false news, wrong communication, and at the expense, for example, of whoever lives with disability, because anyway they describe things also in a wrong way, giving also a wrong sense to a collective image about what disability is but also other aspects. And therefore not always in my opinion [have trust in press], newspapers have worsened a lot in my opinion, a lot through the years but also at the media level, and they should have been revaluated I think

because there are many journalists who are really competent, doing their job and others who unfortunately carry on populism and I don't like this thing. Phoebe (P)

[police] in general yes, only that in my opinion there is the risk in the police, but also like in the other institutions, to exist an abuse of institutional power and I think some news stories can prove it. Generally I trust in them but sometimes they make wrong choices. Christine (P)

[parliament] I do not feel like telling you… I mean I do not have a clear idea where I am. It seems to me that they have a lot of words and few actions, so I would say more no [trust in parliament]. In the political institutions I see a lot of words and then few actions, at both national and local levels. So on the one side I am happy to be living in Milan because it is a city where things are working better or worse, and also because I am feeling lucky to be actively involved in the association of my pathology but also to be in contact with others, I am able to have the necessary information to be able to manage in an easy way bureaucracy and things. But if many people are not lucky enough to come across competent associations, they stay at the mercy of law procedures that have neither a head nor a tail[33]. Lucy (P)

[justice] it is a big issue, sometimes justice is complicated, it is not that I do not trust justice per se, sometimes I wonder to what point can judgment really exist, a different description because everything is so complex so I can't say yes for sure, but not because I do not trust Italian judiciary, but because I believe that really sometimes things are very complicated, so sometimes it is really difficult to have a scale. Penny (P)

No sociodemographic similarities emerged for participants under this theme.

Core Theme 11. Opinion on specific civic norms

Relevantly to the cognitive dimension of social networks in terms of trust within a community, participants were asked whether they agree or not with specific statements as civic norms – based on Kaasa & Parts (2008) – to explore the degree of trustworthiness within their community. These statements were relevant to: tax evasion, claiming government benefit that one is not entitled to, and accepting a bribe during one's duties.

11.1 Disagree with tax evasion, claiming government benefit that one is not entitled to or accepting a bribe during work

The vast majority of participants disagreed about claiming government benefit if one is not entitled to it and avoiding paying taxes in total. About accepting a bribe during the course of one's duties, all participants disagreed with this statement:

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[33] Italian expression meaning 'neither beginning nor end'.

No [do not agree], these things such as bribes make me very angry. Phoebe (P)

No, I do not agree with this. Because tax evasion is a very big problem, and whoever has the resources to pay taxes, must pay them. Lucy (P)

No sociodemographic similarities emerged for participants under this theme.

11.2 Agree with claiming benefits one is not entitled to or it depends on the motive about tax evasion

There were two participants who differentiated on their opinion about tax evasion and claiming benefits from the State that one is not entitled to. In specific, Amy responded initially that if a person has the right to a benefit, but the State does not satisfy the rights of the person, then it is right for the person to “rebel”, as she put it, but then she changed her answer a bit, saying that then people who really need the benefit will not be able to get it and she disagreed with that. Another participant, Brenda, said that it depends on the motive for tax evasion, if someone is paying more than they should or if they had a loss from the State and then asked to pay taxes, then that is not right according to her:

Hmm if a person is not entitled to claim for... it is right that she/he does not claim it... But if a person has the right… but if these rights are not heard or satisfied by the State, then it is fair that the person goes to... that the person can in some way in quotation marks “rebel”, because it is not fair that the rights of a person are not becoming satisfied or heard. So… but sorry I did not understand the question well exactly how it was, I mean… (…) So you... the subject passes over a person who really needs this help and it is absolutely incorrect and unthinkable in my opinion to do such a thing. Amy (P)

It depends on the motives, in the sense that if there is a good reason to not do it, because there were problems with the State itself, then yes. If I had a loss from the State and at the same time I have to pay the taxes anyway, then it is not ok for me. As a citizen who pays taxes, I want to pay what is fair, not more. Or if I had problems I would have wanted that the State would have met me [my needs]. Brenda (P)

Both participants who differentiated under the theme of civic norms were younger than 30 years old and never married, and were two of the respondents who did not mention regularly going out socially.

Core Theme 12. Political participation

12.1 Voting at elections

All participants stated that they are active voters – apart from Rebecca who did not reply to this question. One of the participants, Janet, stated that she also does electoral campaign for herself and dealing with the common affairs while she has a disability had a positive effect on her life, considering politics as therapeutic for her. On the other hand, another participant, Amy, pointed out that when she goes to vote her mother marks Amy's vote with the pencil, not her, although it is her right to vote on her own, but this is not possible since there are no appropriate places at the election centres for persons in a wheelchair in order for them to vote alone, without needing anyone's help. Or when she goes to the post-office she cannot sign a document because the counter is too high for her to reach it while she is in the wheelchair, so her mother signs it for her, because there are no appropriate conditions for her to sign administrative things by herself and she also mentioned the human right of persons with disability to be independent in their life from others, including their parents:

> Obviously, I also do an electoral campaign. Politics for me has been a very important thing because for me individually and at existential level, I come from family where politics has always had an important meaning, positive and I think that when some dramatic things happen to people, because having a disability is not a nice thing, it is a very tiring thing, being occupied with public issues and going outside oneself and look at the world for me it has a great calming effect. So it has helped me a lot to put my problems into another perspective, it has had a therapeutic effect, so I am very grateful to politics. Janet (P)

> I voted, I voted also in the last referendum but the tick with the pencil was done not by me but by my mum. And for me this thing is a delusion because I would like to be able to do it on my own, because it is my vote and not of my mum. So I would like a suitable situation for me and the thousands of people who are like me. The society knows that disabled in wheelchair exist, why not creating a post also for them? To guarantee their autonomy, their privacy when they are voting, for example? Or let's make another example, I go to the post office and have to sign a document, the counter also here is high at eye level. I cannot reach it to sign that document, and so I always have to ask if my mum can sign it instead of me. And this is not right because if I have to sign it, then I have to sing it, Amy. (…) These things are unacceptable, I have to sign, have to do it and have to do it in the conditions most suitable for me, if these do not exist, you have to... there should be provided in some way and as soon as possible. (…) so the disabled cannot perform their duties from an administrative point of view and they must be let's say accompanied and helped by someone else, and this is not possible, because we exist, we are persons, we exist and we have the right to lead an independent life from the parent. Amy (P)

No sociodemographic similarities emerged for participants under this theme.

12.2 Participation at demonstration or signed a petition

Half of the participants had never participated at a demonstration, while the other half had participated, although one of them, Diana, said she had been protesting online through her social media (i.e. personal blog and Facebook) on causes she believed in. The rest of participants, Phoebe, Janet, Brenda and Penny, had participated at demonstrations on various issues, and all participants had signed petitions, some of them to a greater extent than others. The issues participants were interested in varied. Most of them referred to rights of persons with disability, environment/ecology/climate change, animals, and bio-tests/experiments, but also to autonomy, mobility, violence against women, same-sex marriage, human rights, politics in general, and pollution of a town from asbestos:

I have signed petition online on the rights... things like that... and for the things that I believe in, essentially. (…) For the rights of persons with disability for sure, I am always in the first line, also because it concerns me. For the animals also and violence against women. (…) Protests online, yes. And I publish things regarding complaints, I write articles, I make interviews also in newspapers. Fundamentally the State for us does not exist. (…) I have a Google blog (…) My personal and then I use Facebook a lot. Diana (P)

Yes, last year. Now here with the baby girl it is more difficult for me, but when there was a thing on equality of egalitarian marriage, in these things I have always been present, I went to the square. (…) Yes, I am one who also at political level I have done something minimum, but I enjoyed anyway getting myself in the game a bit, then it is a very particular environment, unfortunately I am an idealist and I am aware that unfortunately you cannot live on ideals. But now for example on the issue of bio-test, things like that, I have my political ideas, I express them also on the social media, but unfortunately we live in a world that is still very backward very but most of all culturally, so my ideals yes, they are good but it is difficult to put them into practice. Phoebe (P)

Demonstrations no, I sign, I have signed petitions especially related to the context of disability, because really there are a lot of things which were updated in the 1950s and since then they have never been touched again and they require a revision more than signing petitions on situations of law that could make more complex the situation of autonomy, etc. etc. Lucy (P)

Absolutely yes. (...) actually the biggest part of manifestations to which I participated as I lived in [name of Italian town], a town in which there was the issue of asbestos, in my town in the last 6-7 years I participated in more manifestations because there was this process going on, so I often participated in manifestations

> that were related to sensitivity to this issue and also the position of the local population in comparison sometimes with the municipality that on the contrary wanted to have different positions. The biggest part of manifestations to which I have participated were of this kind. Penny (P)

All the participants who had participated at demonstrations were working.

Core Theme 13. Employment difficulty due to health issue

About employment, as mentioned previously, 8 out of the 10 participants with physical disability were employed and the other two were university students, not looking for a job in their field yet.

13.1 Employment barriers due to inaccessible workplace

Participants who were not in paid employment but were self-employed or in volunteer work were asked whether they wanted to find a job in their field but could not due to their physical health issue. One of them, Christine, stated that she had done internships during her master's degree and had been currently – during the period the interview – applying to vacancies in her field, but some of the companies she applied to, when she was asking them if their buildings were accessible for persons with disability they responded that they were not accessible. Apart from accessibility issues of the workplace, if she would find a job then she would also need a person to accompany her with the wheelchair and another one to help her with personal hygiene, and she would have to pay these people herself. Another participant, Brenda, who was self-employed at the time of the interview, she tried to do an internship too while she was studying, but she could not do it due to architectural barriers of the old buildings in the city, thus she decided to work from home with her partner:

> So I am sending my CV around and what I encountered is that some companies when I asked them if their offices were accessible because I specify in my CV that I belong to a protected category according to the law, but when I talk on the phone with the people in charge of these companies that contact me I specify this to them and some of them responded me that their offices are not accessible because buildings were old etc. etc. however with others I have scheduled some interviews in the nearest future via Skype, and so we will see how it can be done. Because for work experience or internship etc. etc. I need a person to accompany and a person to help use the toilet, where I am not autonomous. [and these people have to be paid by you?] yes, yes. Christine (P)

> Yes, so with university we tried making a request for a stage [work project] or some work experience and there were difficulties, so much that I did not actually carry out any of the types of workshops and I had to arrange to obtain the extracurricular credits in another way, actually because they were not prepared for the possibility of sending a person with motor disability, in structures that have excessive architectural barriers, because buildings were old, the city is the way it is. For this reason I and my boyfriend decided to work together from home as freelancers to resolve this problem. Brenda (P)

Both of the participants who did not have a job in their field yet were among the youngest participants with physical disability (i.e. both were 24 years old) and both had a bachelor's degree, thus belonging to an educated and productive part of the population.

Core Theme 14. Barriers for social participation and suggestions for removing them

Participants were asked to state if they had ever experienced any barriers for social participation, in terms of social or physical (built or natural) environment.

14.1 Barriers related to physical environment and accessibility issues

All participants mentioned at least one barrier for social participation related to accessibility to places and services, mainly regarding public transport, due to inappropriate facilities for persons with physical disability. In particular, participants mentioned issues they have encountered using public physical environment of the city of Milan, such as inaccessible public transport services due to steps at the entrance of old trams or lack of slopes for wheelchair users in the subway, steps and stairs at the entrance of public offices/buildings, inappropriate lack of or too small elevators in public buildings, steps in entrances to public restrooms, only stairs to attend exhibitions at Castello Sforzesco[34], cinema, bars, lack of stairlift or not working properly, pavements without dropped kerbs/inclinations, companies not having accessible buildings, and one participant, Brenda, mentioned that she wanted to go to an arts school which was not accessible so she had to choose another one, and the university she attended in Milan, although it was private, had many architectural barriers for a wheelchair user. Participants stated that it is complicated to go around Milan in a wheelchair, and although Milan has improved in terms of accessibility, it needs to improve more. Some of the participants

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[34] The Castello Sforzesco is called in English 'Sforza Castle' or 'Milan Castle' and is a 14th century castle which is currently a museum hosting exhibitions at the centre of the city of Milan.

mentioned that in other European countries accessibility for persons with disability is facilitated a lot more compared to Italy.

Thus, persons with physical disability have to wait for the problem to be resolved, for example a slope to be fixed so they can get off the subway, or do not participate in social activities such as going to bars with friends, a concert, a football game, or to attend a course or meditation class or other seminars because their entrance or bathroom is not accessible to them, or tickets for persons with disability finish instantly, or someone has to carry them in her/his arms in order to enter somewhere. As one of the participants said, Janet, it is not dignified for a 44-year-old professional to be carried in the arms of a person in order to enter a building and she wants to be able to enter with her wheelchair wherever she wants to go, otherwise she chooses not to go there anymore. The same participant also pointed out that if a place is not accessible for persons with physical disability then it is similar as having a sign saying that persons with disability are not welcome in this place. Another participant, Lucy, gave a recent example from her working life, when her boss moved the microwave to the basement of their office, so she could not enter there anymore to warm her lunch because there were stairs to the basement. She did not argue about it but said she will give it to a colleague to warm it up and will eat at her desk, so she said she found a solution to this barrier without any arguments:

> Oh there are many. In Milan for example you cannot go around on your own. (…) So there are steps, holes everywhere, cars parked on the sidewalks, there are public transport that are not completely accessible, all the lines [of public transport], there are no elevators in some stops, you cannot use them because there are stairs. Some trams are old and you cannot get on them. In the centre if you need a public toilet, most of them have steps. (…) Even going around the centre of Milan becomes complicated because there is nothing accessible. That. Nothing more. And in everyday life that… hmm… you have to work on performing the everyday tasks, imagine on the things that you would want. Diana (P)

> So, those more evident are the architectural barriers, meaning steps, sidewalks without a slope, or the lack of slopes in some zones [of the city] where they would have been very convenient… sometimes I have encountered the lack of stairlifts... when I see.. I don’t know, there are some places where there are a lot of steps and maybe there are no stairlifts or if there are, they are not working. Amy (P)

> The architectural barriers in the social and non-social environment unfortunately are many, the stairs when they maybe should not have been there, even small steps sometimes, the toilets also sometimes planned badly. The toilets placed maybe in an environment where it is written that there are accessible places but

> then the toilet is at the end of a small stair, but the place is accessible, these are slightly absurd things. Then also in public places sometimes you see strange things such as small elevators. It has happened to me also in public offices, you arrive there and the stairlift is not working. For example the subway of Milan, some stops have a stairlift from the end of 1980s, 1989-1990, wheelchairs in the meantime have evolved a bit and they weight almost twice as much and the wheelchairs that there were in the 1980s-1990s, and so you get blocked upstairs. These things here are a little bit paradoxical. So, for us it is impossible to move around with public transport unless you have to do a short distance. (..) so they make you lose time, you are a disabled person, and unfortunately sometimes people think that you have all time in the world, but you don't, also my time has value as much as yours. Phoebe (P)

> With age I now start becoming intolerant, I am here now because now I am more self-confident and calmer, and if a place is not accessible, I am not going there. I am sick of it that in Italy this thing is solved by saying "ah we Italians are good and generous and we will carry you". I think it is not respectable to be carried by others for a person at the age of 44, professional, I want to enter with my wheelchair and not having someone who carries me. For that of course these barriers can be dealt with, but I want to eliminate them, not having someone who brings me in their arms. We have to start thinking that when a place is inaccessible it is as if there was a sign on the door saying that disabled persons are not welcome. And I believe if there was a sign saying that persons of colour are not welcome then this would be a scandal. It is exactly the same scandal. Janet (P)

> For example the choice of the type of lyceum [high school] was determined also by the architectural barriers for me at the various buildings. I wanted to go to an academy of arts and I could not do that because the building was not accessible in any way from this point of view. (…) My university although it is a private one it has a lot of architectural barriers, I encountered many of them especially motor, more than of mental obstructionism, due to possibly the lack of public resources. Brenda (P)

> To tell you, yesterday at work our boss decided that all the catering area, so the microwave, etc. etc. would be moved to the basement which was accessible only by stairs, because the platforms are only on the ground floor. Everyone looked at me to say "like this she will not eat anymore", and they were waiting a reaction from me, but it is not that it had not come; I simply responded to them that "I will eat in the office". So I will ask colleagues to warm up my things. "Ah but you found the solution without any arguments", but does it worth arguing about it? After a point one realises that this does not work. Lucy (P)

No sociodemographic similarities emerged for participants under this theme.

14.2 Barriers related to social environment

Almost all participants stated that they had experienced barriers related to their social environment as well regarding their social participation, whether experienced directly by them or know others with physical disability that experienced this kind of barriers. Only two of the participants, Rebecca and Nicole did not mention any barriers related clearly to the social environment, with Rebecca saying that she had never experienced any barriers at social level, only physical.

Participants who experienced barriers in terms of the social environment, mainly referred to the prejudice that people of the wider society have towards persons with disability. Diana said that people see them as rare cases and in another country when you ask for help people are very helpful whereas in Italy people look at you badly. Amy stated that people with disability experience prejudice and it hurts them, because people with disability are not handicapped, but just people who have a smaller or larger problem in terms of physical limitation and are equal to everyone else, have a mind too and think. So the mentality barriers are the barriers which are most dangerous, because people think of persons with disability as poor ones and not being able, while they just use diverse instruments to communicate but we all can communicate and have the right to be treated as humans. Phoebe said that from her personal experience when she wants to go out with friends she needs someone to drive her there and to help her use the bathroom, and not all friends are willing to do that, so if she wants to go out without her husband, it is difficult for her. There is also the mentality that when people give you what you deserve, they say that persons with disability are poor ones and need help, but it is the right of any person to have equal treatment, not because they are poor ones. Thus it is a cultural problem to overcome and in some countries you see it more while in others less. She also said that people are ignorant about persons with disability, for example the reaction of people on that she could have a baby, there is a lot of fear of diversity, not only in terms of disability but also of different colour or gay persons triggered by false news, hatred from the media, political situation, etc. Janet said that she was lucky coming from an educated and forward-thinking family about her education and goals she wanted to achieve, so this gave her the strength to impose herself within her social environments, but not everyone is this lucky so the social barriers exist thus there should be life projects helping persons with disability to reach their maximum potential which are currently hindered by social barriers. For Christine, there is a division between the world of disability and the rest of the world, there is not a concrete inclusion yet and in order to remove architectural barriers have to be removed the mental barriers first, such as a recent case she read in the news of bullying of a boy with disability, and hopes that these prejudices, which unfortunately still exist in 2018, will be eliminated from society. For Lucy, the first barriers she faced were more cultural than physical, for example, when she was at secondary school she faced physical barriers which she overcame them with the help of her sister and schoolmates, and suggested that young persons with similar pathology to hers should try to find a solution to their problem with the means that they have, before getting angry and blame someone for the barrier they are facing. Brenda mentioned a barrier put by employees of a building who try to follow the law but do not see anything beyond the end of their nose and she is fighting with them due to their lack of understanding. Another participant, Penny, said that she did not face any problems with interactions with others when she was at school, maybe a bit at elementary she experienced problems with making friends but she is a proactive person so she would go near her schoolmates and show them how they can play with her and make jokes with her. She is using a lot irony to remove any social barriers but did not have any negative experiences at level of relationships or private level relevant to her disability. However, in her working place when she was younger she had experienced discrimination in the working place when her supervisor went to maternity leave and they did not interview her for the position although she had experience, so when she asked them for the reason they told her they excluded her because they did not want the responsible for the search of personnel to be in a wheelchair. She was very angry but she did nothing and then her employees created some “mobbing mechanisms” as she called them and three months later she chose to leave. But she was 23 years old and did not have yet the instruments of awareness, so the fact that she did nothing about it remained within her, because she could have done something about her rights but she chose an easier way, to be serene and just go away:

> There are many [barriers of social environment]. But they are in the mentality of persons. It is up to you to make them understand that you are not a rare case, and so make them try to understand you. But this is not always possible and feasible, so… you have to live with that. (…) It is a continuous battle every day for the right thing. There is no particular episode, it is a continuous battle every day from when you wake up in the morning till when you go to sleep in the evening. There are no particular episodes, it is the lived experience, the lived experience. Depends on the things that you want to do. Diana (P)

> Then there are the mental barriers, there are prejudices and in my opinion those hurt the most. From my own direct experience I have not received in particular any prejudices, but I know people who... and I hear about people who are subjected to them [prejudices] and those really hurt at heart, because we are persons

with disability, we are neither handicapped or... we are only persons who have a little problem or a big problem, but from a physical point of view, but we are equal to everyone else. Amy (P)

First of all, sometimes institutions do not… I think it is a wrong thing when they give you rights they give them to you to say “poor thing she needs a hand”, but no, they are the rights because they are disabled people equal to everyone else, not because “poor ones they are disabled and have to help them”. The cultural problem still needs to be overcome, which maybe in some countries you see it a bit less, by going around a bit I have noticed that, maybe in others no, but there still more that needs to be done. (…) And people I think they have wrong ideas about others, so the disabled person is seen like a poor one. So for example when I was pregnant they would not see my belly because I was pregnant, but they were thinking that I was a person who was a bit overweight. Or the other day I went with my baby girl to [name of shop] and I was stopped by an employee and she asked me if the baby girl was my daughter and then she said “that was unexpected”, because at social level there is still a lot of ignorance. (…) Too much fear of the diverse, that can be a disabled person, can be a person of colour, can be a gay person, so there is too much fear still that is fed by erroneous news, by media hatred, by a political situation that is heavy at universal level, etc. etc. Phoebe (P)

I have had a very forward-thinking family from various points of view, also in terms of teaching me self-awareness, the goals that I wanted to achieve, so this gave me the strength to impose myself with respect to the social environments in which I have lived in a certain way. I know that not everyone is this lucky, and so I think that the social barriers exist and I believe that overall one of the things that I wish that will be understood, and mostly for young generations about persons who have disability, it is important to invest not only in terms of assistance but also a life project. I wish that all the little Janets that exist now, someone, even if it cannot be a family, an institution will help them to understand how they can build their life in autonomy starting from an analysis of the reality. Janet (P)

The social barriers. In general there is discussion about this distinction between the world of disability and the rest of the world, there is no concrete inclusion yet as I have said before. To the point of arriving to terrible episodes, like recently I’ve read the last case on the news about the bullying against a disabled boy. In my opinion in order to destroy architectural barriers, first have to be destroyed the mental ones. Also here I have confidence, in my opinion I hope that we will arrive to the elimination of these prejudices that unfortunately still exist in 2018. Christine (P)

Yes certainly, as I was telling you before, the very first barriers that I remember are strongly related, maybe even more cultural than physical. Only to think that around me I have had very positive people, I mean my classmates in middle school, when we happened to be in a kind of swamp and I was not able to move with the wheelchair, beyond the professor, contrary to the professor, my classmates and my sister would think about an alternative way to enable me to do that activity there. For that it is something that the same, when I talk to younger kids with the same pathology as mine I find myself telling them this thing and I tell them that there will be things that you won’t be able to do, but it is not necessarily someone’s fault. So you have

> to evaluate always if there is a way to do it, which allows you to do it equally. So it is yourselves who put a limit, because you don't want to think out of the box and say "I'll find a solution to do it". But if you cannot do it because it is impossible to do it, you can get angry but to a certain degree. I mean that then it is not worth carrying with you all the resentment towards people who are stones and they cannot understand this thing. Lucy (P)

> It comes to mind the workplace, at my first work I was only a lot… (…) I started as an assistant in the selection of personnel. My supervisor after about seven months that I was went on maternity leave and so the position of the supervisor of selection of personnel was vacant, and interviews took place with people who were younger than me and had no experience, and I was not called at all to do an interview. So I went to ask for explanations saying that the position of my supervisor is vacant, I have been here for six months, you don't call me but you are seeing people who have less experience then me and it was clearly said to me that it was because they did not want the supervisor of selection of personnel, of the selection of the research of personnel in a wheelchair. Penny (P)

The two participants who stated that they had never experienced barriers for social participation related to the social environment, were both university students – one a master's degree student and the other one an undergraduate student – and one of them working and being active socially and politically, while the other one was active in terms of activities related to sports.

14.3 Suggestions for implementation of existing laws on accessibility and denouncement of accessibility problems to institutions

When asked to suggest ways to overcome barriers for social participation, half of the participants, Nicole, Phoebe, Lucy, Brenda and Penny, suggested ways related to overcoming issues related to physical environment, such as accessibility issues and architectural barriers. In particular, three of the participants, Phoebe, Lucy and Penny, pointed out that although there is legislation on accessibility, it has not been implemented properly in Milan since, for example, there is lack of parking spaces for persons with disability, all public and local places should be accessible for wheelchair users, tickets for concerts are limited for persons with disability and there is not enough space for their wheelchair which limits their social participation, and relevant laws should be better defined and oblige all public spaces to pay attention to accessibility without this attention being optional, but obligatory by law. However, one participant, Penny, also stressed that persons with disability themselves have also responsibility for removing barriers and become promoters of accessibility, for example, when deciding to go to a restaurant and calling in advance to find out if it is accessible for them, if it is not, then suggest to the owner a solution such as putting a slope, so if every person with physical disability did that then the owner would maybe decide to keep the slope and make the restaurant accessible. Brenda suggested that there should be conducted a study in each neighbourhood of Milan to assess the needs of the population and make a plan where at least the subway of the city, which she said that it was considered European city for disability 2017 and hosted the Expo[35] exhibition, would have all subway services accessible for a person with disability. Finally, Nicole, stated that persons with disability they only thing they can do is continuously denounce to the institutions any accessibility issues that they encounter, but even so, institutions respond too late or do not respond at all:

It is important to continuously report problems to the institutions, but they always respond too late, or they do not respond at all. The only thing that we can do is to continue reporting them. Nicole (P)

It comes to my mind this and then more with respect to the norms, the law, we have too many laws but they are not applied, and then you find yourself in situation like a new environment and the parking for disabled that does not exist or I don't know, there should be more civil sense also on a social level.

It comes to my mind this and then more with respect to the norms, the laws, we have too many laws but they are not becoming applied, then you find yourself in a situation like in a new environment and the parking for disabled does not exist or I don't know, there should also be more civil sense at social level. Phoebe (P)

First of all I believe that for social participation an essential thing would be to make a raid at public places and imposing the norms of accessibility, more than already exist, because in my opinion what hinders social participation is actually this, the fact that for me to go to a concert I need to ask for a ticket through a different channel and then this is relegated to a small space where we are all piled up with the wheelchairs, when actually I would like to buy a ticket like everyone else. For goodness' sake of course there has to be a protected space, but maybe there is the disabled person who wants to go in the middle and nobody... in some way it is her/his own risk that she/he takes and danger. And I believe that these decisions are born from unconsciousness but also from a lot of consciousness. Whoever has a disability knows what are the risks and if she/he decides to take them knows which are the consequences in most of cases. Maybe not in all cases, but in most cases, yes. Lucy (P)

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[35] Expo Milano 2015 was the Universal Exhibition that Milan, Italy, was hosting from May 1 to October 31, 2015 (http://www.expo2015.org/archive/en/index.html).

> To do a focused study on this specific topic, so neighbourhood by neighbourhood and to identify the main needs. I understand that one cannot fix everything, because there is no money and the resources, but to make a plan where at least the subway of the city considered European city for disability 2017 and that hosted EXPO, should have a whole subway that works for a person with disability. Brenda (P)

> Also in this case I believe that it has to do a lot with going out, asking. It has often happened to me when I call or verify that there is no barrier I say but they could have been... I give also solutions. It would be enough having a slope, but if I do that and then nobody else does that too, then remains like this. If all of us went and asked and became promoters of what our needs are I believe that for sure on the other side they would take it for granted. On the other hand, undeniable there is a legislation that still does not oblige all places to pay attention to architectural barriers or if it obliges, it obliges always with the possibility that a lot of owners of public places do not pay attention. So on the one side there is our responsibility, and on the other side there are laws that could be more a bit precise and defined. Penny (P)

The participants who made the suggestions for implementation of existing laws on accessibility and denouncement of accessibility problems to institutions did not have any sociodemographic or other common characteristic among them.

14.4 Suggestions for change of mentality of the public, more public visibility of and communication about persons with disability, education of the public, and life projects for persons with disability

Six of the participants suggested ways for overcoming barriers for social participation related to the social environment. In specific, two of the participants, Diana and Penny, mentioned that there should be a change of mentality. Diana said that in the wider society there is not a predisposition in favour of diversity or difficulty one might have and the abatement of the barriers does not exist, unless you do it. Penny said that persons with disability have a responsibility of their way to live in the world, for example, if one goes out to the world as a disabled person only in search of recognition or satisfaction of their needs, it is obvious that the world will see this person as an individual that constantly needs help. So persons with disabilities should not only ask for their rights, such as equal treatment at job interview or convenient working hours, but also keep in mind that they also have obligations, for example, to take the responsibility to stay at work on certain working hours, which Penny believed that could change the mentality of others a lot within the workplace.

The suggestion that persons with disability should become more visible to the public was mentioned by two of the participants, Christine and Penny. Christine said that for inclusion of persons with disability people should not make programmes dedicated to disability, or films or books on disability, but when there is a common context, such as the festival of Sanremo[36], if there is presented a person with disability as a host or presenter, then there would be inclusion. Because focusing on disability can be instructive, but on the other hand can emphasise on the aspect of disability and then people will emphasise on this characteristic too. Penny suggested that persons with disability could do more if they could go out of their house more, because there are less people with disability on the street in Italy compared to other European countries, because in Italy there are more looks from the wider society of ignorance and wonder when they see a person with disability and not of familiarity like in other countries that they look at you like everyone else, but she believes that persons with disability have responsibility in this too.

Another suggestion for removing barriers was to communicate more about disability, as Phoebe suggested, such as to start speaking about things in a lighter way, without giving always the idea that disability is a heavy thing. Unfortunately sometimes it seems that people think too much about themselves and have little empathy towards others, but our social duty is to help others understand also that things are a bit different than what they seem. A similar suggestion came from another participant, Amy, who said that there has to be more education on how to confront the physical disability issue as a common issue and not as an insurmountable thing of which to be afraid or ashamed of. This requires education of the operators, citizens, and teenagers who sometimes maybe naively use terms which are not very nice to persons with disability. Lastly, Janet pointed out that Italy is a country advanced in terms of accessible physical environment and having inclusive education, but need to invest more on a life project for the inclusion of persons with disability:

> Actually there is nothing to suggest, because actually it is a question of mentality, it should be a view of everyone, but this does not exist. It depends on you because you can stand up, take off and go and if you

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[36] *Festival della canzone italiana di Sanremo* (Italian song festival of Sanremo) is a very popular annual song contest in Italy shown on the Italian TV station Rai 1.

want you can arrive at the Madonnina of Duomo[37], but I can't. So up to the Madonnina of Duomo I cannot go. It is a question of how things are structured. There is no predisposition at diversity, in my opinion. Then I think diversity is not the exact word for difficulty. Because diversity we all are different from each other. And this is the problem. The word is 'difficulty'. Destruction of barriers does not exist, unless if you don't it. Diana (P)

I believe that we have a responsibility, it is the responsibility of our way to live in this world, if I go to the world as a disable always in constant search of recognition, of satisfaction of my needs, of aiding on things, it is obvious that the world will see me as a person who has a constant need. So I believe I have needs like all of us, the needs are particular, special, but I believe I have a duty first of all towards myself to be responsible of what I am doing in the world, and also to bring to the world what I am. I do not have only needs but also duties and I believe… I would like this a lot if this thing entered a little bit because often the attitude that I see is very assistance-oriented, so you have to give me a job, the convenience and working hours that I want, maybe no. I have a right to participate in the job selection as everyone else, I have the right to do an interview as everyone else, but I also have the duty to take responsibility to remain at work certain working hours; this is a thing that for me could change a lot the mentality, questions related to the working environment. In the more social environment I truly believe we could do more if we went out of the house more, still today I travel a lot in Europe, a little bit in Italy, and I notice that in Italy I meet in the streets less disabled people, and it is obvious if we are closed at home if nobody sees us it is obvious that inevitably there is less attention towards our discussions. Penny (P)

I found that there start having some openness towards disability for example with programs focused on love without barriers, or I remember at the last Sanremo [song contest] when Ezio Bosso the pianist with ALS (Amyotrophic lateral sclerosis) participated, it was a beautiful thing because in my opinion the risk of doing programs dedicated to disability, films or books on disability, on one side it achieves that inclusion because it is presented to the people also this world, which is not a world apart, but a part of the world, a phrase that I have heard often, but I believe that this inclusion is not of 100%, it is not integrated, in the sense that in my opinion integrated inclusion there is and will be when there will be presented a lot more occasions like that evening at the festival of Sanremo, where in a common context, in a common broadcasting and not specifically dedicated, there is a person with disability, that could be a guest or a presenter, all these programs, variety, quiz, if there was an idea a competitor with disability, that in my opinion would verify really an inclusion, if you talk about disability and inclusion. But this focusing on disability on one side can be informative, but on the other side it always denotes that barrier, I mean disability is that, it is one thing but then you have your own world, denotes always indirectly this barrier. But if disability becomes included in a non-exhibitionistic way, not evident, but in a spontaneous and silent way, if disability becomes included without giving emphasis, in a way that it is almost unseen, in my opinion in this way there can be a total inclusion. Christine (P)

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[37] Duomo is the main Cathedral in the centre of Milan and in specific is the Cathedral Church of the Diocese of Milan. The Madonnina is the golden statue of Virgin Mary at the top of the Duomo of Milan. For more info: https://www.duomomilano.it/en/infopage/the-madonnina/54/

> First of all with communication, in my opinion, starting to talk a bit about things also in a lighter way, without giving always the idea that disability is something very hard. I mean it is true, you have a life that might be limited, but if you as society allow me to have an equal life, a less limited life, and the differences maybe become less differences. In my opinion first of all at communicational level to make a good revolution and then there should be less paranoia in general. Phoebe (P)

> So suggestions, I don't know. Regarding removal of architectural barriers, I don't know, because [laughs] I am neither an architect nor... Regarding removal of mental barriers, I can say that there should be more education on this topic also from the part of people who take care of us: social health workers, auxiliary social support workers… a lot of education to deal with the problem as a normal problem and not like an insurmountable thing of which to be afraid or be ashamed. There needs to be education, of operators/workers, of citizens…and… education also to adolescents who sometimes maybe with ingenuousness use some terms which are not nice in our discussions. Amy (P)

The two participants who suggested that persons with disability should become more visible to the public were both educated to a bachelor's degree level or higher and never been married. The similarities among participants who suggested change of mentality of the wider society towards persons with physical disability were that both were of similar age (i.e. 34 and 36), working in paid employment and never been married too.

Core Theme 15. Barriers for independent/autonomous living and suggestions for removing them

15.1 Major dependency from parents and/or partner and/or need of more financial support

Six of the participants mentioned that they had no other choice but to depend partly or entirely from both or one of their parents or their partner to help them perform everyday tasks or are in need of more financial support from the State. Most of them stated that without their parents they would not have been able to live on their own with care assistance given that they would not be able to cover the financial cost of paid caregivers. Participants suggested that more financial support from the State would allow them to have more help in their everyday life and thus lead a more independent life, while at the same time relieve their parents and partners from the burden of caregiving, since the older these persons become, the less able will be to physically help participants. One of the participants, Janet, mentioned that although she renounced the disability benefit since she is able to cover all expenses for her care assistants by her salary, she does not have any fiscal relief since she cannot deduct the expenses of the people who help her and the fiscal system treats her as a rich person with home assistance:

If I needed a caregiver tomorrow, when my mum won’t exist anymore, the [financial] contribution is derisory to manage to cover the cost with it. In fact, this is a big social problem that in my opinion has not been resolved. Because you should have the economic resources to then employ that person. So it would become burdensome... something that honestly I will think about it when it happens. Diana (P)

The problem is that, when your family is not able to sustain you anymore, or you become hospitalised but at that point everything that you have achieved becomes less, because my life is to work and go to do my things, or it is necessary to find a way to have economical support, but also not directly given to the person but to a person who helps her/him. Substantially. Rebecca (P)

Eh, a help, exactly, as I was telling you, also even economic to be able then to have a person that can in some way substitute my mum, because my mum… anyway she has a certain age, she is still capable, but obviously she won’t be able to do everything till the end, so she will need to be helped, my dad works, he is the only one that brings a salary at home and so my mum has to be helped to manage this situation also from a physical point of view because she cannot do everything. Amy (P)

It depends, certainly yes, because as it happens with situations where inside of the nucleus of a family where there is present a person with disability, there is also financial difficulty, and that means having little possibilities for an accessible life, because ASL [azienda sanitaria locale – local health service] helps you to a certain point, then all the rest that is extra you have to pay by yourself and costs a lot, and so you have to limit your possibilities because you also have to eat. There are disabilities which are more serious, those more manageable, disabilities that need a lot of equipment, and so it goes from case to case. The State should help much more, taking into consideration that the nomenclature of equipment was modified a year ago after 20 years; that’s all I can say. Brenda (P)

Unfortunately I cannot live an independent life yet, I need assistance 24 hours per day by my mother. Nicole (P)

A disabled person today, with a physical disability, because clearly cognitive disability is another thing and requires other types of help… but a person who has a physical disability, to be autonomous has to have a lot of money today, it is a financial issue, because this person has to pay people to help her/him. I think also that it is a financial help which has to be given to this person to be able to emancipate from family, because family cannot be the place where one passes her/his life, and so unfortunately my life is very expensive, a lot more expensive than of any of my peers, and I believe that about that the State should be aware of it, not

> only in the sense of helping whoever does not have resources, but also to recognise… for example I do not ask for resources from the State, but fiscally I do not have any recognition, I cannot deduct the expenses for the people who help me, I think that this thing is unacceptable. Half of my salary, even more than half, goes to people who help me and I from a fiscal point of view I get treated as a lady who has a housemaid who cleans my house all day. And that is not really the same thing. Janet (P)

No sociodemographic similarities emerged for participants under this theme.

15.2 Physical environment / accessibility barriers

Four of the participants, Amy, Phoebe, Christine and Penny, referred to physical environment and/or accessibility barriers which hinder autonomous living. Examples given by participants were various, two of them already mentioned previously were mentioned by Amy, that election centres usually do not provide places for persons in a wheelchair to be able to vote, so someone else has to place their vote for them, but should have had the right to vote on their own. Another example was that the post offices have counters at eye-height so the person in a wheelchair cannot reach to sign anything and again another person has to do it for them. Phoebe also mentioned examples, that when she and her husband had to find a place to stay, they had great difficulty finding an accessible apartment within their budget since there are no municipality apartments for persons with disability, then if one has to go to work and takes the public transport might arrive late because the stairlift gets blocked or the elevator is broken. Also, the offices are not always accessible, so it is not easy to find a job. So then persons with disability become less integrated, as Phoebe said, and it becomes more difficult for them to have a social life. If persons with disability work less and move around less, then they become disadvantaged. Christine mentioned that even a small step at the entrance of the bar is a barrier for living independently for a person in a wheelchair, so there is a lot that has to be done. Penny said that everyone is facing barriers for independent living, it is just that her limitations are more visible to others. But despite the everyday difficulties moving around outside her comfort zone, she still works and travels and said she has an autonomous life:

> So, for example... it has happened to me to... very often to sign documents in public places like the post office... or for example a more ordinary thing, the vote, voting, when people vote. I enter into the handicap booth and I expect to find there a table at the correct height, no? On the contrary when I enter I find it at eye level. I cannot reach to express my vote, so I lose the possibility to express my opinion, for a thing that is resolvable in a way. But I cannot vote and have to enter with my mum who must vote on my behalf,

obviously I tell her who I want to vote and she does it, but it is not right, it is not right neither for me being in this condition, nor for everyone else in this condition. Because everyone should be able to express their opinion and if in order to express an opinion in this case is needed is a lower table, you have to guarantee in the booth a lower table at the height of whoever goes to vote. Otherwise there are then citizens of series A and citizens of series B, according to their logic, but if they fixed the booths, it would be easier for everyone, but they do not do that. Amy (P)

For example, in our condition in order to find an accessible house it is a real disaster, then finally we found it, but the rent is a lot higher because it is a new building. For example, my municipality does not have public housing for disabled people because they are not common, do not have them. For this reason I am saying that it is important to think about that if a disabled person who wants to live autonomously has more difficulties. Because if you cannot take public transport because you arrive at work late because maybe the stairlift gets blocked, the elevator is broken, the subway line does not work well, you have to change it a bit further and it is already not ok. Regarding buildings they are not always accessible, so also just that. Work, is not easy to find it, because not all companies, not all employers have the idea that a disabled person can work, so it is more difficult to find work even if there are laws, but many people do not care about them. And then all of this causes that disabled people are less integrated, and then from that point on it is more difficult for them to have social life. If they can work less, if they can move less, if they can live less, then they are disadvantaged. We are still very backwards as a society in my opinion. Phoebe (P)

Yes, well, even a simple step at the entrance of a bar does not allow the access to the disabled with a manual wheelchair, because the electric wheelchair you cannot lift it, you can do it if there is a person who helps you. So if we are talking about autonomous life and completely independent, even a simple step at the entrance of the bar does not facilitate. I think it is necessary to do a lot. Christine (P)

I deal with barriers, I live in a world where barriers exist, I deal with them, I believe that everyone deals with them. Mine maybe are more visible, my limitation is more visible. Saying that it is like saying that I am afraid of flying, afraid of planes, but I continue taking them I have never stopped because I want to reach places, I want to travel, to work. The barriers is a part of my wish to go to the world, I want to be independent. (…) Yes, if you ask me in a more concrete way, as years go by I have organised my life… in my daily life I can say that I have an autonomous life in which I don’t have difficulties with daily tasks, I have difficulties when I go out of my comfort zone, but in my comfort zone I have definitely overcome them. Penny (P)

No sociodemographic similarities emerged for participants under this theme.

15.3 Lack of a common law, cultural and bureaucratic barriers

Two of the participants, Phoebe and Lucy, referred to additional barriers for autonomous living, such as the lack of a common national law in Italy on distribution of funds on persons with disability, that Phoebe mentioned, and the fact that independent living is not adequately considered in Italy and people depend a lot on their families thus Italy is behind a lot at European level. Another participant, Lucy, referred to the fact that there are bureaucratic barriers, such as having to do a lot of paperwork to get something done, and cultural barriers for autonomously living, for example, at her building, the other residents thought that her partner was her care assistant, because they did not think that persons with disability can live also independently and have a life like everyone else:

> I can say one thing, you know, one thing that is missing a lot here in Italy is the consideration of an independent life, because there is no law, people in wheelchair will tell you as well if you talk to them, there is no unified law, so every region does whatever it wants, also municipality does whatever it wants, because it is true that maybe the region perhaps uses some of the State’s self-sufficiency funds, but then every region uses them as it wants and distributes them and municipalities in turn distribute them as they want. So there is lack of a unique legislation. And as a consequence there are holes, maybe there are regions that have nothing and regions that have a lot more. And people… there is already a gap among people perhaps between one region and the other, between one municipality and the other. (..) and just this in my opinion is wrong, it is not ok, they should definitely look again at this situation. And then independent life unfortunately is not yet considered enough, people depend too much on their families, there is none [independency]. And in my opinion at European level Italy is very much backwards, very much backwards.
> Phoebe (P)

> They are always part of cultural barriers in most cases and also of bureaucratic barriers. It is still difficult to think that a person with a disability can live alone, to have an autonomous life etc. In the beginning when Max [her partner] started living with me, occasionally they were asking me “how is it going on with this care worker?” and I said “it is not my care worker, it is my boyfriend”. To think that we can have life with the same steps of other people, yes, it is still very difficult, the bureaucracy does not make it easy, for every little thing you have to produce thousands of kilos of paper and passages often useless or apparently useless.
> Lucy (P)

Both participants who reported lack of a common law, cultural and bureaucratic barriers were of similar age (i.e. 30 and 35), cohabitating with their partner, and working in paid employment. They were also both involved in organisations of persons with disability, one of them through her work and political interests and the other one through an international sports team.

15.4 Suggestions of changing mentality of the wider society on persons with disability and/or removing architectural barriers

In terms of suggestions for removing barriers for autonomous living, three of the participants, Diana, Brenda and Janet, stated that there should be change of mentality of the wider society on persons with disability to make people understand that persons with disability are only seated and have a difficulty, that persons with disability are not a problem and just think about things in a different manner, such as in terms of accessibility. For example, Diana referred to existing problematic accessibility in trains and bus, thus one must have a car with footrest otherwise one cannot trust the public transport since not all parts of the city are reachable with the lines and not all lines have an elevator. Institutions should allow one to move around the city with public transport calmly. As Brenda suggested that since there is no difference in making a stair instead of a ramp, there should be unified the design with mobility thus make constructions which are pleasant to the eye, so that even for people without disability will not be bothered seeing excessive forms of structural integration. Similarly, Janet suggested that for persons with physical disability there is need for a large investment on removing the architectural barriers, with great attention to the new constructions to verify this in practice, and a great effort of cultural education of the project designers:

That’s the thing, it is the mentality that must change, that I am only sitting and I have a difficulty compared to you, but… I should be given the possibility of doing, the way. And the way sometimes does not exist, because starting from trains, from buses, from who brings you in and out, how you get up, how you get out. And so it becomes complicated, daily life becomes complicated. Because if I, for example, was not able to allow myself to have a car with mechanical platform, I would not able to move around because to rely on public transport would have become a problem, because they do not bring you everywhere, because there isn’t an elevator in every line. So… to be able to go to work I had to use a vehicle. If I did not have the possibility to do that... because it is true that they give you a financial aid, but you have to pay in advance for everything, and then they give it to you with their convenience, with a lot of their convenience. So had I not had a vehicle, I would have been a lot more limited in being able to do things. The institutions do not allow you to move around calmly by bus, so you either have a car or you have a car. Diana (P)

Unfortunately it would be necessary to change the mentality, to make understood that we are not a problem but simply have to think things in a different way because there is no difference between going on a small stair and going on a ramp which is always aesthetically nice and functional, to combine the design with mobility, in a way that also in the eyes of people without disability who are not used to and maybe are bothered by seeing excessive forms of structural integration, one could make them in a way that they are pleasant and beautiful to see. Brenda (P)

In case of physical disability there is need for a big investment in the elimination of architectural barriers, a lot of attention to new constructions to be verified concretely, and a big effort on cultural education of the planners. Janet (P)

The only similar characteristic among the three participants above was that they were working.

15.5 Suggestions to provide financial support, employment opportunities and advanced education to persons with disability

In terms of autonomous living, it was suggested by Janet also that one has to understand how the life of a person with disability functions and develop the conditions which will allow this person to be autonomous financially and there should be a serious investment on the employment of persons with disability because work is an aspect of dignity. Moreover, there should be more understanding and a life project especially regarding young persons with disability, and it is necessary for a person with disability to have an advanced level of education to live independently:

In the case of autonomy I believe it is important to understand how the life of a person with disability works, and create conditions for that person to be economically autonomous, so a big investment in occupation of disabled persons seriously, and not just ‘parking’ persons, because work is a part of dignity. And then when a person starts making contributions [to taxes], and takes into consideration that her/his life is very expensive, and so to help her/him to go where he does not go if he does not go, to be revenue-friendly. (…) and to learn how to deal with disability in a different way, whoever is young nowadays has to build a whole life, needs policies of investment on a life project. And on the other hand the disability of older persons who get assisted till the end and helped, but do not have a problem such as after ten years. I mean a child who is born today with the same pathology I have, I have to ask myself how I can help this child to make it until a university degree, because this child should have a university degree, in terms that it is necessary for a disabled person to have a higher level of education. Janet (P)

15.6 Suggestions to denounce barriers to institutions and provide institutional support at municipality level

Another participant, Nicole, repeated her suggestion to denounce barriers for autonomous living to the institutions and given that Milan is not an accessible city, she suggested that there should be a team created within the municipality consisting of persons with disability who would try to find ways to improve the city:

> Exactly, as I was saying before, it is important to continue reporting [issues] to the institutions because unfortunately it is them who have to put their hands [do something], we cannot do this on our own. (…) but we simply live in a city like Milan but which is not accessible, so whoever is in charge at the institutions should create teams within municipalities with people who have disability in order to find out how to improve the city. Nicole (P)

15.7 Suggestions towards self-empowerment, finding the resources to reach autonomy and not focusing on disability

Finally, two participants, Lucy and Penny, made suggestions directed towards persons with disability themselves for removing barriers for living autonomously. Lucy suggested that persons with disability should believe in themselves and not give up with the first difficulty, whether this difficulty is bureaucratic, cultural, or physical, because one must have a realistic target in terms of autonomy in order to be able to reach it. As the same participant stated, in Italy there are both positive and negative things in terms of support from the government for reaching autonomy and one has to evaluate the bureaucratic steps and be prepared and build a network of people who can direct her/him, such as occupational therapists, associations, etc. The other participant, Penny, suggested that persons with disability themselves should try to find the resources to move the shift the focus away from disability and orientate it towards life itself and she said that if she sees herself as a person with disability then she will see only her limitations. There are many things that she is, a person, a woman, a professional, a friend, but when disability becomes the distinctive aspect then it is difficult to move forward:

> To believe and not be discouraged by the first difficulty whether it is bureaucratic, cultural or physical basically. To come prepared for it. In my opinion for many people having information and arriving prepared mentally and physically, as much as possible, it is fundamental. Being self-conscious because it is not possible to reach autonomy without knowing the type of autonomy that you want to achieve, otherwise you risk having a dream and staying unsatisfied and to chase something that does not depend on anyone and could not happen, and to be realistic. I am realistic when I think that at the end we decided to stay in Italy, and certainly having many positive things, but also many negative things in terms of actual governmental support for achieving of autonomy. If I had decided to move to Finland to his place [her partner's] I would have had much more help in daily life, but also because the welfare system works differently actually with basic principles, it is not that it works better or worse, because they have their criticisms also in the rest of

Europe, but I would have had much more support in daily life, maybe I would have had less financial help, things are in balance. There were difficulties related to the environment, having snow seven months per year in comparison to here, and so for this I am telling you there is always an evaluation and criticism of the person, and preventive information, so when you go to evaluate bureaucratic steps there will be few that will surprise you. If you arrive prepared and you create around you a group of people with whom you can blow steam off because they make you angry a lot, having people who can give you indications, such as occupational therapists, associations, etc. it is a path that maybe is easier. Lucy (P)

Certainly, it is to try to look for resources to move the gaze away from disability and to orient it towards your life. If I look myself in the mirror continuously as a disabled person I will see only my limits, and often working with disabled people I have noticed, I am talking to you, I communicate with you as a disabled person. I am a person, I am a woman, I am a professional, I am a lover of music, I am a friend, I am many things, my disability is just one part of them, disability becomes my distinctive characteristic therefore it is difficult to move forwards. Penny (P)

Both participants who suggested self-empowerment, finding the resources to reach autonomy and not focusing on disability, in order to remove barriers for living autonomously, were of similar age (i.e. 30 and 34), both educated to a master’s degree level, in paid employment, and not living with their family of origin, but their partner or alone.

Main tendencies of Main Area 2: Social relationships, social participation and disability

In terms of the **size of the social network** of participants with physical disability, the smallest number of ties reported was about 5 persons and the largest about 20 persons, with the majority of participants having about 10 people in their close social network.

The findings on the **type of relationship** with the ties of their social network revealed that almost all of them mentioned family and friends, who they had known since childhood, school, university or work. Some of the participants also referred to having friends through sports groups, such as hockey team, and from rehabilitation centre. However, only one participant mentioned among her friends a health care provider (a physiotherapist), while another participant when asked specifically about including in her close social network her care assistants she replied that she sees them only as persons helping her do the things she cannot do by herself and is counterproductive to mix emotions.

The results above confirm partly the findings of a previous study (Guilcher, Casciaro, Lemieux-Charles, Craven, McColl, & Jaglal, 2012) in which on a sample of 14 adults, with spinal cord injury severity of tetraplegia and paraplegia, the overall median for available informal networks were 11 persons, with a range from 3 to 19 persons; closely similar to the range of 5 to 20 persons reported here. Moreover, based on the same source, ten participants identified as members of their social networks only family and/or friends and informal care providers, whereas three of the participants identified also within their social network paid formal health care providers (Guilcher, Casciaro, Lemieux-Charles, Craven, McColl, & Jaglal, 2012). Thus, the finding of this thesis that only one out of the ten participants included a paid health care provider within her social network, confirms the findings of this previous study too.

About the **frequency of contact** with the ties of their social network, it emerged that most participants were speaking with their close friends at least once a week, but were meeting them in person less often – the majority of them about once a month. However, those who included also colleagues in the close social network were seeing their colleagues every day. In addition, the most common **way of contact** used by participants was a mobile application (i.e. WhatsApp), which is a very common way of communication among young people in general nowadays, including Italy, and then less often they also used standard phone calls and social media (i.e. Facebook), whereas they reported having face-to-face contact the least often.

On formal social networks, in terms of **membership at organisations or volunteered groups**, half of the participants have been members of associations for persons with disability and/or part of sports groups, such as hockey team, or mutual-help groups at a rehabilitation centre. Two participants belonged to political groups, one of them at a trade union and the other one at a political party she was a representative of. There were, however, three participants who did not belong during the time of the interview at any organised or volunteer group, but one of them stated that she does not belong to any volunteer group, although she stated in other parts of the interview that she was writing articles for a group of women with disability within an association of persons with disability.

In respect to the findings above, a recent study (Mithen, Aitken, Ziersch, & Kavanagh, 2015) comparing social capital and health between 15,028 persons with and without various types of disability, found that of all the types of disability they explored (i.e. sensory and speech, physical, psychological and intellectual), only the participants with physical disability had lower levels of group membership compared to persons without disability. The authors of this study suggested that this may be due to practical and logistical barriers to group participation for persons with physical disability, which should be considered when aiming to strengthen group participation among persons with disabilities (Mithen, Aitken, Ziersch, & Kavanagh, 2015). According to the same study, persons with disability had lower level of both frequent direct contact (i.e. face-to-face once a week or more) and indirect contact (i.e. telephone, e-mail or mail a few times a week or more) with their family or friends, compared to persons without disability. Thus, the findings of this thesis on participants with physical disability not meeting frequently with friends face-to-face could be confirming this previous evidence. Furthermore, persons with disability had lower level of membership to formal networks as well, compared to the general population, with persons with physical disability demonstrating lower odds of belonging to groups (Mithen, Aitken, Ziersch, & Kavanagh, 2015). However, in this thesis more than 2/3 of participants belonged to a formal social network, thus not confirming this latter finding of the previous study.

All participants stated that they were performing various **daily activities**, with eight out of ten working in paid, freelance or volunteer work. As leisure activities, the majority of them mentioned watching a film at home or at cinema, while housework was mainly done by their mother, partner, or care assistant; however there were two participants who mentioned doing housework themselves. The main difference among participants was that six of them mentioned going out socially as part of their daily activities, whereas four of them did not. This finding closely matches previous data reporting that 45% of persons with physical disability meet their friends at least once a week, and persons with severe disability want to go out more frequently, compared to people with mild or moderate disability, to do more activities in their leisure time, and have more social contact (Meulenkamp, Cardol, Van der Hoek, Francke, & Rijken, 2013).

Nevertheless, in this thesis, participants mentioned doing also numerous leisure activities during the week, such as going to concerts, exhibitions or museums, being occupied with trade union, writing articles on a personal blog or for association of women with disability, drawing, knitting, reading, listening to music, checking on internet and social media, doing sports for rehabilitation or pleasure, as well as meditation. On this latter activity mentioned by one of the participants, previous evidence has shown that the practice of mindfulness meditation can be used as a basis for effective behavioural programme on self-regulation in persons with chronic pain, since after 10 weeks of practicing mindfulness meditation, 65% of the participants showed a reduction of about 33% in the mean total Pain Rating Index and 50% of participants showed a reduction of 50% respectively (Kabat-Zinn, 1982).

Only two of the participants stated that they were currently doing a physical activity (i.e. going to the pool for rehabilitation), while another participant said she wanted to start fencing again. Moreover, as another participant mentioned in terms of type of relationships within her social network, when she was doing hockey it helped her at social level very much in order to integrate and suggested that doing sports is a great way to bring people together and meet people, and she said she met her husband too in the hockey field. Nonetheless, as it has been argued in another study (Ruddell & Shinew, 2006), many people are not aware that there are leisure and sport opportunities available to persons with disability, thus the participants of that study, who were women doing wheelchair basketball, reported that this sport played a big role in their lives. In addition, many of that study's participants were frustrated that the opportunity to do this sport was not made available to them earlier, since their physical education teachers, who could potentially socialise them into sports, had lack of awareness and education, or that there was unavailability to others who might be interested in doing this sport too (Ruddell & Shinew, 2006). Thus, women with disabilities could possibly benefit from socialisation through physical activity and engagement on team sports. Lastly, to enhance leisure activities for persons with disabilities it has been found elsewhere that the most frequently mentioned facilitators for leisure activities within relevant studies on persons with disability have been attitudes, availability of information and knowledge, support from persons of the social network as well as support from the legislation (Hästbacka, Nygård, & Nyqvist, 2016).

On the core theme of **homophilious or heterophilious social networks based on disability**, the majority of respondents stated that they had both friends with and without disability within their social networks, and the other participants that they had only one or no friends with disability. Thus, all participants with physical disability had heterophilious social networks and none of them reported having only friends with physical disability. As mentioned in previous parts of this thesis, having mainly heterophilious social networks indicates bridging social capital, thus participants with physical disability had stronger bridging social capital, whereas weaker bonding social capital (Putnam, 2000). However, as some participants mentioned, they were very close to other persons with disability too, such as one participant with her friends with disability who she meets at the rehabilitation centre, thus it is likely that these participants have had stronger bonding social capital and weaker bridging social capital; but the tie strength within the social network of participants was not assessed in this study. In addition, as one of these participants mentioned, she finds it easier to share her doubts regarding her health issue with her friends who also have the same pathology as hers, whereas it is difficult for her friends without disability to have this outlook. As it has been suggested elsewhere, homophily in social networks has the important role of providing crucial social support, probably because persons who share similar characteristics can provide among them trust, reciprocity and enhanced communication (Langford, Lengnick-Hall, & Kulkarni, 2013).

On the core theme of **change of attitudes of social network due to disability**, there were participants who stated that they had never experienced any change of attitude from others, because their health issue developed too early in their life to have noticed any differences in attitudes or had no problems in socialising with their peers or never received any negative prejudice towards them from others. On the other hand, some of the participants had experienced negative change of attitude from others when they realised that the participant had a physical disability, or when presented to a group of people who do not know how to react to the fact that the participant has a disability, and difficulty making friends due to disability, and possibly someone becoming distant after realising the participant has a disability. Nowadays there are laws and policies to ensure equal treatment of persons with disability and their integration into society, whereas open antipathy and dislike towards persons who are physically different is not acceptable socially (Krahé & Altwasser, 2006). However, there are still cases of rejection, fear, and discomfort towards persons with disability, and these negative attitudes begin to emerge early in life with young children categorising people into persons with disability and persons without disability, while favouring the latter ones, and at the same time existing social and cultural norms endorse maintaining beauty, fitness and youth, whereas media depict persons with disability as sick and suffering (Krahé & Altwasser, 2006).

The majority of respondents **received social support** mainly from their mother or partner and their friends (i.e. informal support), for performing everyday tasks. The rest of the participants were more independent, at least financially, from their family and some of them did not receive disability benefit or only a carer’s allowance or neither. These participants received support partly in order to perform daily tasks from parents or partner, and mainly from care assistants and/or health professionals or other persons (i.e. formal support) under payment – privately or through institutional support – to help them, for example to go to the bathroom during working hours. Two participants mentioned receiving or having received psychological support as well and two other participants had a live-in care assistant overnight too. Activities of daily living (ADLs) include fundamental skills required in order to perform basic daily needs, such as grooming, personal hygiene, toileting, transferring and eating, and physical functioning is often an important driver of ADL ability (Mlinac & Feng, 2016). Regarding persons who have restrictions in independent self-care and physical functioning, thus require assistance to perform ADLs, it has been shown that ADL dependence by others is correlated with poorer quality of life and increased health care costs, among other aspects (Mlinac & Feng, 2016). Indeed, the issue of high costs for care assistance and desire – or worry – about the future to live independently emerged in this core theme too, as some of the participants stressed the lack of resources to cover financial demands for care assistance in case they wanted to live more independently from their parents or their parents or partner might not be able in the future to help them anymore. All participants received institutional financial support, whether disability benefit or carer’s allowance or both, apart from one participant who due to having a well-paid job she was not eligible for any financial support from the State, and said that she would never allow herself to ask for such help given that there are others who need this help a lot more than she does. Despite the financial help participants received, the vast majority of them reported that the financial institutional support they receive is not adequate to cover all costs. This fact presumably caused stress to participants and insecurity about their future, which may affect negatively their quality of life and well-being. As it has been argued elsewhere, the average income of persons with chronic physical illness is considerably lower compared to that of persons without disability, and their health issue brings additional direct costs such as for health care utilisation, domestic care, and technical aids, as well as indirect costs, such as higher energy bills for recharging an electric wheelchair, higher telephone or heating costs because they stay at home longer, and other costs (Rijken & Groenewegen, 2008).

Apart from receiving support, many of the participants stated that they also **provided social support** to others, whether a more formal support, such as within the framework of associations/organisation of persons with disability and/or through political activity, for example to promote issues on accessibility at municipality level and practical assistance at national and international events of a sport group. There were also participants who reported that they provided more informal support, in terms of psychological support to others and encouragement, mainly to young persons and others with the same health issue, such as giving a talk or just chatting with them at a hospital or rehabilitation centre. On the topic of provision of peer support, according to a previous study reporting on a psychoeducational-based intervention for women with physical disability (Hughes, Nosek, Howland, Groff, & Mullen, 2003), concluded that peer-facilitated wellness workshop for women with physical disabilities can improve physical, psychological, and social health status. Therefore, peer-facilitated support appears to be beneficial for women with physical disability.

Regarding **general trust**, as it emerged, seven out of the ten participants with physical disability reported that they trust other people in their community in general, whereas only three participants stated that they do not trust others at all, or not always, or it depends from time to time. Thus it can be assumed that overall participants with physical disability showed moderate to high levels of general trust. About **institutional trust**, overall participants trusted the most the police, whereas the least the parliament, while for the justice and the press they seemed more divided in their responses. The finding on moderate to high level of trust reported by participants here is an indication of trustworthiness within their community, and relevantly, strong ties have been found to be important especially when a person is in a more vulnerable position and there is a need for trust and certainty (Guilcher, Casciaro, Lemieux-Charles, Craven, McColl, & Jaglal, 2012). In addition, the finding here that participants trusted the parliament the least, confirms previous data that for the 28 EU Member States, the average trust in parliament score amongst people reporting severe impairment was lower compared to people with a moderate impairment, and even lower for persons with no impairment; thus persons with severe disability having the lowest level of trust in the parliament among citizens of the EU (Priestley, et al., 2016).

Relevantly to the cognitive dimension of social networks, in terms of the **opinion of participants on specific civic norms**, it was found that the vast majority of them disagreed about claiming government benefit if one is not entitled to it and avoiding paying taxes in total, while about accepting a bribe during the course of one's duties, all participants disagreed with this statement. The only different opinions on civic norms emerged from two participants, with one of them initially agreeing on claiming benefits one is not entitled to, in the sense that if the State is not giving a benefit to the person then it is right for the person to 'rebel' – as she put it –, but then she changed her reply to disagreeing to the statement. The other participant said that she it depends for her on tax evasion, because if someone pays more taxes than they should if they had a loss from the State then it is not right for her. Again here emerged almost matching opinions based on opinion on civic norms among participants living in the same metropolitan area, indicating high reciprocity among community members.

Almost all participants stated that they are **active voters**, apart from one who did not reply to this question. One of the participants had also been doing electoral campaign for herself and said that dealing with the common affairs while she has a disability had a positive effect on her life, and considers politics is therapeutic for her. Another participant stated that she cannot place her vote alone because the facilities at the electoral centre are not appropriate for persons in a wheelchair to be able to vote so her mother marks her vote on her behalf, which should not happen because she has the right to be able to vote alone. Another example mentioned by the same participant on not being able due to inappropriate facilities to perform her civic rights, is at the post office when the counter is at eye-height for someone in a wheelchair and she is not able to sign a document, so her mother signs it for her again. As the participant said, it is the human right of persons with disability to be independent in their life from others, including their parents. Apparently, persons with disability seem to be highly active members of the country's voting body, thus it is shocking that in one of the largest European cities of the 21st century, persons with physical disability are not given the opportunity to perform one of the fundamental human rights and their basic civic right within democracy, that is to vote independently and in privacy like any other walking citizen does. This is clearly a discrimination and deprivation of human rights against persons with disability. As it has been stated elsewhere (Lord, Stein , & Fiala-Butora, 2014), common barriers to physical access for persons with disability to be able to perform their voting right include polling stations which are in rooms too small to accommodate persons using a wheelchair, voting boxes placed on high tables, polling booths are often entirely inaccessible for voters using a wheelchair due to inability to surmount booth thresholds or to turn inside a booth. Such barriers cause exclusion and isolation of persons with disabilities from the political and public life (Lord, Stein , & Fiala-Butora, 2014). Moreover, based on a recent study examining leading longitudinal surveys, cross-country, and national data on political participation of persons with disability in Europe (Priestley, et al., 2016), concluded that estimates of the proportion of accessible polling stations in practice for persons with disability ranged between 2% and 50% (but not higher), suggesting that at least half of the countries might exclude some voters. In 12 countries some official data had been collected by public authorities, but it was often incomplete, while in 13 out of the 28 EU Member States there was no source of information on polling station accessibility, and this is a concerning fact (Priestley, et al., 2016).

Above all, according to the Article 29 of the United Nations Convention on the Rights of Persons with Disability (United Nations, UN Convention on the rights of people with disabilities and optional protocol, 2006), State Parties should guarantee to persons with disability political rights by:

> i. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use; ii. Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate [from Article 29 (United Nations, UN Convention on the rights of people with disabilities and optional protocol, 2006)].

As mentioned in a previous chapter of this thesis, it has been recently recorded formally that Italy is not in line with the recommendations of the United Nations Convention on the Rights of Persons with Disability, as according to the report of the Committee on the Rights of Persons with Disabilities (2016), persons with disabilities in Italy cannot vote wherever they choose and the regulations for their assistance in order to be able to vote are not consistent with the United Nations Convention on the Rights of Persons with Disability. Thus, this Committee recommended that Italian State should support and provide assistance to persons with disabilities in order for them to be able to vote wherever they choose.

On participation in **demonstrations and signing petitions** as activities of political participation, it emerged that all participants had signed a petition and half of them had participated at a demonstration. The topics they were more interested in were relevant to the rights of persons with disability, environment/ecology/climate change, animals, and bio-tests/experiments, but participants were also interested in issues related to autonomy, mobility, violence against women, same-sex marriage, human rights, politics – in general –, and one participant mentioned protesting against the pollution of a town from asbestos. The concept of political participation has expanded and includes also signing petitions or activism in political protests and new social movements (Priestley, et al., 2016), which clearly participants with physical disability reported that they have engaged in.

Based on all above, women with physical disability appeared to have high level of political participation, whether directly, as active voters and members of associations/organisations of persons with disability or members of political groups, such as trade union or elected member of a political party within municipality public authorities, or indirectly, since all them have signed at least one petition in their life, and half of them have participated in demonstrations, despite their mobility limitations, not only protesting for the rights of persons of disability, but also other marginalised groups or topics at a more global level.

Based on the sociodemographic information, 8 out of the 10 participants with physical disability were employed and the other two were university students – not actively looking for a job in their field yet. The ones who were not in paid employment in their field but were self-employed or in volunteer work, were asked about having ever **experienced difficulty finding a job in their field due to their health issue**. Both of them reported that they had experienced difficulty finding a job mainly due to inaccessibility of the workplace for wheelchair users. The facilities of the buildings/offices of the potential employers/internship bodies were not appropriate for wheelchair users, thus, barriers of the physical environment of the workplace did not allow them to be involved in an employment on their field. After that, one of them was still looking for a job at the time of the interview, whereas the other one decided to work from home with her partner. Results from a recent study reporting on a sample of 2,282 persons living in the USA (Anand & Sevak, 2017), have shown that for the employment of persons with various types of disability plays an important role the provision of accommodations in the workplace, while those who did not receive workplace accommodations in their current or more recent employment were found to be more likely to have a physical disability. Based on the same source, at least one third of non-working persons with disabilities reported barriers to their employment, such as an inaccessible workplace or lack of transportation, which could be addressed with accommodations provided by employers (Anand & Sevak, 2017).

All participants with physical disability mentioned **barriers for social participation** which were related to physical environment and accessibility issues, while almost all of them – apart from two – mentioned also respective barriers related to social environment.

As it emerged, all participants reported barriers they have encountered within public spaces of the physical environment of the city of Milan, making it difficult for persons in a wheelchair to move around the city, mainly concerning inaccessible public transport services, inaccessible public (such as public services, museums) or private (such as company offices, cinemas, bars) buildings, inaccessible public restrooms, pavements without dropped kerbs/inclinations, and lack of appropriate elevators or stairlifts for wheelchair users within buildings and the subway. Relevantly, a study published recently on accessibility issues in the cities of Milan and Como, based on experiences of manual and electric wheelchair users (Comai, Kayange, Mangiarotti, Matteucci, Yavuz, & Valentini, 2015), reported that for both groups the main accessibility problem was public transportation, with information about accessibility to subway stations being crucial for them; a finding confirmed in this study as well. In addition, a recent literature review on factors influencing participation in social and community activities for wheelchair users (Smith, Sakakibara, & Miller, 2016), similarly found that accessibility was the factor influencing participation which was reported in most of the studies of the review, followed by wheelchair factors (including comfort, durability and fit), wheelchair skills, pain (including shoulder pain), finances, societal attitudes (including stigma), level of education, age, and sex. The evidence from both previous studies confirms the high importance of the accessibility and public transportation for persons with physical disability, as it emerged in this study as well.

Moreover, one of the participants mentioned that she believes that it is not dignified for persons with disability to be carried in the arms of someone just to be able to get in an inaccessible place. As stated elsewhere, the term ‘accessibility’ refers to the degree to which an environment *“can be approached, entered, operated in, or used safely and with dignity by people with disabilities”* (Welage & Liu, 2011). Thus, accessibility is by definition not only an issue of physically entering or not a space, but doing it also with dignity, as rightfully mentioned by one of the participants here.

In terms of barriers related to the social environment, participants mainly referred to prejudice and mentality barriers that people of the wider society have against persons with disability, such as people in Italy looking at them "badly" when they ask for help, or others considering them as handicapped or poor ones, which was suggested as a cultural problem. There is also the mentality that when people give you what you deserve, they say that persons with disability are poor ones and need help, but it is the right of any person to have equal treatment, and people are ignorant about the lives of persons with disability, for example, that they could have a baby too. Before removing architectural barriers it was suggested that mental barriers should be removed first, such as in cases of being bullied because of disability. Similarly to the evidence reported here, a recent scoping review on studies focusing on societal participation of persons with disability, found that among the barriers frequently emphasised within the reviewed studies were attitudinal barriers, in terms of stigmatisation and discrimination against persons with disability, either directly by receiving unfriendly behaviour from others, or indirectly, such as *"through ignorance, fears and prejudices, as strict ideals of beauty and normality or as hardening values in the society"* (Hästbacka, Nygård, & Nyqvist, 2016, p. 209). Moreover, as it has been mentioned in a previous chapter of this thesis, prejudice is so harmful that it has been argued that persons with impairment become disabled not only by material discrimination, but prejudice as well (Shakespeare, 1994).

The mass media were also mentioned as triggering fear of diversity for any kind of marginalised group. Based on a previous study, persons with disability believed that mass media in general portray them as 'supercrips'[38], disadvantaged, or ill victims, with the second and the third considered as stigmatising and negative media representations, thus disability activists try to change this portrayal *"because media have the power to shape what public knows about disability"* (Zhang & Haller, 2013, p. 329).

An example from the barriers in the workplace was inaccessibility to the room of kitchen appliances of the office, so the participant decided to eat on her desk, and not argue about it, but tried finding an alternative solution. Another participant faced discrimination in the workplace when a position came available internally and they told her that they did not

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[38] *"In the supercrip model, people with disabilities are represented as ''superhuman'' because they achieve unexpected accomplishments or live a normal life just like people with no disabilities"* (Zhang & Haller, 2013, p. 321).

interview her for this position because she was in a wheelchair. Apart from barriers in terms of inaccessibility of facilities within workplace reported also in another study (Hästbacka, Nygård, & Nyqvist, 2016), it has been found elsewhere that young people with communication, mobility or cognitive impairments have experienced work discrimination, such as being refused an interview or promotion (Lindsay, 2011), as it happened to one of the participants of this study.

On positive experiences, schoolmates were helping one of the respondents to participate in outdoor activities together with them, despite the opposite opinion of the professors, while another participant said that at school she did not face any major issues, only in elementary school, but overcame them by going to schoolmates and showing them how they can play with her. This finding is similar to a previous argument that the process of leisure and sport socialisation can be different for persons with disability because their parents, teachers and/or peers are not aware of the opportunities which are available to persons with disability for participating in such activities (Ruddell & Shinew, 2006). Nevertheless, it has been also found in a classical qualitative study (Davis F. , 1961) that persons with visible disability have a recurring problem with their friends, in the sense that their friends often overlook the fact that these persons have a disability which imposes restrictions on them, thus persons with a visible disability find themselves participating in activities with their friends, which might not be convenient or comfortable for them, due to their restrictions.

The **suggestions for removing barriers related to social participation** by participants with physical disability, were mainly related to implementation of existing laws on accessibility, and denouncement of accessibility problems to institutions, as well as change of mentality of the public, more public visibility of and communication about persons with disability, education of the public, and life projects for persons with disability.

In specific, for overcoming barriers of the physical environment, it was suggested by participants that existing laws on accessibility should be implemented in Milan and oblige all public spaces to pay attention to accessibility, without it being optional, and assessing the needs in terms of accessibility for every neighbourhood in the city and make a plan at least for accessibility in the subway. About the issue of implementation of existing laws on accessibility, a literature review (Welage & Liu, 2011) has reported that architectural barriers persist in public buildings for wheelchair users, despite wheelchair accessibility being legally compulsory in many countries, and found also that the knowledge on providing wheelchair accessibility to public buildings is inadequate. Relevant to the latter suggestion made by one of the participants here on making a needs assessment for accessibility, there has been an ongoing project in Milan and Como (Comai, Kayange, Mangiarotti, Matteucci, Yavuz, & Valentini, 2015), aiming to map information about the accessibility of urban pedestrian pathways for people with mobility problems and provide this information through a mobile application[39]. The same participant also mentioned that there should be a plan at least for the subway of Milan which was considered European city for disability 2017 so that it becomes accessible for persons with disability. Milan indeed received the 'Disabilities: Access City Award'[40] for accessible-friendly cities in 2016, although, based on the testimonies of participants in this study, it is obvious that the city has accessibility issues, particularly regarding public transportation, thus more should be done for improving this situation. It was also suggested here by the side of the persons with disability to continuously denounce to the institutions any accessibility issues that persons with disability encounter, but even so, the institutions do not reply or reply too late. Apart from issues suggested to be amended by institutions, persons with disability themselves have also responsibility for removing barriers, such as by promoting accessibility when suggesting to owners of inaccessible places how they could make them accessible, for example, by putting a slope at the entrance. If all persons with physical disability did that, then the owners of these places would consider keeping an accessible entrance. These suggestions for removing the barriers for social participation by action and involvement of persons with disability themselves, are similar to previous findings that many studies have referred to the importance of inclusion of persons with disabilities in the decision-making process for relevant policies and legislation, a bottom-up perspective which is crucial for persons with disability as they wish to have their needs expressed and heard (Hästbacka, Nygård, & Nyqvist, 2016).

Suggestions by participants were also relevant to change of mentality, since in the wider society there is not a predisposition in favour of diversity or difficulty one might have. As participants mentioned, persons with disability are just people who have a smaller or larger problem in terms of physical limitation or just use diverse instruments for

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[39] For more information on the mobile application and how to download it visit the website of the project MEP (Maps for Easy Paths): http://mep5x1000.wixsite.com/mepapp [Accessed 14 September 2018].

[40] European Commission → Employment, Social Affairs & Inclusion → News (Date: 08/12/2015) Disabilities: Access City Award 2016 for accessible-friendly cities goes to Milan. Available at: http://ec.europa.eu/social/main.jsp?langId=en&catId=1141&newsId=2410&furtherNews=yes&furtherNews=yes [Accessed 13 September 2018].

communication, are equal to everyone else, and thus have the right to be treated as humans equally to the rest of the population. For persons with disability to be included, it was suggested that they should become more visible to the public by participating in wider contexts, such as being hosts or participants in a famous song contest, instead of writing books or making films in which disability is emphasised, and go out of their house more so that others would be more familiar with persons with disability, as it occurs in other European countries. Other ways suggested were to communicate about things related to disability in a lighter way, people to have more empathy, the wider public to be educated more on how to confront the physical disability issue as a common issue and not as an insurmountable thing of which to be afraid or ashamed of, and need to invest more on a life project for the inclusion of persons with disability. Lastly, persons with disability should not only be asking for their rights and needs to be fulfilled, but also respect their obligations, such as staying at work for certain hours; in this way others will not see persons with disability only as people in need, especially in the workplace. An abovementioned scoping review on societal participation of persons with disability in Europe (Hästbacka, Nygård, & Nyqvist, 2016), found that more than half of the included studies referred to the importance of supportive values and viewpoints and changing attitudes on disability, and the importance of seeing disability as a human rights and equality issue, along with the acknowledgement of potential and capabilities of persons with disabilities. Moreover, based on the same source, many of the reviewed studies reported as important facilitators for societal participation of and change of attitudes towards persons with disability to increase visibility, information and knowledge about persons with disability (Hästbacka, Nygård, & Nyqvist, 2016); closely similar to the above suggestions made by the participants of this study as well.

As it emerged, the majority of participants reported as **barriers for autonomous living** the fact that they had to depend on their family and/or partner for support and/or needed more financial support to be able to cope with the expenses of care assistance due to their disability without the help of their family or partner. Thus, as they stated, they would benefit from more financial support from the State for them, since their parents or partner might not be able to help them for a long time to cope with everyday tasks. It is known that the majority of care to persons with disability is provided by caregivers who help them with activities of daily living such as eating, bathing, taking medication, while it has been found that 60% of caregivers are women and 65% of the recipients of care are women too (Buhse, 2008); the evidence of this thesis correspond to this proportion of mothers being reported also here as the main caregivers of participants. However, family members providing assistance to a partner or child with physical disability can cause physical and economic burden on the family member, known as caregiver burden, which might have implications such as added financial expenses or stress and strain for caregivers (Buhse, 2008). Moreover, families with one member with disability have median incomes which are 15% lower than families without a member with disability, with poverty rate and out-of-pocket expenses for care being higher in families with a member with disability (Buhse, 2008).

Physical environment and accessibility barriers also emerged as barriers for autonomous living, such as inaccessible election centres or high front desks at the post office, difficulty finding an accessible and affordable house to stay within the city, delays on public transport due to inappropriate facilities for persons with disability, such as a broken elevator or a blocked stairlift or even a small step at the entrance of a bar. It has been also reported elsewhere that one of the barriers of the built environment is facility front desk being too high for a person in a wheelchair to be able to communicate with the person behind the desk (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). As one of the participants said, such barriers hinder social life for persons with disability and their integration, and if they move around the city less and work less then they become disadvantaged. There was one participant who said that everyone is facing barriers for independent living, it is just that her limitations are more visible to others, and despite these limitations she is working, travelling and has an autonomous life.

The lack of a common national law in Italy on the distribution of funds for persons with disability was also mentioned by participants as a barrier for autonomous living, and the fact that independent living for persons with disability is not adequately considered as in other countries, plus, there are bureaucratic barriers in Italy for getting things done. Cultural barriers mentioned included that others are not aware that persons with disability can also live independently have a partner and a life like everyone else.

In terms of **suggestions for removing barriers for living autonomously**, it was suggested by participants that there should be change of mentality of the wider society towards persons with disability so that people would understand that persons with disability are only seated and have a difficulty, they are not a problem, and start thinking of them in a different way. As mentioned also previously in terms of social participation, it has been found that previous relevant studies reported as important facilitators for societal participation of and change of attitudes towards persons with disability to increase visibility and knowledge about persons with disability and their lives (Hästbacka, Nygård, & Nyqvist, 2016). Removing barriers related to accessibility would help persons with disability to move around the city calmly and more autonomously, as mentioned by participants, such as by improving problematic accessibility to public transport, removing architectural barriers in new constructions, and designing buildings and spaces being both accessible and pleasant to the eye for persons without disability too, with cultural education of the project designers. As it has been stated elsewhere, despite laws being implemented on accessibility, there are still many difficulties for wheelchair users around the world to access public built environment facilities, and transforming them is still in developmental stages, which hinders their full participation in the community (Welage & Liu, 2011). For this reason it has been suggested as important that professionals in this practice would advocate for persons with disability to have access to public buildings and participate fully in community life (Welage & Liu, 2011).

It was a also suggested that persons with disability should be also provided with financial support to be able to live autonomously, and seriously invest on employment of persons with disability because work is dignity, as well as young persons with disability to have advanced level of education that would help them live independently. Similarly it has been mentioned also in another study, that programmes and policies for young persons with disability should address the concerns and barriers that they encounter in trying to find paid employment, as well as that persons with disability with lower education levels typically encounter more barriers for employment (Lindsay, 2011).

At the same time, persons with disability should denounce issues to institutions and there should be institutional support for accessibility as well as a team at municipality level including persons with disability for trying to find ways to improve the city. Likewise, it has been suggested in another study that architects would advocate providing the context for persons with disabilities to become key informants in the design process of architects, for example within university or high school to involve personnel and student in the design process or to interview persons with disabilities about their experiences and preferences in terms of space, and based on these design parameters architects can work with during the design process (Heylighen, 2008).

Suggestions were also made by participants directed to their peers for self-empowerment and finding the resources to reach autonomy and not be focusing only on disability. Self-empowerment was suggested in the sense that they should believe in themselves and not give up with the first difficulty, while having a realistic target for their autonomy, and then assess bureaucratic steps and build up a network of people around them who can help them achieve this target, such as occupational therapists and associations. There was also the suggestion that persons with disability themselves should shift the focus away from disability and orientate it towards life itself, because if they see themselves as persons with disability then they will see only their limitations, but should see themselves as a woman, professional, friend, without disability being their distinctive characteristic.

4.3.3 Sensory disability

Similarly to the analysis of the other two types of disability (i.e. mental and physical) presented above, in order to allow comparisons across types of disability, the Main Areas and Core themes included in the final template for persons with mental disability were used as the basis for the analysis of the data on sensory disability as well. However, themes and sub-themes were modified according to the aim of the study and the data reported by participants with sensory disability, independently – meaning without any influence on the selection of themes between types of disability. The final template of the themes identified for participants with sensory disability are presented in Table 4 below.

Table 4. Final template of themes for participants with sensory disability.

MAIN AREA 1: THE BODY, SELF AND DISABILITY
CORE THEME 1. BIOGRAPHICAL EXPERIENCE OF HEALTH ISSUE
1.1 Age of onset
1.2 Cause of onset
CORE THEME 2. COPING MECHANISMS FOR DISABILITY AND FEELINGS OF LONELINESS
2.1 Communication difficulties with social relationships
2.2 No deafness-related difficulties encountered in everyday life
2.3 When feeling lonely doing various indoor or outdoor activities
2.4 Having no discomfort being alone or seeking loneliness
CORE THEME 3. PERCEIVED GENDER DIFFERENCES BASED ON HEALTH ISSUE
3.1 No gender differences based on deafness
3.2 Gender differences among deaf persons on various personality aspects
CORE THEME 4. EXPECTATIONS ABOUT THE FUTURE AT INDIVIDUAL LEVEL
4.1 Expectations related to deafness at general and/or personal level
4.2 Expectations related mainly to family life and work
4.3 Not having any expectations about the future.

MAIN AREA 2: SOCIAL RELATIONSHIPS, SOCIAL PARTICIPATION AND DISABILITY
CORE THEME 5. SOCIAL NETWORKS (STRUCTURAL ASPECTS)
5.1 About size of social network and type of relationship
5.1.1 Size of social network
5.1.2 Feeling closer to family primarily, and then friends
5.1.3 Family and friends and/or colleagues without any difference in the degree of closeness
5.1.4 Not included family in close social network
5.2 Frequency and way of contact with ties of social network
5.2.1 Speak and/or meet with friends every or almost every day
5.2.2 Not meeting with friends very often or meeting them sometimes
5.3 Membership at organisation or volunteer groups (formal social networks)
5.3.1 Not members of any group
5.3.2 Membership at sport and theatre groups
CORE THEME 6. DAILY ACTIVITIES
6.1 Meeting friends regularly
6.2 Did not mention meeting friends regularly
CORE THEME 7. DISABILITY-BASED HOMOPHILIOUS OR HETEROPHILIOUS SOCIAL NETWORKS
7.1 Homophilious social network
7.2 Heterophilious social network; mainly consisting of deaf persons

7.3 Heterophilious social network; not including any deaf person or only a few

CORE THEME 8. CHANGE OF ATTITUDES OF SOCIAL NETWORK DUE TO DISABILITY

8.1 Experienced prejudice and change of attitude of others due to deafness

CORE THEME 9. SOCIAL SUPPORT (RECEIVED AND PROVIDED)

9.1 Received social support

9.1.1 Support received from the family and/or the State and/or others

9.1.2 No support from others or the State

9.2 Provided social support

9.2.1 Have provided support to others

9.2.2 Have not provided any support to others

CORE THEME 10. TRUST

10.1 General trust

10.1.1 Have trust in others

10.1.2 It depends or gradually have trust in others or uncertain

10.1.3 Difficulty trusting or no trust in others

10.2 Institutional trust

10.2.1 More trust in the police and justice, less trust in the parliament

CORE THEME 11. OPINION ON SPECIFIC CIVIC NORMS

11.1 Majority disagree with tax evasion, claiming government benefit that one is not entitled to or accepting a bribe during work

11.2 It depends on the situation about tax evasion or do not know whether they agree or not

CORE THEME 12. POLITICAL PARTICIPATION

12.1 Voting at elections

12.2 Participation at demonstration or signed a petition

12.2.1 Have participated at demonstrations and signed a petition

12.2.2 Have not participated at a demonstration, but have signed a petition

12.2.3 Have never participated at demonstrations or signed a petition

CORE THEME 13. EMPLOYMENT DIFFICULTY DUE TO HEALTH ISSUE

13.1 Experienced difficulty finding a job due to less employment opportunities for deaf persons or other reasons

13.2 Not experienced any difficulty finding a job

CORE THEME 14. BARRIERS FOR SOCIAL PARTICIPATION AND SUGGESTIONS FOR REMOVING THEM

14.1 Lack of a sign language interpreter and/or accessibility at public places and/or avoiding socialisation due to deafness

14.2 Limited choices for employment

14.3 No barriers experienced for social participation

14.4 Suggestions for calling a sign language interpreter or requesting for direct subtitling or cooperation from others for communication

14.5 Suggestion for sensitisation of and information to the wider society on diversity and deafness

14.6 Avoiding situations where they do not feel included or do not know what to do

CORE THEME 15. BARRIERS FOR INDEPENDENT/AUTONOMOUS LIVING AND SUGGESTIONS FOR REMOVING THEM

15.1 Facing communication barriers; thus depend on others for communication

15.2 Limitations for deaf persons finding a job and variety of barriers among deaf persons

15.3 Experiencing no barriers for living autonomously

15.4 Suggestions for asking a sign language interpreter or family member to help them overcome communication difficulties

15.5 Suggestions for more activities, priority, accessibility, attention and inclusion for deaf persons

15.6 Suggestions for more effort for personal growth and development.

If the activities are organised by hearing people and for hearing people yes, there are some barriers, but if there are some deaf people who participate, it becomes easier for me, I can participate, have a chat and share this thing. Among hearing persons being the only deaf person, yes, it makes me uncomfortable, I would not participate. (…) Years ago when I was little I used to have a hearing friend who invited me to parties, to occasions, and I attended them because I wanted to participate in them. But then I would stay

> aside watching the others chatting, playing, so I didn't feel satisfied, for me this was really a problem, I was not experiencing it well. As the time passed I asked this friend to avoid creating these occasions and to involve me, I said thanks to her but I explained to her that I was deaf and so I could not manage to participate, it was becoming a bit of a torture for me to see that everyone else is having fun and smiling and I was not involved in these situations. If she and I were going out alone and doing something together, then it was going well our relationship, but within the group in which I was the only deaf person, I was not well. Sharon (S)

Main Area 1: The body, self and disability

Core Theme 1. Biographical experience of health issue

1.1 Age of onset

Participants with deafness were asked to state when their hearing loss occurred. Seven of them expressed that they had congenital hearing loss, whereas three, Megan, Sharon and Kylie, that it occurred before the age of 3 due to a treatment for an illness. One of the participants, Monica, mentioned that when her parents realised that she had hearing loss, they took her to speech therapy and music therapy until elementary school, then she lived with her family in Belgium for some years, where in terms of her social relationships, she mentioned did not hang out with friends who were deaf and was trying to hide her hearing difficulty, for example when there was a guy she liked she was hiding her ears because she was embarrassed about it. When later on she went back to Italy, she mentioned that she started meeting people who were also deaf and started to accept deafness and live more peacefully with it and how to handle it. Another participant, Betty, expressed that her teacher at nursery school realised she was deaf because when some toys fell down and made a loud noise, she was the only one among the children that was not scared by the noise and did not cry, so then she started doing speech therapy too and had a hearing aid:

> Practically it all started when I was about two years old, when a girl threw down a lot of toys that made an incredible noise, and a lot of children started crying because they got scared so... and once my teacher noticed that I was the only child who was playing on my own. They made my parents aware of this and from that moment on they started searching, they brought me to the specialised centre on the problem of deafness, all tests, and the prostheses [hearing aids], I have prostheses, so it is from when I was two years old, I was practically deaf since birth. I do not have any memory from when I could hear, I don't know, I don't remember. Betty (S)

> I was not born with a hearing problem, I became [deaf] as a cause of third-party factors. So when I was 10 months old I had a bronchial pneumonia, at that time there was no treatment in place like nowadays, but I was treated at the hospital. (...) When I was about two years old my parents came here to Milan to a luminary who was specialized on the diagnosis of deafness (…). So they made the diagnosis and confirmed the diagnosis of my father that I was not born deaf, but I became [deaf]. Kylie (S)

> I was born deaf, but my parents realised it late, they diagnosed me with deafness when I was two and a half years old. At the age of three I got prosthesis… and then I started the training. Shirley (S)

No sociodemographic similarities emerged for participants under this theme.

1.2 Cause of onset

Participants who did not have a congenital hearing loss, Megan, Sharon, and Kylie, reported that their hearing loss occurred after an illness or infection during infancy, two of them mentioning an infection related to their tonsils or lungs, and the treatment they received was not appropriate thus caused them hearing loss:

> The cause was an illness, I had a problem with my throat, maybe with tonsils… In my family we all know that I was sick and that I had this problem that caused my deafness. I asked my mum to explain it to me, she told me that I did to me some vaccinations, some injections, but they did not explain to me exactly how it happened. In Bulgaria it is like this, the doctor did not actually give full explanations and ok, we decided not to report it, we do not know the real cause of my deafness. Megan (S)

> I got an illness when I was little, I was born hearing, then I had an illness, I was brought to the hospital, I received treatment with injections and I became deaf. Sharon (S)

All three participants who did not have a congenital hearing loss were older than 40 (i.e. 40-44), and were among the four oldest participants with sensory disability, possibly indicating that four decades ago the potential side effects of some medication for children were not as known as nowadays.

Core Theme 2. Coping mechanisms for disability and feelings of loneliness

2.1 Communication difficulties with social relationships

The majority of respondents reported trying to cope often with communication difficulties with persons of the wider society mainly. Five of the non-speaking participants came from other countries to Italy (i.e. Dorothy and Megan from Bulgaria, Carol and Sharon from Ukraine, and Nancy from USA) so they expressed that apart from difficulty in communication using the sign language and lip-reading, they had an added difficulty of not knowing all of them to use the Italian sign language well, or to read and write in Italian, so this hindered their communication with others even more. One of the participants, Sharon, mentioned that her son, who is not deaf, helps her when she does not understand something. Nancy expressed that she has difficulty making friends and finding a job, and only communicates with her family, while Claire mentioned that during school she did not face any problems because she had lessons in sign language and the school was accessible, but when she went out in the society she faced many problems in terms of accessibility.

Apart from the difficulties reported by non-verbal participants, two of the verbal participants also reported difficulties in terms of coping with their health issue every day. Monica reported that she has to be in a silent environment in order to be able to hear others, otherwise she tries to read their lips. But there are people who do not do not move or hide their lips or have a beard, so it often occurs to her that she meets people who she is not able to understand so she becomes distant from them or cannot benefit from this friendship. Kylie mentioned that she found how to cope with deafness and there difficulties that she is facing every day, for example, when she is meeting someone for the first time she mentioned that she has to understand the movement of the lips of this person to read them, or when she needs to book an appointment, for example with the doctor, she has to always ask someone else to do it for her because there is no logistic support to simplify the life of deaf persons, such as to be able to write an e-mail to book medical visits, or when the subway stops and she sees people get off the train but cannot hear what the speaker says, or when there is an emergency deaf persons cannot call for help so there has to be support to make deaf persons' life easier in such cases:

> The communication is a big problem, sometimes I write, I use the written language, or I rely on facial expressions. I try using phone applications that translate language, but actually there are problems, it is difficult for me to understand lip-reading, I do not always understand it, sometimes I do not get them, when I don't understand it I ask [others] to repeat. Carol (S)

> When I was little and I was deaf I had several difficulties, because I have a hearing family, so I had difficulties with communication, I couldn't express myself. Then some people advised me of going to a school where it was used the sign language. And when I saw the sign language used for the first time I started crying, because my family was talking and that was creating a lot of difficulties for me. But with sign language I was able to understand. My mum started using a little bit of fingerspelling, but she already had an advanced age, she could not sign well, and she wanted me to have been able to speak. I was brought to a doctor, a speech therapist to rehabilitate my speech, and so I had to learn reading lips, it was very difficult, very tiring because I could not hear anything at all. Sharon (S)

> I also need to see, so in a silent environment if one speaks behind me, I could ever understand him, but it should be silent. When we already are in a noisy environment, I need to read lips, there are some people who do not move their lips, or they have a beard and hide their lips, so it happens often that I meet a new person but not understand him well, not being able to read his lips, I tend to keep distance or not to deepen let's say the friendship, because I am really feeling very uncomfortable. Monica (S)

Apart from the fact that five non-speaking participants had a country of origin other than Italy, no other common sociodemographic characteristic was discerned under this theme.

2.2 No deafness-related difficulties encountered in everyday life

Two of the verbal participants, Betty and Shirley, reported that they were not facing any issues to cope with in terms of hearing loss, and communicated with others without major issues:

> I live my life as everyone else. I don't have any problems. Betty (S)

> No, I manage to get by on my own, I have always managed by myself. I interact with everyone, verbal communication, of course with lip reading, I do not know the sign language, so the verbal and lip-reading communication. Shirley (S)

Both participants who expressed that they were not facing any difficulties related to their hearing loss in everyday life were speaking participants, with no sociodemographic characteristics in common.

2.3 When feeling lonely doing various indoor or outdoor activities

Seven of the participants expressed that there are moments that they are feeling lonely and for coping with loneliness most of them read a book or go out alone or with their friends and try to react positively and do activities that cheer them up. One of them, Nancy, mentioned she is feeling sad when she is lonely and goes out alone for a walk since she does not have any friends, whereas Dorothy also mentioned she does not like being alone, but she is never lonely because in such moments she easily contacts her friends through mobile phone or internet and meets with them. Another participant, Shirley, mentioned only that she is thinking a lot when she is feeling lonely. Other activities they were doing to cope with loneliness were hanging out with their children, whether to chat or read a book with them, or go to an exhibition or watch a film:

> I have to think.... now there is the computer or the mobile phone, or I read a book. If my son is at home, I talk with him, I ask him how the school went, how it goes with school, and so I chat a little bit with him. Sharon (S)

> I am looking to go out with friends, to make me cheer up a little bit, to make me feel less lonely, especially with my dear friends, they make me feel let's say kind of special. Betty (S)

> I feel a little bit sad, a little bit disheartened, and maybe I go out for a walk, but I don't know anyone, so… Nancy (S)

> No, actually I am never alone, because through SMS [mobile phone messages], through the internet I can arrange instantly with my friends to meet me, I cannot stay alone, I am not interested in it, I don't like it. Dorothy (S)

No sociodemographic similarities emerged for participants under this theme.

2.4 Having no discomfort being alone or seeking loneliness

Three of the participants, Megan, Carol and Monica, expressed that they do not feel any discomfort being alone, on the contrary, they reported feeling well when they are alone, while one of them, Carol, mentioned that for her, loneliness is tranquility. Megan mentioned that she needs loneliness to reflect on herself and she likes loneliness, but not every day. Then Monica expressed that she likes loneliness and she never feels lonely because she is in terms with herself and calm, but is afraid of growing old alone without any children. However, now, although she has friends inviting her out, she prefers staying home alone to watch a good film on television. The reason for that was that after a working day deaf persons get tired more easily compared to the general population, because during social interactions a deaf person has to put a lot of mental and physical effort into understanding what others are saying, so at the end of the day she is feeling more tired. Therefore, she cannot also go out in the evening with friends at a restaurant, for example, where there is a lot of noise and trying again to make the effort to understand what the others are saying. When she decides to stay alone she goes for a walk for window shopping, or to a museum to see an exhibition if others do not want to go as well, but she is not forced to stay alone because she does not have any friends, and this fact makes her calm and happy:

> I need solitude, I need to reflect on myself, I need to deal with my thoughts, I need my moments of solitude, I like it, I like staying alone, yes. (...) Obvisouly sometimes, not every day. Megan (S)

> I don’t know, I would not know how to respond to this question. Solitude is tranquility, no? I feel calm, it is not a problem. Carol (S)

> So I like a lot solitude, in the sense that I never feel lonely because I feel good about myself, I am very calm, so... I can say that I am afraid of being alone, I mean tomorrow when I get old, not having children, being alone, yes, I am afraid of that. But right now, it happens to me often, so often… sometimes in the evening they invite me out for dinner, but I prefer staying on my won at home, in front of the TV, on the sofa to watch a good movie. It happens to me often, because maybe after a day at work, so us the non-hearing ones anyway get tired more easily than hearing people because we live in a society in which you relate with people, you have to always be very attentive and try to understand what is being said, which requires a lot of mental and physical strength that at the end of the day you go back home very tired. So sometimes the idea of going out also in the evening, to go for example to the restaurant where there is a lot of noise and force yourself again to try to understand everything, yes, sometimes I just cannot do it. Monica (S)

The two of the three participants who expressed that have no discomfort being alone and seeking loneliness were both mothers, thus possibly indicating that they devote a lot of their free time to their family so there is free time for themselves, whereas the third participant who enjoyed loneliness was working full time and preferred relaxing at home after work.

Core Theme 3. Perceived gender differences based on health issue

3.1 No gender differences based on deafness

Almost all participants expressed that they had never noticed any differences among men and women with deafness and all mean and women are equal, while two of the participants, Kylie and Shirley, mentioned that it is subjective and one cannot generalise any differences and depends on the character and individual case. Dorothy also mentioned that there are gender differences related to social roles in the sense that men are able to have more social life compared to women who focus more on family, but these differences are not related to deafness either:

I think it is subjective, because everyone has experienced it [deafness] differently. For example, I can talk about my experience and my husband's, which was very different. Because the condition that brought us to deafness it was very different, my husband's was more traumatic. (…) yes, there is some diversity. But the way I have experienced it, I have never felt this thing that much, I haven't experienced it personally, I wouldn't know what to tell you, I have not felt it. Kylie (S)

Yes, yes, deaf women and men are very different. And because of this also I participate in the manifestations on the rights on freedom of sexual choice. (…). No, no, really not, I think that it does not have to do if a person is a woman or a man, from the moment in which they are deaf and are using the sign language we are all equal... yes, maybe the difference lies in the fact that women have to take a little bit more care of their family, while men go out more let's say to entertain themselves, to meet, they have more social life. Dorothy (S)

No sociodemographic similarities emerged for participants under this theme.

3.2 Gender differences among deaf persons on various personality aspects

Only one of the respondents, Megan, expressed that she has noticed differences among men and women with deafness, in terms of different opinions, behaviour, way of thinking, and noticed that there is little empathy between a deaf man and a deaf woman:

Yes, yes, there is a lot of difference, from my point of view, yes, they are very different, but also in Bulgaria not only in Italy, between deaf woman and deaf man, yes, there is a lot of difference (…) They have different opinions, different behaviours, different ways of thinking, I don't know how... it depends, maybe one says one thing, and other one says the opposite, there is little empathy, I think there is little empathy between a man and a woman, yes, I believe they are very different. Megan (S)

As it emerged, Megan is the deviant case under this theme since she was the only one who expressed that she had noticed differences among deaf women and deaf men, contrary to the rest of the participants with hearing loss.

Core Theme 4. Expectations about the future at individual level

4.1 Expectations related to deafness at general and/or personal level

When participants were asked to describe their expectations about the future in the next ten years, some of them referred to deafness, whether at general or personal level. In particular, Claire hopes that in ten years there will be full accessibility for sign language, and it will become recognised and taught at every university. Shirley hopes that there will be fewer barriers for inclusion for deaf persons, and Kylie hopes that there will be progress on hearing aids which will be more advanced to assist hearing more, and that there will be improvement on the quality of life of deaf persons. Kylie mentioned deafness at a personal level too, in the sense that she hopes she will not encounter any other problems with her deafness in the future, but also mentioned that she hopes to have progress in her personal life and evolve more as a teacher. Lastly, Monica is more focused on the future but has concerns also occasionally for personal issues, such as whether she will find the right man or if she will be still working at her current job, but is also concerned if she loses her ability to hear with the hearing aid she has:

For the future in 10 years' time, I sincerely hope that there is complete accessibility in sign language, and that it becomes recognised at universities, that information in sign language, in my language, becomes recognized my language, that in every university there are lessons in sign language, this is my dream, and that there is complete accessibility. Claire (S)

I hope that there are always fewer barriers. I make also the example of mobile phones, 25 years ago they did not exist and it was a big step forward, it really got better in the past few years with the arrival of social media, it allowed… it became easier to integrate, to get to know other people. I hope that also in next 10 years there is something more than that. Shirley (S)

Regarding deafness I have to say that don't… the only worry I have is losing my hearing, I mean to lose even the last possibility I have to hear with the prostheses (…) So the possibility that maybe... knock on wood… maybe I will lose completely the use of the prostheses, that is my only fear... for the rest I do not have big worries regarding my hearing.. And then for the rest there are the usual worries that everyone has, hoping that the world goes well, that the future is good, that’s it. Monica (S)

All four participants who expressed future expectations related to deafness were all of them in paid employment, and three of them were speaking participants.

4.2 Expectations related mainly to family life and work

Participants had expectations related mainly to family life, such as having a child and/or getting married, having their own family, or if they already have a family, such as Sharon, for her child to finish school and find a job. In terms of employment, four of the participants mentioned finding a job they enjoy doing and Carol mentioned having a house too while Betty being able to pay the rent, and Dorothy mentioned that she would like to continue staying in Italy. Betty also mentioned that although she would like to have a child, it is difficult to see herself with a child due to her hearing difficulty, because children make very high-pitched noises that disturb her:

I would like to have a house, a job, I would like to be relaxed with my husband, to stay here because I am fine here, I think positively about the future. Carol (S)

For sure a house, a roof, a job, a good job, my son finishes school in two years’ time, so a job for him as well maybe, I wish he would find a job too. (…) Now he is in high school, the third year, he still has the fourth and the fifth to finish, so in two years he will have finished and so I hope that also he will have a job. Sharon (S)

I hope with a nice family, a nice job that allows me to be able to pay rent, I hope, at least I see myself this way, with children I doubt because it annoys me, because they make high-pitched noises that annoy me a lot, so I have doubts about it, even though I would like to have them. Betty (S)

No sociodemographic similarities emerged for participants under this theme.

4.3 Not having any expectations about the future

Only one of the participants did not mention any expectations about the future. In specific, Megan expressed that she did not want to have great expectations about the future because they might not become reality, so she prefers to think only about the present:

> I don’t know. To imagine this thing in advance, I don’t know, the future will be different of course, maybe… I prefer concentrating on the present, I don’t want to have big expectations that later maybe go... do not become reality, so I usually do not project myself in the future, I think about today. Megan (S)

The deviant case here was, again, Megan who differentiated from the rest of the participants stating that she prefers not to think about the future.

Main tendencies of Main Area 1: The body, self and disability

As it emerged above, in terms of **onset of sensory disability**, seven of the participants had congenital deafness, whereas an acquired hearing loss before the age of 3. In terms of socialisation, it was mentioned by one of the participants that when she was younger she did not socialise with any deaf peers and tried to hide her hearing aid by putting for example her hair on top of her ears, however, later on she started meeting deaf people too and to accept deafness more. As it has been reported elsewhere, that the body of literature strongly supports the view that it is likely that psychosocial factors influence the decision of young people to wear or not to wear hearing aids (Kent & Smith, 2006). Thus it is not uncommon for persons using hearing aids to sometimes reduce the visibility of the hearing aids by not wearing them, or having long hair, or choosing a discreet colour for the hearing aids, such as transparent or skin colour (Kent & Smith, 2006). Consequently the attitude reported by one of the participants here that she was hiding her hearing aid when interacting with her peers confirms findings of this previous study.

About the **onset of the hearing loss**, the three participants who did not have congenital loss reported that it occurred after a treatment for an illness or infection at infancy. The finding that three of the four oldest participants with sensory disability had a hearing loss due to medical treatments during infancy is in accordance with a previous study on activities of WHO referring also to the major causes of deafness and hearing impairment in childhood which include, among others, ototoxic drugs (aminoglycoside antibiotics such as streptomycin, gentamicin) (Smith A. W., 2001, p. 96) as mentioned by participants in this thesis too.

On the topic of **coping mechanisms for their hearing difficulty**, participants mentioned mainly trying to cope with difficulties related to communication with others. Since five of the participants who were using only the sign language had a country of origin other than Italy, faced added difficulty in communicating with others, which as it emerged had an impact on their sociality and some of them had difficulty communicating even with deaf Italians since they did not know the language well yet, and one of them also mentioned that she had no friends in Italy. They mainly expressed that they faced difficulties communicating with social relationships, and used sign language or lips reading, but when people do not speak clearly to them or put their hand in front of their mouth or have a beard then it becomes difficult to communicate with them. Examples of challenging situations in terms of coping with communication difficulties, as reported by participants, include when they have to book a medical visit and they have to ask someone else to do it for them, because there is no e-mail designated for this, or when the subway stops and cannot hear what the announcement on the speaker is about, or when there is an emergency and deaf persons cannot call for help. Particularly about medical visits, it has been found also elsewhere that physicians frequently do not have teletypewriters or telecommunications devices for the deaf persons or deaf persons do not hear when they are called in waiting rooms and lose their turn or when physicians hire sign language interpreters to accommodate deaf persons sometimes sign language interpreters are not trained specifically in medical sign language (Iezzoni, O'Day, Killeen, & Harker, 2004). Apart from the problematic booking system for medical visits over the phone via the Italian national health system, it has to be taken into consideration also a finding from another study that deaf and hard-of-hearing persons face communication problems that could compromise several dimensions of health care quality too, such as risks for medication errors and misdiagnoses, and less complete and accurate information compared to those received by other patients (Iezzoni, O'Day, Killeen, & Harker, 2004). Nonetheless, there were also participants who expressed that they face no difficulties to cope their deafness within their everyday life. Regarding **coping mechanisms for feelings of loneliness**, the vast majority of the participants mentioned that there are moments that they are feeling lonely and at these times most of them read a book or go out alone or with their friends and try to react positively and do also other activities that cheer them up, such as hanging out with their children to chat or read a book with them, or go to an exhibition or watch a film. On the other hand, there were also participants who reported feeling well when they are alone and loneliness is tranquility or need it to reflect on themselves. It was also mentioned that at the end of the day deaf persons get more tired because they struggle during the day to understand what the other people are saying so going out also to a busy place in the evening would make them feel even more tired, that is why they seek to be alone and relax. Similarly, it has been found elsewhere that deaf persons have comfort with solitude, being comfortable being alone, having many things to do when they are alone, and prefer being alone and do not get frustrated when they are alone (Rogers, Muir, & Evenson, 2003). Furthermore, based on a previous survey on a sample of 359 patients with hearing loss in hospitalised care showed that common obstacles to good communication for participants were: *"noisy background, fast speech, shouting, unfamiliar accents or inflections, speaker's mouth obscured, stress and/or tiredness of the listener, and speaker unaware of the listener's disability"* (Hines, 2000, pp. 34-35); difficulties with communication which almost all of them emerged in this study too.

As it emerged, almost all participants, but one, expressed that they had never noticed any **gender differences** among deaf persons and consider deaf men and deaf women equal. The only differences reported by one participant were relevant to personality aspects, such as different opinions, behaviour, and way of thinking, as well as that there is little empathy between a deaf man and a deaf woman. This could be due to the fact that deaf women appear to have significantly more worry compared to hearing women, deaf men, and hearing men, as it has been found by a study exploring socio-emotional issues of young deaf and hearing persons (Lukomski, 2007). Thus, the differences reported in the thesis by the participant could have their origin in this higher degree of worry that deaf women have, compared to deaf men.

In terms of **expectations at personal and/or professional level about the future**, participants referred to expectations related mainly to family life, companionship and work, such as to make a family and find a job that they enjoy, and one of the participants mentioned that although she would like to have a child, it would be difficult for her because the noises children make can be disturbing for her. Four participants referred to hopes of improvement of the circumstances for deaf persons such as full accessibility and fewer barriers for inclusion, sign language recognition and being taught at every university, and hoping not to have any complications with their hearing in their future. Finally, one participant expressed that she does not want to have great expectations about the future, because they might not become reality, so she prefers to think only about the present. The finding here show that deaf women have overall positive outlook on the future, however, they also worry about their hearing difficulty deteriorating, but as mentioned above, deaf women have been found to worry more compared to hearing women and deaf or hearing men (Lukomski, 2007).

Main Area 2: Social relationships, social participation and disability

Core Theme 5. Social networks (structural aspects)

5.1 About size of social network and type of relationship

5.1.1 Size of social network

Overall, the majority of participants reported that in their close social network they had about 5 to 10 persons, with one participant mentioning having about 15-20 persons in her social network and two others, Megan and Nancy, mentioned having no close friends in Italy, only in another country.

5.1.2 Feeling closer to family primarily, and then friends

Six participants, Megan, Nancy, Sharon, Claire, Kylie and Monica, expressed that they were feeling very close to their family and then to some friends. Some of them even specifically stressed that family comes first and they are very attached with their family. They also mentioned having friends only in Italy and many of them also in other countries, while others, such as Megan and Nancy, had no friends in Italy, only in other countries, and were both foreigners. Participants who had in their close network also friends, apart from their family, expressed that they had known them since school days, or an association of deaf persons, or meet them occasionally at demonstrations and events concerning issues around deafness, are current or ex-colleagues, family friends, or friends living in other countries. One of the participants, Kylie, when talking about her social network she referred to the “fragmented world of deaf persons”, meaning the division between verbal (oralisti) and non-verbal (segnanti) deaf persons, and deaf persons who had support from their family while growing up and others who did not. So there is space between these two worlds and despite being “on the same island” as she graphically put it, they cannot get together, because there is a network of interests which hinders the unity of these two groups in order to be able to fight for their rights. She also expressed that she is bilingual, meaning she is able to understand both verbal and sign language, although she did not say that she can sign too, and she is in favour of bilingualism among deaf persons, because we all make facial expressions and moving our hands while we are speaking so there is something innate that we all have. Lastly, she hopes that we will reach this point that the two worlds of the deaf persons will coexist, without any dispute on whether one method is better than the other, and thus unite the forces for their rights:

I am connected to, I am in love with my family, but I don’t have any particular feelings for other people. There isn’t anybody else. (...) Yes, in America yes, here no, I am talking about Italy. Here no. (...) Here in Italy I have bonds only with my family members. Nancy (S)

First of all, my family, my family clearly, the closest relationships I have them inside my family. Then of course I have other people that I care for, to whom I am connected, but first of all my family. (…). Neighbors, friends, colleagues, I get along with everyone, also people who attend the school with me. Of course there are people who do not see me well because I am deaf and we do not manage well to communicate. Sharon (S)

I have to say something about the world of deafness, in the sense that the world of deaf people is very fragmented. There are speaking deaf people, deaf who speak the sign language, and each one of us has their own luggage of experiences. There are those who have lived it in a dramatic way because they were not supported by the family, because maybe were not accepted by their family, on the other hand there are also those who like me had excellent support from the family. So there is space between these worlds that although being on the same island they cannot manage to meet, there is a network of interests, conflicts which impedes that this group together would be all cohesive to be able to fight for their rights. (…) I am in favor of bilingualism, meaning to accompany the speaking deafness with the sign language, I think that they can coexist. It is true that the linguistic structure is completely different but if we think about how we speak, we move our lips, we make facial expressions, we move our hands, always accompany with a gesture, so I think it is something innate that a bit all of us have. Kylie (S)

No sociodemographic similarities emerged for participants under this sub-theme.

5.1.3 Family and friends and/or colleagues without any difference in the degree of closeness

Other participants, Carol, Betty and Shirley, also mentioned family, but not specifically stressing the closeness they have with their family compared to the other ties of their social network, thus not making any distinction among them on the basis of the degree of closeness with them. Among their social network they also mentioned friends, whom they had known since school days or vacation or as an adult, living in Italy or other countries, and colleagues:

Friends, family in the same way. (…) My family and my friends, or colleagues from work, yes, let’s say that I have affection for all of them, without distinguishing, friends, colleagues and family. (…) Some of them are in Italy, others in Ukraine, I have friends here and there. I also use the sign language with them, so we understand each other. (…) More or less 20 or 30 I don’t know... 15, 20. Carol (S)

All my family is close to me in all difficult moments, also at the university context, but especially my friends who see me as a normal person apart from my problem of deafness, and I like this a lot. They do not make it a burden, I wouldn’t know how to deal with that, it is really a low blow. (…) Friends, friends, the girlfriends that you saw earlier (...) With one of them we were classmates in secondary school, the other girl I met her in the mountains, where I used to go every summer with my grandma. Betty (S)

My partner and some friends. And my mum (...) no, I have not remained in contact with anyone from school. My friends are more recent, not even one colleague. But they are friends that I made as an adult. Shirley (S)

The only common sociodemographic characteristic among the participants under this sub-theme was that their highest educational level was upper or post-secondary school certificate.

5.1.4 Not included family in close social network

Only one of the participants, Dorothy, did not mention any family member among their close social network, although she was living together with her husband and her father. Probably the participant did not understand the question correctly since she was a foreigner or the sign language interpreter omitted to mention family within the question regarding social network. In any case, the majority of the participant’s friends as well were living in other countries, not Italy:

Friends, they are deaf people, and more than anything else, friends (…) I have close friends and friends who are far, both. (…) I cannot count them, let’s say that I have friends, normal, I have a friend in Italy, the majority of them in fact are in Poland, Bulgaria, Russia, in that zone. Dorothy (S)

Based on the findings under this sub-theme, Dorothy is the deviant case given that all other participants included family within their close social network.

5.2 Frequency and way of contact with ties of social network

5.2.1 Speak and/or meet with friends every or almost every day

The majority of participants with hearing difficulty expressed that they speak using text messages (mostly on WhatsApp) or video-calls with one or more of their close friends every day or almost every day, and meet often depending on their availability, such as during weekends, or two or four times per week, and they go for a coffee or a beer, but those who have friends who are not living in the same city in Italy or they live in another country, they see them less often. One of the participants, Monica, who is using verbal language, specified that she does not often use phone calls to communicate with others, only when she is in a silent space, but when she is at work, for example, where there is too much noise she cannot use the telephone:

> Every day, from the morning until the evening. (..) in the weekend we meet in person, for the rest of the time we exchange messages on WhatsApp, because some of them are here in the area, others are spread over Italy, so WhatsApp is the mean of communication that I use the most. Claire (S)

> The mobile phone I use it a little, only if I am in a silent environment like this I can speak on the phone. In the office I don't use it because being an open space, not being alone in the office, but I have colleagues so there is always a lot of noise and it is very hard for me. Monica (S)

> Moderately. So I have various friends, I have many, I cannot manage to meet with all of them frequently, but on average twice a week, it depends also on the periods. (…) Face to face. Then the others I talk to them maybe more often via WhatsApp, almost every day I am always talking with someone. But to meet in person it depends also on commitments, not having a house, a number of things. Shirley (S)

No sociodemographic similarities emerged for participants under this sub-theme.

5.2.2 Not meeting with friends very often or meeting them sometimes

Two participants, Sharon and Dorothy, expressed that they do not often meet with friends or they meet them sometimes. In specific, one of the participants, Sharon, mentioned that she does not meet with the ties of her close social network very often, and when she is free she arranges to meet them and go for shopping or window shopping, chatting, in the city centre, and then they also arrange between them to attend events from an organisation of deaf persons that organises events, such as projection of a film or a party and they meet. Another participant, Dorothy, mentioned that they write to each other with her friends and arrange to meet sometimes depending on the availability to go for a walk, have a coffee, go shopping, eat together, and sometimes also go to the cinema or theatre or an exhibition:

> No, not very often, sometimes, if I am free maybe I agree with my friends and we see each other, we fix an appointment, we decide a place and time and maybe we meet for a coffee, to chat a little bit. Sharon (S)

> Yes, we meet face to face to drink a coffee or we go to the theatre, generally these are the things we are do (…) Sometimes, depending on availability, but more often we meet maybe for a walk, to go shopping, to eat together, to drink a coffee, sometimes it happens that we also go to the theatre, to the cinema, to see an exhibition... Maybe during the day I work a little bit on the computer to prepare my CV or to study and then when I finish I meet with my friends to drink a coffee or go for a walk. Dorothy (S)

Both participants, who expressed that they do not meet with friends very often, were married, unemployed, and using sign language, thus possibly indicating that did not have the financial resources or interest in meeting socially with friends more often.

5.3 Membership at organisation or volunteer groups (formal social networks)

5.3.1 Not members of any group

The majority of respondents reported that they are not members of an association or an organised group. However, almost all participants using the sign language were recruited in this study during a group meeting of an association for family psychophysical health, thus obviously they were belonging to this group. Similarly, during other parts of the interview participants mentioned attending events or meeting other persons with hearing difficulties through another specific association for deaf persons in Milan, but they did not mention it when asked directly if they belonged to any association.

> No, at this moment no. Shirley (S)

No sociodemographic similarities emerged for participants under this sub-theme.

5.3.2 Membership at sport and theatre groups

There were only two participants who expressed that they belonged to groups, one of them, Claire, at a theatrical association and the other one, Monica, at a sports group of Olympic games for deaf persons (Deaflympics) doing snowboard:

> Yes, I am a part of a sports group. (…) I don't know if you know it but there is... European Olympics of non-hearing persons, a little bit like the Paralympics, but we are not part of the Paralympics but we have our own competitions for almost all sports. I am a member of the snowboard Italian National team of deaf persons. (…). I have participated at European championships and the Olympics. Monica (S)

> Theatre etc. Yes, yes, I do not have any problem, I have an 'Arci'[41] [membership] card, I go to the theatre, I am a member of a theatrical association, I don't have problems. Claire (S)

Both participants who expressed that they belonged to a group were never married and working in paid employment.

Core Theme 6. Daily activities

6.1 Meeting friends regularly

Half of the respondents, when asked about their daily activities, they expressed that they meet with their friends during the week to chat with them, or go for a walk with them, or at dinner, or at their house for board games. They were also doing other activities during the day, such as taking care of their child or husband, doing housework, going shopping, making knitted clothes, going to doctor's visit, participating in the organisation of a theatrical group for deaf persons, going for walks, travelling to other Italian cities to meet friends, going to the mountains for skiing in the winter or the lake for walks and bicycle riding, going to the cinema or watching television, one participant also mentioned doing dog-sitting apart from her morning job:

> I wake up, I have breakfast, I do housework, I do some laundry, if there is something to mend, I knit, I make knitted clothes, then I go shopping, if I have to go to any medical visit, I go to the doctor, or I meet a friend. Let's say that until the evening these are my activities, I prepare food or my husband helps me to cook something, normal things, daily stuff. (…) Maybe I check my mobile phone, I knit a sweater. Carol (S)

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[41] 'Arci' is a cultural association in Italy of which members can attend various events using their membership card. For more info: https://www.arci.it/chi-siamo/ [Accessed 02 April 2019].

> I work, then I go back home, it depends on the day. Some days I clean my house, sometimes also the dogs as a dog-sitter. It depends. If not, then I cook, do the shopping, prepare dinner, I read when I can, I keep up with the news in general and watch a film. (…) yes, I work for a bank group. But every now and then they call me as a dog-sitter (...) Now I am not doing any sports, nothing. I was always into sports. Lately no, I have a lot of expenses and I don't have time. I will get things resolved and then when I have more time I will get back into sports. (…) meeting friends. Meeting with friends for dinner. Shirley (S)

No sociodemographic similarities emerged for participants under this theme.

6.2 Did not mention meeting friends regularly

The other half participants did not mention meeting their friends when asked about their daily activities and reported taking care of their child, doing housework, shopping, going for errands and walks during the weekend, going looking for a job through the association of deaf persons, going to parties with their child, just staying at home all day, studying, watching series, going horse-riding, or preparing material before going to work and speaking after work with colleagues for updates and things to do at work. Two of the participants, Dorothy and Megan, mentioned they do not have a lot of free time during the day with all the activities they are doing, although they were not employed:

> I am unemployed, but anyway I have many commitments because I have a child, a son, his school is far from the house and so I have to bring him to school, to bring him to the speech therapist, to go to the Italian National Agency for the Deaf (ENS[42]), when I have communication problems in order to do some paperwork I have to go to the front office of ENS. Also to look for a job, I don't know if I will find a position, but I have many commitments and I am on the move all day, meaning that in the evening I come back dead and completely tired, I fall asleep, I collapse. I collapse from sleepiness. Megan (S)

> In the morning I accompany my brother to school, in the afternoon I stay at home and also in the evening. Sometimes I go out or stay at home, it depends. (…) I like swimming and playing basketball. (...). No, there are things that I would like to do but I don't do them here. Nancy (S)

The five participants who did not mention meeting with their friends the highest education level they had attained was of upper or post-secondary school certificate or lower.

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[42] Ente Nazionale Sordi - Onlus (ENS). For more info: https://www.ens.it/ [Accessed 04 April 2019].

Core Theme 7. Disability-based homophilious or heterophilious social networks

7.1 Homophilious social network

Four of the participants had homophilious social networks, composed only by deaf persons. One of them, Kylie, was not asked directly this question because she had already told me she had only one friend who had hearing difficulty and her husband too, therefore she was considered as having a homophilious social network too:

Yes, yes, all of them are deaf. Carol (S)

Deaf, they are deaf people, all of them deaf. Sharon (S)

As it emerged, three out of the four participants with mainly homophilious social networks were using the sign language and were 36 years old or above.

7.2 Heterophilious social network; mainly consisting of deaf persons

Three participants, Nancy, Megan and Dorothy, expressed that they within their close social network they had both persons with hearing difficulty and persons without hearing difficulty, but mainly the persons they were feeling closer were deaf persons too. One of the participants, Megan, mentioned that she has a friend that they grew up together who does not have a hearing difficulty but she learned the sign language so they can communicate with each other. All three participants were using the sign language:

Yes, yes, they are deaf. (…) I have a lot of deaf friends in the USA and… I have a lot of deaf friends in the USA, in my family they are hearing persons, so let's say that I have ties with hearing people within my family. Nancy (S)

Yes, yes, yes, absolutely, inevitably yes, they are deaf, and one of them is a hearing person, we grew up together as neighbours and I taught her the Bulgarian sign language and so we communicate with sign language with this hearing friend, and yes, we are still friends, she is an important person. Megan (S)

I have hearing cousins, aunts/uncles, but I have few hearing persons close to me, most of them are deaf. Dorothy (S)

The participants who had heterophilious social networks mainly consisting of deaf persons were educated to upper or post-secondary school certificate level or lower and were unemployed or doing volunteer work.

7.3 Heterophilious social network; not including any deaf person or only a few

The other three participants, Betty, Monica and Shirley, also had social networks including both persons with and without hearing difficulty, but those with hearing difficulty were a small minority in their social networks, whereas one of them, Betty, mentioned that she has no friends with hearing difficulty. All three of them were using verbal communication with others and not the sign language:

> No, they are normal people. Betty (S)

> I attend the world of the hearing people... eh... more in the sense of work than for my private life, so I attend it a lot more. I have few dear friends who are deaf, so I have many acquaintances who are deaf persons, but friends-friends very few. Monica (S)

> All of my friends are [hearing persons], I only have two deaf persons, with whom I am in touch, they are two. Then the people that I meet more often are hearing people, also my partner is a hearing person. Shirley (S)

All three of the participants who reported having heterophilious social networks, in which were not included any deaf persons or only a few, were speaking participants. This was obviously related to the fact that they could communicate easier with persons without hearing loss, compared to participants using the sign language, but also it might be due to the fact that they did not seek to socialise with other deaf persons.

Core Theme 8. Change of attitudes of social network due to disability

8.1 Experienced prejudice and change of attitude of others due to deafness

Participants were also asked whether they had ever experienced any change of the attitude of persons from their social network when they realised that they have a hearing difficulty[43], and three of them, Claire, Kylie and Shirley, mentioned that they had experienced such change in attitude of others. Claire expressed that others understand immediately that she is deaf and she informs them about this too, so the difficulty is more in the other person that discovers she is deaf, and if she sees that they have too much difficulty with her deafness then she leaves first. On the other hand, Shirley, who communicates verbally, mentioned that maybe she does not say to others from the start that she is deaf, and it depends on the context and the factors whether she can say it to them or not and explain to them that she needs to read their lips to understand them. Another participant, Kylie, who also communicates verbally, mentioned that she has experienced prejudice from her colleagues (she is a teacher) and this hurt her, but she moved on. As a child and adolescent she was lonely because in her hometown there were no other deaf children and she had this diversity which started becoming obvious, although her parents tried to make her live her life as everyone else and not focus on the difference between hearing and non-hearing persons. She was reading books a lot as an adolescent which helped her greatly in improving her vocabulary, open her mind, and travel with her mind. She also mentioned that when someone is healthy can become ill, but when someone has a health issue all their life then they develop resilience and with the help of her family too she developed a mechanism of resilience that helped her a lot in her life:

> Yes, it has occurred. In fact people who are my friends they find out immediately that I am deaf, because it is immediate. And then I am the kind of person who makes things clear right away. So the difficulty is more on the part of the other person who finds out that I am deaf, it is not my difficulty. If I see that there is a lot of difficulty I let it go, I don't waste time, I am the one who steps back first. Claire (S)

> There has been prejudice from colleagues, I have often experienced it on my own skin indirectly with attitudes and behaviours. I got hurt but I moved on following my way. With respect to friendship I have a lot of difficulty, because before coming to Milan in terms of my social life I have always hung out with hearing people, because I come from a very small town, where I was the only girl with a problem like mine, so I did not have a chance to compare myself with people with my problem, and if they were I did not understand where they were and where to find them. (…) I don't deny that I also have experienced some difficult moments because difficulty nowadays scares people, it was enough for me to see what they show on TV, in advertisements, they give an artificial image of reality that does not correspond to what we really

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[43] Deafness is not a visible disability thus participants with cochlear implant could conceal the fact that they had a hearing difficulty, while participants who were using the sign language could have had a written communication with an acquaintance before meeting them (such as through social media). Thus explored if there were any changes of attitude from others when they realised the participant had a hearing difficulty.

live, because a person who is born healthy can become ill. On the other hand a person who has encountered difficulties in life has more energy to deal with [issues], they call it ‘resilience’. So I have to say that I have developed a strong resilience and what helped me a lot was my family undoubtedly. I had a father and a mother who always supported me, also my siblings, who pushed me a lot to improve, to not withdraw to myself, so to constantly improve, to contribute to the society the best way I can, showing that we can do it despite difficulties. I hope this is what I can teach to my 4-year-old son and would like to give him these ideals and principles. I wish to myself that he assimilates well these things. Kylie (S)

It has happened to me, yes. (…) In any setting. It all depends on the person, to understand her/him, to identify her/him, and maybe to ask myself. Maybe in the beginning I don’t say it, but I say it immediately, it depends on the context, to understand when the context is right to say it, also to not put the person that I have in front of me in a condition to be biased towards me. To put the person in a condition to understand, and to calm her/him, so I also explain, to explain that for me it is fundamental the lip-reading nature, otherwise I would not be able to understand her/him, it depends on the context, on factors. Shirley (S)

The three participants who experienced prejudice and change of attitude of others due to deafness were 36-40 years old, had all the same educational level (upper or post-secondary school certificate), and were working in paid employment.

Core Theme 9. Social support (received and provided)

9.1 Received social support

9.1.1 Support received from the family and/or the State and/or others

The vast majority of respondents with sensory disability reported that they receive support mainly from their family (such as parents, son, or husband/partner), the State or municipality (in terms of institutional support financially mainly), or others, such as a sign language interpreter. The nature of the support they received was related to their hearing difficulty, for example, when they require assistance of a sign language interpreter or to book a medical appointment. So for these tasks they ask a family member, usually, to make this call on behalf of them because they have difficulty hearing on the phone or there is no other option available for persons using the sign language to book a medical appointment. Two of the participants, Monica and Kylie, expressed that they have difficulty hearing announcements through speakers or alarms in case of emergencies, so in the first case ask for help from nearby persons or in the second case try with the help of a colleague, for example, to install an illuminated alarm at school where Kylie was working as a teacher. Received psychological support was mentioned by only one of the participants, Shirley, who mentioned that she sometimes visits a psychologist to help her deal with the challenges of living with deafness, because it is not easy for her. She also expressed that her parents chose her to grow up among persons who could hear, and not learn the LIS, so she would be integrated socially among the hearing persons only, but this caused difficulties for her which she tries to overcome. Finally, Betty mentioned that she required help from someone in completing her tasks for her university studies.

In terms of financial institutional support received by participants with hearing difficulty, the majority of them reported that they had received support – whether in the present or past –, such as from the municipality, Carol and Sharon were given places to stay and financial help, because they were not working, while Sharon also received financial help from the social services for her son to go to school and buy books. Both Shirley and Monica received benefit for persons with deafness (called in Italian *indennità di comunicazione*), while Kylie mentioned that she uses the Law 104 (mentioned above also) for being absent from work in order to book medical visits, attend a medical appointment or repair/maintenance of the hearing aid. On the other hand, two of the participants, Dorothy and Nancy, mentioned that they had never received any institutional support although they have tried to:

> I.. the need that I have when my father who is a hearing person cannot help me, I need to call an interpreter or I ask a friend to accompany me, but my father works from 08:00 in the morning till the evening, so often he cannot help me and I need an interpreter. (…) All my expenses I cover them privately, I have never gotten any financial support from the State (…). Even if Bulgaria is in Europe I don’t receive any aid. I know that in Ukraine yes, there are social aids, pensions, different types of financial aid, but I don’t have this type of aid, I have to cover by myself the expenses for rent, etc. Dorothy (S)

> But actually it is more him [her son] that helps me, because I am deaf and so it is difficult for me to speak, often I ask him to give me a hand with communication, so first of all it is him who helps me. (…) The municipality some time ago was giving me a financial aid, they used to give me also a place to sleep. Now my husband found a job, it is not confirmed yet, he has a trimestral contract and so we manage to pay the expenses with that. My son receives a financial aid that allows my son to go to school, to buy books for school, etc. The social services know about our situation and yes, we receive these contributions, these aids. Sharon (S)

> Yes maybe I ask my mum, for example if I have to make a call to book a medical appointment, it has often happened to me on the other side of the phone to find a voice, a person who is not very clear, so… in order

not to find myself in these situations and be in difficulty, I ask my mum to make a quick call and she books for me an appointment. So the only help regarding my deafness is this. (...) So yes, in Italy people who have a disability, any type of disability, receive a benefit that is called… it has various names, I take one part monthly.. it is called communication benefit, yes… I am taking it. Monica (S)

Mainly I help myself, my family is far, my mother and my father live in Sicily, so for the daily tasks I manage however I can. The major difficulties were in the office where I am working at my school, I have to solicit for a communication via e-mail, I had to fight a bit to get to this passage. One thing that I still find difficult to this day are emergency alarms, because working with children I have a problem in evacuation and alarms that do not work well, only auditory I am not able to hear them, so I need a bright signposting and I fight for it, one colleague is helping me a lot with this with whom I've been working for about three years. This colleague she worked for a long time for civil protection and she became aware of this problem, so we fight together to make my situation more legal, to avoid in the future to have to deal with enormous responsibilities. So this is one of my little battles that I am doing daily. Kylie (S)

So, yes, I cyclically ask support from a psychologist, that yes, periodically, because she helps me... sometimes I confide in, I ask help to elaborate also... how you can live with deafness, it is not easy. It is not easy (…) it is a question that opens a lot of questions, it is complex, I wouldn't know where to start from, it is not possible to summarise in two lines, in two words. So I making a premise, my parents made this choice to raise me among hearing people and so not to teach me, they did it in a way so that I would not learn the Italian sign language, so that I would remain the most possibly integrated among hearing persons, integrated also socially. (…) So this is a reason for which I sometimes ask for psychological support to work also on my inner person, on my capacity to deal with, to reflect on myself really. (…) I receive a communication benefit. Shirley (S)

No sociodemographic similarities emerged for participants under this sub-theme.

9.1.2 No support from others or the State

Only two of the respondents, Megan and Claire, expressed that they have never received any support from other people or institutions. However, Megan mentioned that she receives some support from her collaborators due to her hearing difficulty but did not specify further about it. She does not have institutional support and had to struggle for her son receiving support at school and is very disappointed by the Italian services on this matter. Claire also expressed that she receives no financial support from the State or others, and if she has any problem she can ask for a sign language interpreter:

Assistance, no, no, some help because I am deaf yes, in fact there are... I don't know... there are people who collaborate with me, but it is not exactly assistance, maybe... yes, they help me at collaboration level. (…)

As if… I had to fight a lot for school support for my son but the situation is terrible and I am very displeased, I am very displeased. (…) When I went deeply into this thing I saw what the State was really offering and I was really upset, from fright. (…) I don't have full… there are no services at 100% in Italy, I don't have full assistance, it is not easy our life. And we have to fight every day, and we have to go ahead, fight every day. Megan (S)

No, no, I am ok in this sense, I don't have any problems. In daily life I am independent, I am on my own. If I have any problem, I can call an interpreter, but the rest of the things I do them without any problems. (…) No, no, till now I have not had any financial aid, because there was never an occasion to have aids of this kind. Claire (S)

Both participants who did not receive any support from others or the Italian state were of similar age (i.e. 36 and 40), their highest educational degree was upper or post-secondary school certificate, and were using the sign language.

9.2 Provided social support

9.2.1 Have provided support to others

The vast majority of participants expressed that they have provided support to others, such as to non-Italians coming to stay in Italy, for going to the public services for residency or other offices, or other kind of help they might need, and one of them, Sharon, mentioned that the municipality has asked her to help them as a mediator. One of the participants, Claire, mentioned that she has a friend living in a small town, who feels lonely and discriminated, and supports her by providing advice to her or finding a sign language interpreter for her or persons she can meet. Monica also mentioned she had been doing voluntary work helping young persons with paralysis by chatting and playing cards with them, whereas Shirley mentioned that she provides help to others in the context of friendly relationships:

When people come from Ukraine, yes, I help them. (…) For example, to look for a residence in municipality, I accompany them, I go with them to the offices because they don't know the city, they don't know where the respective offices are and so I accompany them. Carol (S)

Yes (...) it depends, I have a friend who lives in a small town and she feels lonely and discriminated, she is a little bit weak, whereas I have a strong character, I support her, I give her my advices, I give her positive support, when she tries to come to me and I find her solutions, maybe I look for an interpreter for her, if I know another deaf person, a friend of mine, I send her to him, etc. Claire (S)

> Yes, I did some volunteering some time ago (..) At the hospital [in Milan], at the Spinal Unit, so young people… of my age... I did that about five years ago. Young people of my age who remained paralysed after an accident, we used to go there, to help them with eating, because many people not being able not even to move their arms they have to be fed, because their relatives could not always be there, and so we used to go there also to chat a little bit, to play cards... I had this volunteering experience. But at the moment I am not doing anything of… I mean I do not have this commitment, unfortunately there is little time, I would like to, but it is not always possible to do everything. Monica (S)

No sociodemographic similarities emerged for participants under this sub-theme.

9.2.2 Have not provided any support to others

Two participants, Nancy and Betty, expressed that they have not provided any support to others. The two participants who expressed that they did not provide any social support to others were the two youngest participants with sensory disability.

Core Theme 10. Trust

10.1 General trust

10.1.1 Have trust in others

Regarding general trust towards other people in the community, only two of the participants, Carol and Monica, expressed clearly that they have trust in others:

> Yes, yes, yes, I have trust, yes, everything is fine, I relate positively and in the same way with everyone. Carol (S)

> I am very... optimist, I am a lot, so despite everything, I mean we see how the world goes, I should also be a bit pessimist, but I still have hope in human kindness, I like people, I am very optimist, so... it has nothing to do with deafness, I don't allow myself to be influenced by my handicap. I like meeting new people, I am very curious, open to diversity, at whatever is different from what I know, to whatever is new. (…) [laughs] exactly, yes. Monica (S)

No sociodemographic similarities emerged for participants under this sub-theme.

10.1.2 It depends or gradually have trust in others or uncertain

Most of the participants expressed that it depends whether they trust others or not by the person, saying that they understand people a lot by just meeting them or do not trust others at first but prefer to get to know better the other person and then decide if they can trust them or not. One of the participants, Betty, also mentioned that it depends if the other person accepts directly her hearing difficulty, if not then she avoids telling them about it because she does not know how they are going to take it:

> It depends, because if there are people who accept my problem as it is, then I trust, if not, I can avoid saying that I have a problem with hearing because you never know how that person can take it. Betty (S)

> Actually my first approach with people that I don't know is not immediately of trust, then actually with communication, when a relationship starts, when a communication starts, then yes, I am ready to trust. But if I don't know people, no I don't trust others immediately, I need first to relate a little bit, and then little by little when the relationship and communication go forward, yes, I am ready to trust. Sharon (S)

> So, the trust... so… person who trusts easily. Let's say that I try to be prudent, gradually. But do you mean in respect to people? (...) I go gradually. To see what happens and little by little. Shirley (S)

No sociodemographic similarities emerged for participants under this theme.

10.1.3 Difficulty trusting or no trust in others

Two of the participants, Nancy and Kylie, reported that they do not trust others in general, because have not met many people in Italy or have difficulty trusting others because people have become very selfish and self-centred:

> No, no. Actually I don't have friends, I arrived in Italy not a lot of time ago, so I don't know people, I couldn't say that I trust. Nancy (S)

> Lately I find it difficult to trust others. I see a widespread selfishness. I see that we all are too focused on ourselves. Also human relationships have weakened a lot. So I want to hope that there is a glimmer of humanity in every one of us that will come out, but listening also to the TV news does not make me very hopeful. Therefore I do not know, I have many doubts on that. Kylie (S)

The two participants who reported having difficulty trusting or no trust in others had no similarity in terms of sociodemographic characteristics. However, both of them had expressed that they had one or no friends in Italy and in their close social network they stressed their close relationship with their family; thus possibly having difficulty for sociality, whether due to difficulty communicating with others, as one of them being from another country of origin than Italy, while the other one expressed here that she sees a lot of egoism from others so has difficulty trusting others.

10.2 Institutional trust

10.2.1 More trust in the police and justice, less trust in the parliament

It appeared that in terms of institutional trust to the police, justice, parliament and the press, that more participants had trust in the police and justice, whereas none of the participants expressed to have trust in the parliament, and they had low trust in the press too – with only one participant, Betty, stating to have trust in the press. In some cases participants mentioned that it depends whether they have trust or no in institutions, for example, they assess the news they read in the press, while some of them mentioned they are not certain or do not know if they trust these institutions because they never had any experience related to them in Italy or in general:

[press] No, no, no, no, it depends on the newspaper. I was saying that for example I don't know… 'La Repubblica' or, now nothing else comes to my mind, but for example on every fact that happens every newspaper has its own version, so they don't have the same interpretation of the same fact, of the same reality, and so everyone expresses her/his opinion, a little bit reshaping in their favour the… how they express this fact, no? So not a lot of trust, no. Megan (S)

[press] Italian [press] no, I am sorry, Italian no. Russian and Ukrainian yes, Italian no. (…) And anyway I need to read Italian newspapers I need an interpreter because I am cannot orient myself in the comprehension of written Italian language. Sharon (S)

[justice] Justice, not a lot, I know there are frauds, scams, not a lot. Megan (S)

[parliament] I don't know, I don't know. Because there are people in parliament who, it seems that they are making fun of others, so to trust them, I don't know. There are people who play double games, it depends on which topics it is, because on some points I feel that they are making fun of me, so I cannot place my trust. Claire (S)

[police] It depends, I think yes. I have one uncle who is a policeman, so I want to trust in the police. But more than anything else, also they should become sensitised on this type of problems. Because also in the

> context of the police and policemen there isn't often a lot of awareness about the problem, of persons who have hearing problems. Kylie (S)

No sociodemographic similarities emerged for participants under this sub-theme.

Core Theme 11. Opinion on specific civic norms

Regarding opinion on civic norms, participants were asked whether they agree or not with specific statements – based on Kaasa & Parts (2008) – relevantly to trustworthiness within their community. These statements referred to: tax evasion, claiming government benefit that one is not entitled to, and accepting a bribe during one's duties.

11.1 Majority disagree with tax evasion, claiming government benefit that one is not entitled to or accepting a bribe during work

It was found that the vast majority of participants disagreed with all four statement, thus disagreed with tax evasion, claiming government benefit that one is not entitled to, and accepting a bribe during one's duties:

> I don't like this way of asking for things as if they were taken for granted... If there is a financial help because one has a right to it, that is fine, otherwise no, and you should not demand anything, you can ask but not demand, and ask and if you get something you say thank you, otherwise nothing. Sharon (S)

> I do not agree with tax evasion, because I pay taxes regularly and I am a State's employee, my taxes and contributions get deducted automatically... it is not right that freelancers are sly and then who pays are public or State's employees, I don't find it right. Kylie (S)

No sociodemographic similarities emerged for participants under this theme.

11.2 It depends on the situation about tax evasion or do not know whether they agree or not

There were three participants, Claire, Betty, and Monica, who expressed that it depends whether they agree or not with tax evasion on the situation, for example, if there are no subtitles on public television channels, thus there is no full accessibility for deaf persons to watch them, then it is not right to pay the tax for the Italian public television, or if someone has severe financial difficulties then should have some support from the State and pay less taxes, or when taxes are getting paid and there are not equivalent services offered to citizens while politicians get immense salaries then taxes should get paid if there are appropriate services in return. Another participant, Dorothy, did not respond to the questions about tax evasion and claiming benefits one is not entitled to, because she mentioned she does not know anything about these issues and cannot answer to them:

> One moment. I believe there is the right for example if, I am making an example, if during the month in which I am using my phone rate, being deaf I have a right to some discounts, and they are not getting applied, I have a right to go and demand that this discount will be refunded to me, but on the examples that you made, no, I do not agree. Dorothy (S)

> No, they [the taxes] must be paid. But actually it depends on the situation. I know that some people like me wouldn't want to pay taxes and wouldn't want to pay the RAI tax, because there are no subtitles and thus there is no complete accessibility and so in that case I would agree. But now the RAI tax is included in the electricity bill, so we are cheated in this sense. Claire (S)

> What reason should one have if she/he wanted to pay less taxes depends if you have severe financial conditions it is a problem because if you cannot pay, and if you are unemployed, this is an enormous problem, the State should support her/him a little bit, but if it doesn't, then yes, I do not agree. Betty (S)

> It depends on the situation. If one does not have the right to get financial help and she/he receives it, now I am thinking about the fake disabled people who receive monthly financial aid, of course in that case I do not agree, ok but nobody would agree. Eh... no, the economic advantage should go to those who really need it, now I am thinking about seriously ill people, multiple sclerosis, you often hear about protests against the State because they don't receive the help they need. So there it is right to pay more attention, then there are other financial aids that make you say "but it does not make sense", also there it depends a lot on the situation, the important is that everything is logical, in the sense that it is right. I think about disabled people because myself I am diversely able, I have a handicap, so I am thinking about this immediately. Monica (S)

No sociodemographic similarities emerged for participants under this theme.

Core Theme 12. Political participation

12.1 Voting at elections

All participants reported that they were active voters whether in Italy or their country of origin (i.e. Bulgaria, Ukraine, or USA):

Oh, yes, yes, yes, in Bulgaria yes. Actually, here in Italy it has never happened to me to vote, I wouldn't even know if I have the right, I have not received an electoral card. Dorothy (S)

Yes, yes, yes, in Bulgaria I vote, here in Italy I would like to, but... I don't have yet the citizenship, I am waiting for it to come on the 10th year of residence within Italian territory and in two years I will have the citizenship, so then yes, I will be able to vote, but for now I cannot. Megan (S)

Then politics is not pure politics, it's all about debates, you here, so I mean everything is about arguing between them the parties. So a clear vision on politics I do not have it yet, I should be more interested in it. I vote, yes, but... I should try to have clearer ideas, so try to understand politics better, because without politics... so yes, my commitment will be that, to inform myself more. Monica (S)

12.2 Participation at demonstration or signed a petition

12.2.1 Have participated at demonstrations and signed a petition

Half of the participants, Dorothy, Megan, Claire, Kylie and Shirley, had participated at demonstrations and signed a petition. The topics they were mostly interested in were rights of gay persons and gay pride, animal rights, children rights in education, against gender violence, unemployment in Italy, issues related to the sign language, for work recognition for deaf persons, employment rights of persons with disability, and to have a number of free mobile phone text messages (SMS) given to deaf persons:

Yes, yes, but it depends on what they are... I have participated at numerous protests, especially for children's rights inside the school, usually the protests yes, they focus on recognition of children's rights, on the fact that there are a lot of unemployed in Italy, so protests for work, etc. Let's say that these are the contexts. Megan (S)

Inevitably, yes. (...) for the sign language, for the recognition of work for deaf persons, actually all manifestations concerning the world of deafness, of accessibility. There has been a period in which the job crisis was very strong, and we organized some manifestations to support sign language, we did manifestations. That. And then I supported a manifestation on gender violence, also organized by hearing people, or for the rights of homosexuals. Claire (S)

Yes, it has happened to me in the past. It was a petition of Luca Coscioni Association that was fighting for giving 50 free SMS to deaf people, because we were paying for them. And because mobile phones are our source of daily life, I signed that petition because I thought it was my right to be able to pay or at least half of it, considering that I always use messages to communicate with the external world. Yes, I signed that petition. Kylie (S)

The participants who had both participated at demonstrations and signed petitions were all of them 30 years old or above.

12.2.2 Have not participated at a demonstration, but have signed a petition

Three of the participants, Sharon, Betty and Monica, reported that they had signed a petition, but never participated at a demonstration; however, one of them, Monica, mentioned she had not participated lately to a demonstration, so maybe in the past she had. In any case, Sharon mentioned that she had never participated at a demonstration because she is deaf so she stayed outside this kind of things. She had signed a petition on the rights of workers, Monica on the internet petitions on social issues or animals, and Betty mentioned she had signed petitions through social media regarding television:

> No, manifestations no, protests no, also because I was never involved in Ukraine, and being a deaf person maybe I was always left a little bit out of these things. Usually, if I am asked to sign something, a petition yes, I can even accept it but it depends, then I have to understand well what it is all about, maybe with a translation to sign language. (…) There was one... there was one protest at company level in the factories for the rights of workers and some hearing people asked me to participate by signing this petition, I signed it but I actually am not occupied a lot how it then went, I just did my job, I did not follow it up. Sharon (S)

> No. (...) Sometimes on social media. In the context of television. Betty (S)

> That yes, it happens to me to sign. I don't know if you know people who stop you around asking if you want to sign, I don't sign those, because no, I don't like it. It comes to mind the website change.org that e-mails arrive, there I read them, and I have signed them more often. (…). Yes, the last one was a while ago, I don't remember on what topic. (…) Anyway, I am interested a lot in all contexts, all fields, whether social or the field of animals, to say, I try to be interested in them all... areas, all fields, yes. (...) No. Lately no, it did not happen to me to participate [at a demonstration]. Monica (S)

No sociodemographic similarities emerged for participants under this sub-theme.

12.2.3 Have never participated at demonstrations or signed a petition

Two of the participants, Nancy and Carol, reported that they had never participated at a demonstration or signed a petition.

The two participants who had never participated at a demonstration or signed a petition were both using sign language, their country of origin was not Italy, and did not have a paid employment.

Core Theme 13. Employment difficulty due to health issue

Participants who were not in paid employment were asked whether they have tried finding a job, but could not find one due to their hearing difficulty. Four of the participants were working in paid employment, whereas six were not working in paid employment, with four of them being unemployed, one working occasionally in volunteer work, and the sixth one was a university student.

13.1 Experienced difficulty finding a job due to less employment opportunities for deaf persons or other reasons

Five participants, Dorothy, Megan, Carol, Nancy and Sharon, expressed that they experienced difficulty finding a job due to the fact that there are less employment opportunities for deaf persons compared to the general population or for other reasons. Sharon was not asked this question during interview because she had already explained during the collection of sociodemographic information that she did not have a job due to non-health-related reasons, thus was included in this theme too. One of them, Dorothy, mentioned that she is trying to find a job but she does not know if she cannot find one due to her hearing difficulty or for other reasons, and similarly, Carol did not state a reason but mentioned she has difficulty finding a job, although she wants to find one and be financially autonomous. Megan mentioned that deaf persons should protest more for their integrating in employment and mentioned she is 40 years old so now it is difficult for her finding a job too:

> I... I have to anyway seek help from an interpreter to deal with also the whole administrative part and bureaucracy, to prepare my CV, to send it, to send an e-mail, to write the text of the e-mail, to wait for a reply, to have it translated to me, and so I am waiting for a job but I do not know if this is the cause. Dorothy (S)

> We, deaf people, should protest a bit more to arrive to a separate category, actually only for deaf people for the work integration. I have reached 40 years old, how can I find a working position? It is difficult. I think

> that it is a problem related to the law, to the law in force. (…) I would like to work, I am available, I would like to, I would be also living more calmly, because anyway I am an active person, I like to move. Megan (S)

> I went with my mum to some offices to look for a job but it is true that it is difficult for deaf persons, or maybe, it is a general difficulty but maybe we, deaf persons, we have an added difficulty. Nancy (S)

For all five participants who experienced difficulty finding a job, Italy was not their country of origin, and they were all using sign language, so the fact that they could not find a job could have been possibly related to their lack of knowledge of the Italian language or employment context, or that they had limited opportunities for employment due to the fact that they were only using sign language to communicate, or to a combination of the two factors.

13.2 Not experienced any difficulty finding a job

Only one of the participants, Betty, who was not working expressed that she has no difficulty finding a job, since she did an internship and her colleagues treated her equally:

> No, I had my internship in a photography studio where I was working for three months, and they actually made me feel not like a deaf person but as a normal person, of course sometimes in some things they were very willing to help me, other times I managed on my own to do things. Betty (S)

Core Theme 14. Barriers for social participation and suggestions for removing them

14.1 Lack of a sign language interpreter and/or accessibility at public places and/or avoiding socialisation due to deafness

In terms of barriers for social participation, eight out of the ten participants with hearing loss referred to personal experiences of lack of a sign language interpreter and/or appropriate provision of information for deaf persons in public places, mostly regarding the lack of: a sign language interpreter or subtitles at a theatre, direct subtitling (i.e. someone typing simultaneously what a person says) at conferences or seminars, subtitles on films at the cinema, or a sign language interpreter (not paid privately) at museums. In most of these situations participants expressed that they have to hire a sign language interpreter to help them participate in them or avoid participating in them altogether, thus these barriers restrict their social participation with others, as they avoid socialisation due to their deafness and find alternative less socialising solutions. For example, one of the participants, Sharon, mentioned that when she was very young one of her friends used to invite her to parties, but she could not interact with the other children so she was isolated sitting on the side watching them chat and play, and this created a problem for her and mentioned that she was not living well due to this situation. So she asked her friend not to invite her anymore, thus lose an opportunity for socialisation. Kylie mentioned that if a film she wants to see at the cinema has no subtitles then she waits for the DVD[44] to come out and buy it, so this does not allow her to have a social moment with others. Claire mentioned feeling discriminated due to lack of accessibility at a theatre to which she asked in advance if a sign language interpreter could have been present, and they told her that the light shed on the interpreter would be annoying. Other examples mentioned by participants were seeing persons being enthusiastic about something but the participant not knowing what the reason was, or not being able to hear the speaker on the station informing people about a strike, or going to the planetarium with her son in the dark without an interpreter, or attending a book presentation without direct subtitling. All these barriers impede social participation in similar situations for participants with hearing difficulty, as well as limit their inclusion and integration, as they expressed:

> Yes, yes, it happened to me, happened to me (…). I would like to say one nice thing but I don’t know how to explain myself. Maybe I see a leaflet that seems interesting to me, but I don’t know, I don’t have with me an interpreter who can explain to me what it is about, etc. I see hearing people who talk about it with enthusiasm, but I do not understand well, unless I go to the office where I have an interpreter’s service, I am not able to access it, so I decide to... (…) to not participate. Dorothy (S)

> Yes, yes, it has happened to me many times [experiencing barriers], then it depends on situation. (…) If there isn’t an interpreter, for example, maybe I am curious and I am trying to follow situations by lip reading, but I do not always manage, it is an exaggerated effort and so I let it go, but if in the various situations, manifestations, occasions, events there is an interpreter, then I am able to follow. Megan (S)

> Yes, it has happened to me to give up participating in some activities because the other people do not understand sign language and I am not able to communicate. So yes, usually I withdraw. (...) in different situations, even just going to buy a dress and not being able to speak with the shop assistant. Nancy (S)

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[44] Digital video disc.

If the activities are organised by hearing people and for hearing people yes, there are some barriers, but if there are some deaf people who participate, it becomes easier for me, I can participate, have a chat and share this thing. Among hearing persons being the only deaf person, yes, it makes me uncomfortable, I would not participate. (…) Years ago when I was little I used to have a hearing friend who invited me to parties, to occasions, and I attended them because I wanted to participate in them. But then I would stay aside watching the others chatting, playing, so I didn't feel satisfied, for me this was really a problem, I was not experiencing it well. As the time passed I asked this friend to avoid creating these occasions and to involve me, I said thanks to her but I explained to her that I was deaf and so I could not manage to participate, it was becoming a bit of a torture for me to see that everyone else is having fun and smiling and I was not involved in these situations. If she and I were going out alone and doing something together, then it was going well our relationship, but within the group in which I was the only deaf person, I was not well. Sharon (S)

Yes it has happened many times. (…) In the theater, because everything is spoken and I maybe in advance ask if it is possible to have an interpreter and it was said to me "no" because the light on the interpreter is annoying, but then I ask where is the accessibility for me? And in this case I was discriminated. Or maybe there are seminars or talks in which I want to participate, but there is no interpreter, and so there is no accessibility, and so I give up participating. At cinema, the same thing, if there are no subtitles, then I don't go to the cinema. If there are screenings in English sometimes they put Italian subtitles and in that case I can go, or at the museums, there are guides or audio-guides but we have to find an interpreter and to pay her/him from our own pocket, and so this is a problem. (…) It is possible that in the station there is a strike of trains or an announcement which is provided only verbally, I do not hear it and that creates me a barrier. Or when a person looks at me as if I am different, but it depends on the various situations, contexts. Claire (S)

There is often. I would like to participate but I can't, this is under another topic… now simply I would like a lot to go to the theater, but I can't, because I can't hear, I mean I don't hear, I don't understand well, there should have been subtitles, then this is another issue. Regarding protests at the square, demonstrations, no, I do not have problems, so I can go, because it is not that my auditory limitation does not allow me to do that, no. Monica (S)

Yes, some things have occurred to me, for example, to go to the planetarium of Milan, I wanted to take my son, but I had to bring with me someone behind who could hear and listen and repeat to my son what they are saying. Because to be in the planetarium means being in the dark, and then they explain how the stars are made. So this kind of things I have set them aside for the moment, I am waiting for subtitles to arrive... or it has happened to me that I had to go to the cinema, but I cannot go. I have to wait for specialised cinemas to make a specific screening of the film that interests me. (…) Or for example when I am going to the museum, when I have to go to see a particular artist that interests me, I have to study things first, his works and the meaning they have, because I know that there are audio-guides but I cannot use them, so some environments limit my being a person. Kylie (S)

> I was saying before about architectural barriers, an issue that would merit more attention. (…) the subtitles. So recently I have participated at a conference organised by the corporation for which I am working. We were about 250-300 people, we filled in a whole conference room of a hotel. They had contacted three Italian sign language interpreters, and of course I did not understand anything, but it is impossible to follow a conversation for different reasons, different factors, the person who puts her/his hand in front of the mouth, the screen behind the person, do not let me focus on lip-reading. Anyway, to maintain the same high level of attention for many hours, it is impossible, I get very tired, I would like to be helped with a support of direct subtitling, to read subtitles. This allows me to be, to feel integrated, to be informed, to know what is happening, despite my deafness. To have also the power to elaborate an opinion of mine, it should be in everyone’s reach, a person’s right, also to live better with one’s own deafness, which is already difficult. For me it would be interesting to have a broader sensitivity. Shirley (S)

Participants using the sign language suggested that they often need a sign language interpreter, whereas speaking participants focused more in their responses on the lack of subtitling.

14.2 Limited choices for employment

One of the participants, Monica, referred also to the restrictions persons with deafness have for specialising in an occupation that is demanding in terms of hearing accuracy and discussion without being able to read the lips, such as in the case of lawyers and surgeons, who have to perform an operation while discussing among them with their mouths covered with masks. Such occupations would be very difficult to be followed by a persons with deafness, thus their hearing difficulty causes limitation in choices for employment for them. Therefore, the same participant mentioned that every person with disability should accept the limitations they have, however, some limitations exist for personal reasons while others because the State does not support these persons, such as in the case of persons in a wheelchair and architectural barriers, so it is the fault of the State and causes anger to them:

> Yes, there are a lot of other things... that objectively are not possible. Simply if I... so maybe a non-hearing person would like to become a surgeon, it could be a little bit... a small problem, because as you well know during a chirurgical operation, there are surgeons who wear little masks, so how do you manage to have a dialogue? Or to become an attorney, then it depends on what type of lawyer, in the court you have to understand everything, so objectively any person with a handicap knows that there are limitations, need to try to accept them. Monica (S)

14.3 No barriers experienced for social participation

Two participants, Carol and Betty, responded that they had never experienced any barriers for social participation due to deafness. One of them, Carol, specified that whenever she finds any barriers she uses applications (on the mobile phone) where she writes phrases she wants to say and uses a translator or interpretation through the mobile phone, so she overcomes these barriers:

> No, no, no [barriers experienced], I do everything. (…) If I don't know… if I go to a celebration with friends I don't have any problems, if I go to any place, I don't find barriers in what I am doing, I go everywhere. (…) but yes, when there are barriers I use applications where I can write the phrases that I have to say and use a translator or an interpreter on the mobile phone, so I overcome the barriers, there is no problem. Carol (S)

The only sociodemographic characteristic shared between the two participants who expressed that they experienced no barriers for social participation was that the highest degree they both had attained was upper or post-secondary school certificate.

14.4 Suggestions for calling a sign language interpreter or requesting for direct subtitling or cooperation from others for communication

The participants who mentioned that they have experienced barriers for social participation related to their hearing difficulty suggested that deaf persons should call a sign language interpreter to overcome communication barriers or request for subtitling. It was mentioned by Claire and Shirley that if there was direct subtitling then the difference between hearing and deaf persons would be accessible and this would be accessible by everyone. Monica mentioned that deaf persons should go and explain to the theatre manager, for example, and tell them that they should have subtitles and then see if they are willing to change things. She also expressed that when she was at school she used to ask her teacher not to turn towards the wall while explaining the mathematical formula, so deaf persons have to insist to be able to communicate with hearing persons. Or when deaf children need a sign language interpreter at school to help them do their homework or the State does not always cover all expenses for hearing aids, so deaf persons have to struggle continuously to get these things:

To remove barriers? In fact, it is as simple right of ours, we are a little bit oppressed by these barriers, I don’t know, I wouldn’t know. (…) By calling an interpreter could... I can deal with situations, but a solution could be to call an interpreter. Then it depends also on the other person, for me it is not a problem to deal with communication with hearing people on my own, but it depends also on the other person if she/he understands me. Megan (S)

I would say... if we had at least the possibility to have subtitles, we could even accept this difference between hearing and deaf persons. Sometimes when hearing people who organise events find out that I am deaf they say “oh no, she is deaf, how are we going to do this”… but I am equal to others, but I wish other people would respect me and look at me as I respect anyone. Claire (S)

Because for example a director, a screenplay writer or rather the manager of a theatre, if she/he does not know that we, with hearing problems, cannot go and see a theatre show, if you don’t know it then obviously it does not matter, but if we go there and we speak and we explain them the reason then things can change there. So to a great extent it is our responsibility, us having a handicap, it is our responsibility anyway to make people understand that there is this problem, then we have to see if from the other side they are willing to meet or no, if they are willing to help us. But it is also about many other things, also individual ones, for example, I remember that often in the classroom of the lyceum [high school] I used to tell to the teacher, “please do not explain things while you are writing them, the mathematical formula when you are facing the blackboard, please could you turn around?” If she/he doesn’t do then she/he is an idiot, in the sense that you have to insist a bit, there are a lot of selfish people that do not understand so to a large extent it is our responsibility, then it is important to see if the State gives you... For example auditory prostheses cost a lot, a lot, a lot. Monica (S)

Because communication for me is easier when there are few people, if there aren’t fewer people, it is clear that it becomes more difficult. There is a course on whichever thing, I am making an absurd example, she/he explains it to you and I would like to attend the whole lesson somehow subtitling would be a fantastic thing. (…) So, an interpreter, as I was saying before, no, because I don’t know the Italian sign language, so… But I would like it a lot if it became spread, made known, widespread, to make available direct subtitling, if I participate in a conference for work reasons, or also at my leisure time. Often there could be an Italian sign language interpreter, but that does not help me. I would like to find instead a person assigned for subtitling, and allow me to follow the conference, but unfortunately that does not exist. (…) But I think it would even be more useful, because it is more accessible for everyone. Nowadays I think that it would deserve a bit more attention. Shirley (S)

The participants who suggested calling an interpreter or requesting subtitling or cooperation from others for communication were 29-40 years old and never married.

14.5 Suggestion for sensitisation of and information to the wider society on diversity and deafness

Two of the participants, Kylie and Shirley, mentioned specifically about sensitisation, in the sense of raising awareness, on deafness and diversity, in general. Kylie suggested that sensitisation has to begin from schools where they should teach children that diversity is not a negative thing, but positive, but the problem is that adults make these distinctions and children adopt their attitude. If the adult does not explain diversity to children then there will be no improvement in society and we will make the same mistakes, so the society has to evolve, change, open their minds, and if this is missing then she does not see a lot of progress in the future. Shirley also referred to the need for a campaign to sensitise the public, an informative campaign, because deafness is an invisible disability – almost always. She mentioned that she had experienced incidents, which were also embarrassing for her sometimes, when she tried to communicate with hearing persons and they got panicked, started to make gestures and shout, refusing to communicate with her. This happened because they do not know how to behave to a deaf person, so there should be more information and sensitisation provided by companies and bodies that organise educational courses:

> What is missing is sensitisation that should start from schools. School is the first environment where children have social relationships, where you explain what diversity is, that it does not have to be seen as a negative thing, but as a positive thing. A moment to grow, to mature. In my class I have a child with cleft lip, it can seem as a common thing, but children find it difficult to accept it because the physiognomy is different. For some days I went to school with my hearing prostheses uncovered, so I said “what is the difference between me and this child?” None. The problem ended. So it is important to make children used to, the problem is that us adults who make differences, and unfortunately if they don’t evolve, within the soul of adults, children will take on this attitude. (…) So if you as an adult do not explain it… I think that improvements at society level and then consequently of institutions which will come later, will not improve the situation, we will always remain attached to the same errors and the same problems. So everything is there, it is society that has to evolve, to change, mental openness, if that is missing, I do not see a lot of progress. I hope that there will be improvements in that sense. Kylie (S)

> Information, also to my mind comes corporations, multinational groups, the field of human resources, they are mainly difficult, human resources that are dealing commonly with the course of the managing director, in which two or three times per year everyone participates, also there it is important, so to sensitise people, surely an information campaign. Then maybe they will do an advertisement, I do not know… if they dedicated a [commercial] spot on deafness. Because deafness is a handicap that cannot be seen, it is a

> disability that often, almost always you do not see it. I remember some embarrassing incidents when I was communicating with a hearing person, they were getting panicked, started making gestures and shouting, refusing communication with me. This is because they do not know how to behave. For example, a person who does not see, it is easier you know how to behave, a person in a wheelchair also you know how to behave, a non-hearing person , there are various shades... more information and more sensitization would be needed. (…) everywhere, I made the example of the organization, but it can be proposed to those institutions that provide training courses, it comes to mind courses of 24 hours [24Ore[45]], or courses for leisure time, training courses, of any type. Shirley (S)

Two participants also suggested that there should be sensitisation of the wider society and information to the wider society on diversity and deafness and both of them had similar age (i.e. 39 and 40), were both in paid employment, cohabitating with their partner or husband, having an upper or post-secondary school certificate and using hearing aids.

14.6 Avoiding situations where they do not feel included or do not know what to do

Two of the participants, Dorothy and Nancy, when they were asked what they suggest could be done to remove barriers for social participation for deaf persons, did not make any suggestion but Dorothy mentioned that she avoids situations where the other person she sees closed-up attitudes and leaves away from such situations, while Nancy mentioned that she does not know how to explain what to do and there are numerous barriers for them:

> Actually when I come across these closed-up attitudes or these barriers I give up insisting and I go away, I go away, so my solution usually is letting the situation go, leaving immediately. Dorothy (S)

For both participants, who did not know how to overcome barriers for social participation or avoided situations that barriers were present, Italy was not their country of origin, their highest degree attained was upper or post-secondary school certificate, were not in paid employment, and both expressed previously that they had never received any institutional support (from the State) although they have tried to, but were receiving support from family mainly.

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[45] Might be referring to the 24ORE Business School in Milan.

Core Theme 15. Barriers for independent/autonomous living and suggestions for removing them

15.1 Facing communication barriers; thus depend on others for communication

Almost all participants, apart from two, Claire and Betty, mentioned that a barrier for living autonomously was their dependence from other persons for helping them with communication difficulties, such as a sign language interpreter (paid by public services or privately), family members (such as father, husband, partner or son), or others, such as colleagues at work. The common contexts in which participants required assistance for communication were for making phone calls, booking medical visits, going to municipality offices, post office, train ticket desk, at the cinema or television (when there are no subtitles), or at work, when arranging with a colleague to be answering the phone instead of the participant. Megan mentioned that is important for her the help she receives from a municipality office offering telephone and interpreting service. Sharon reported that sometimes she uses written language, but if the communication barrier persists then she needs a sign language interpreter or her son helps her to communicate with others. Both Monica and Kylie mentioned the case of lack of direct communication in case of emergency, for example when there is a fire or calling the police, since they cannot make a direct phone call, by the time they text the emergency it might be too late for them. Kylie also mentioned an example of a person at the front desk of a service that have their back turned so the participants asks them to turn around and face them so she can understand what they are saying because she has a hearing difficulty, and if the person does not do it then the participant insists and asks them to write down what they are saying, so it is embarrassing, as she mentioned, for the other person because they are not prepared for confronting this kind of situation. Lastly, Shirley mentioned that she has an independent life, however, she would like to have more support from society to overcome her limitations, such as more appropriate subtitling, and others in communication articulating better with the lips and not putting their hand in front of their mouth:

> Yes, there are anyway problems in living an independent life. I repeat that I do not like staying on my own, but anyway I need to stay with my husband or to stay with my dad. (…) My husband is deaf, my dad is hearing. Dorothy (S)

Eh yes, it depends, to some extent I manage to get by on my own, and to some extent I try various... I have to say, I have to thank a lot the municipality office in Zara avenue that offers a telephone and interpretation service, because without this service I would be dead. Megan (S)

No, no, I am able to have an autonomous life and get by on my own, if things are explained to me, I understand and I am able to move autonomously. Nancy (S)

Yes, a little bit yes [facing barriers]. (...) if I do not call an interpreter and go, for example, to see a doctor, I do not understand what is said to me, so I need the support of an interpreter, or if I go to speak at municipality offices, also there I need an interpreter so that the message is clear, I always need… it is compulsory the presence of an interpreter. (…) The state pays for him [the interpreter]. Carol (S)

Sometimes, it depends, for simpler things no, for more complicated things I need to ask for interpreter. Sometimes I use written language to understand what is being said, but if it is not enough and the communication barrier remains, I need an interpreter or in addition my son helps me a lot. But if he is at school he is not free and so I can't, I have to turn to an interpreter, if he is free and he can accompany me, he helps me. Sharon (S)

Now comes to mind the telephone use, there are a lot of deaf persons who live on their own, they need to make an emergency call, to say that the house is on fire, or they write a message "help, help, there is an accident, come and save me", bye, is dead, a phone call is a lot more immediate, so maybe they should find a solution, also for example to book medical appointments. I often ask if there is an email address that I could write to, so as not having to depend always on others. This is a small example but there are many, many others that at this moment do not come to my mind. (…) Now the first barrier, obstacle for us it is mainly the phone, the phone. (…) ok, the cinema, they should put more films with subtitles so that we can participate, on the television not all films have subtitles, so the news for example do not always have them. Monica (S)

There is a person that for example does not speak well and I find it difficult to understand him and so I have to put more effort to read his lips. This is one of the moments that I make the most effort, or also people who do not remember that I have a hearing problem and they put their hand in front [of their mouth], and therefore I often have to remind them "sorry but I am not able to understand you". Then there are small architectural barriers (...) there are no possibilities for a deaf person to contact institutions, to contact them. If I for example have to call 118[46], how do I do that? There are emergency numbers, but who knows if they respond, and the same goes for the police. But also front desks, when I find myself having to buy a ticket at the train station, or to go to the medical front desk to pay the ticket [medical visit fee] of something, these can be architectural barriers, you find a person with their back turned to you, so I say "excuse me, I have a hearing problem. Then if the person continues then is misbehaved. So I remark it and say "please could you talk in a specific way? Or could you write it on a piece of paper?" So I often find it embarrassing from the

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[46] In Italy the number for ambulance emergency calls is 118.

other side because there is no adequate preparation to deal with this kind of emergency. Also at the front desk at the post office it happens to me, but not always. There are days that I am fortunate to find an intelligent employee, and other days which I do not. So everything depends on the situation, at that moment. Kylie (S)

Yes, daily (...) no, I live anyway, I manage... Every day there are architectural barriers, sometimes I manage, sometime less, it is an independent life, yes. But surely I would like to have more independence, to feel my limits that can be overcome with support and help. (…) [help] of the society. The subtitles also more adequately, enunciating more the lip-reading, and not putting the hand in front [of the mouth]. Shirley (S)

No sociodemographic similarities emerged for participants under this theme.

15.2 Limitations for deaf persons finding a job and variety of barriers among deaf persons

One of the participants, Monica, also expressed that for deaf persons it is also difficult finding a job of a certain level, because it is easier for them finding a manual job where there is not a lot of communication with people. She also mentioned that there are different categories of deaf persons: those who use the sign language, or speak, or both. Therefore deaf persons who only use the sign language have more difficulty finding a job. She referred to persons in a wheelchair as well, saying that they all have the same barriers among them, such as to climb a pavement, but not all deaf persons have the same barriers among them because they have different degree of hearing difficulty and different needs. However, she expressed that deaf persons are more autonomous compared to persons in a wheelchair:

Also job, for us to find a job of a certain level is always very difficult, for us let’s say the easiest work is the manual work, because there is less contact with people. Then it depends also on type of deafness. I mean there are millions of shades, there are persons who without prosthesis can hear something, but with it they can hear better, there is this one who does not hear absolutely anything and cannot speak so uses only the sign language, there is this one who can both speak and use the Italian sign language. I am speaking, the Italian sign language I know it a bit, I have friends who use sign language and they teach it to me, just to... so there are really millions of shades. Fortunately, I managed to find a job of a certain level, people who do not hear anything and who cannot even speak, and communicate only with the Italian sign language, the way of the signs, it is already more difficult to find a job of a certain level. (…) then what else... Maybe a person who is more deaf encounters other limitations that I do not notice, because maybe I hear some

> things, maybe I hear, I don't know, that there are calling us from there so I go there, the other person wouldn't hear that, so there are opinions also very different, it depends on how one lives the relationship with others, the relationship with the world, with the society. So it is a very long research from our point of view, in the sense that a person in a wheelchair, they are all in a wheelchair and have more or less the same let's say architectural barriers as well. A high sidewalk it is not that one manages to get off it and the other not, because all of them have the wheelchair, but us non-hearing who have auditory prostheses, we have really a million of opinions, not different opinions, but we have different barriers, different limitations. Monica (S)

15.3 Experiencing no barriers for living autonomously

Finally, two participants, Claire and Betty, mentioned that they face no barrier for living autonomously. In particular, Betty mentioned that she is not living autonomously yet, but she could try to, and if she faced any problems she would live with a flatmate. Claire mentioned that she was not experiencing any barrier for living autonomously, and when she does not understand something during the communication she uses written language:

> No, none [barrier for living autonomously]. (…) Obviously when I do not understand the communication I prefer using written language. I don't have any problems with the written language. But I do not speak for all deaf persons, the others have difficulties with written language. I believe to be fortunate in that sense. Claire (S)

> Yes, I could [live autonomously], it depends on how things are going, because if I am able to manage things, some things I am doing them, I could manage, otherwise I would find… to live with a housemate, something to do. Betty (S)

Both participants who expressed that they had no barriers for living autonomously had an upper or post-secondary school certificate and were never married.

15.4 Suggestions for asking a sign language interpreter or family member to help them overcome communication difficulties

Three participants, Dorothy, Megan and Carol, suggested that for removing barriers for autonomous living asking from someone to help them with communication difficulties, such as calling a sign language interpreter when they need one, for example, at medical visits, the dentist or municipality offices, or asking a family member to make a phone call for them:

> I call an interpreter, on my own I am not able to understand, to have the information, so I call, I go to the office in charge and I ask for an interpreter, or I give an appointment with an interpreter and then we go together to my appointment. For unimportant things I can manage it on my own, but for example a medical visit for me is complicated because I do not understand what I am being told. Or if I have to go to the dentist, it has happened to me, I had to call an interpreter to translate me what the doctor was saying. Or yes, I can be independent for example in doing the shopping, to buy food, or maybe I go together with deaf friends, if I have to do something a little bit more complex, we do things together, or I call an interpreter. Dorothy (S)

> I call an interpreter and I go for example to the doctor, I do not understand what is being said to me, so I have to be supported by an interpreter, or if I go to talk to the municipality offices also there I need an interpreter for the message to be clear, I always need, it is compulsory the presence of the interpreter. Carol (S)

All three participants who suggested asking a sign language interpreter or family member to help them overcome communication difficulties for overcoming barriers for living autonomously, were 30 years old or above, unemployed, using sign language, living with partner or husband and had expressed previously that all three of them experienced difficulty finding a job due to less employment opportunities for deaf persons or for other reasons.

15.5 Suggestions for more activities, priority, accessibility, attention and inclusion for deaf persons

There were participants who made suggestions about more activities, priority, accessibility, attention and inclusion for deaf persons. In specific, Claire suggested that there could be more activities for deaf persons and that being deaf is not being different from others, all persons as equal. Thus, she also suggested that there should be full accessibility at schools for deaf children, on full time basis, and education that it is the same for deaf and hearing children. Another participant, Kylie, suggested there have to be fast-track lanes for persons with specific problems, for example, at front desks of hospitals, or in the subway they should put on display when there is an announcement for a delay. On national Italian television there should be more programmes with subtitles, such as scientific programmes, and on TV news they should do that for all time periods, not only specific ones. Kylie also suggested that there should be greater attention to deaf persons because they are increasing in numbers in Italy, and this would make their everyday life easier and they would not feel as being left on the side:

> Yes there could be more activities, more trips. Actually I do not feel any difference between me and you, for example, it is not true that if I am deaf I am different from others. We are equal, I feel equal, there is no difference between deaf and hearing people, so we are persons in the same way. (…) I want to add that I wish the accessibility for deaf children at school was complete, full time, that it would be the same being deaf or hearing, because there is nothing to be scared of, we are persons in the same way. This is what I wanted to add. Claire (S)

> To make fast-track lanes, for example, for people with particular problems, at front desks, at the hospitals, for those who have some specific problems, or when you are called by number, the same thing when you go on the subway and they have to announce a delay, to put on display on the screen this kind of action. In TV to have more TV programs with subtitles, because I have noticed that the number of contents with subtitles has decreased. (…) For us it would be easier, would make our daily life better, we would not feel aside as persons, as individuals. Kylie (S)

The two participants who suggested more activities, priority, accessibility, attention and inclusion for deaf persons were of similar age (i.e. 36 and 40) and both in paid employment, and had expressed previously that they both were feeling closer to family primarily, and then friends, had experienced change in attitude of others due to their deafness, and had both participated at demonstrations and signed a petition.

15.6 Suggestions for more effort for personal growth and development

Finally, one of the participants, Shirley, mentioned that she often meets deaf persons who are slightly marginalised and do not know yet the sign language, but she prefers to engage with hearing persons because she can discuss more things with them. She mentioned that deaf persons have the same instruments as hearing persons for personal growth, but deaf persons have to do thrice and four times the effort that hearing people do for developing as persons and spiritually. She concluded that there are deaf persons who want to go forward and progress but have to consider any issues too, such as frustration and feeling marginalised, and manage to process these traumas and become stronger, which is more difficult to allow them to grow as persons:

> It has often happened to me to meet non-hearing persons, who maybe live a little bit more marginalised, they do not know yet the sign language. Me as a person who grew up among hearing persons, I found

difficulties with these people, I prefer hanging out with hearing people, because I have more possibilities of discussion, of exchange, personal, cultural, and intellectual. While with people who preferred for various reasons, due to difficulty, due to convenience, have preferred to in quotation marks ‘stop there’, it is a bit as if they were put backwards, I don’t know how to say it. So I think that it is them like ‘us’, let’s say, always in quotation marks, we have had the same instruments like hearing people. It would have been more right, it would have been also easier. It is an important value, if we all had the same instruments, we could all evolve and also grow up as persons, spiritually. But often in the moment in which we find that we cannot evolve, first to deal with and overcome the frustrations, to do a lot of work with ourselves. To conclude, there are more problems to deal with compared to a hearing person, as if we were working a double or triple or quadruple work. I don’t know if I have managed to explain myself. A hearing person does her/his life, his course, with problems, some with more, some with less. A non-hearing person, also here there are diverse shades, various types of non-hearing persons, there is the one who I think like me wants to go forward and wants to evolve, but has to deal with also with their issues in terms of integra… it means what I was saying earlier, frustration, feeling marginalised, and being able to process these traumas and to fortify themselves which would be up to everyone being human. It is more difficult. To allow also to them a growth, all of us have the right to grow, and it is often denied to us as well. Shirley (S)

Main tendencies of Main Area 2: Social relationships, social participation and disability

In terms of **size of social network**, overall, the majority of participants reported that they included about 5 to 10 persons. Regarding **type of social relationships**, most participants expressed that they were feeling very close to their family primarily and then to some friends, whether these friends were living also in Italy or other countries. Previous evidence reports that deaf persons enjoy a secure sense of long-term attachment to others, and among the three most important aspects or experiences of each person’s life, it was found that social attachments, especially family, ranked first (Rogers, Muir, & Evenson, 2003); thus proving the primary attachment to family that emerged here too. Participants who had in their close network also friends, apart from their family, expressed that they had known them since school days, or an association of deaf persons, or meet them occasionally at demonstrations and events concerning issues around deafness, are current or ex-colleagues, family friends, or friends living in other countries. Two participants who their country of origin was not Italy expressed that they had difficulty making new friends in Italy, while both of them were using only the sign language to communicate, thus had an added difficulty for building social relationships. It is worth mentioning that when talking about the structural aspects of their social relationships, three of the participants referred to the ‘world of deaf persons’, implying that they perceive it as a separate world from the rest. One of them in particular mentioned about this world that it is fragmented since there are deaf persons who use only the sign language (*segnanti*) and deaf persons who speak with the use of hearing aids/cochlear implants (*oralisti*), but there are also differences between them in terms of the way they grew up, with some deaf persons having support from their family, whereas others did not. She also mentioned that there might be a network of interests supporting this distinction, whereas she suggested that all deaf persons should be together, united, fighting for the same rights. The fundamental long-lasting differences of self-identity among deaf persons who speak and deaf persons who use the sign language has been reported extensively also in previous parts of this thesis [e.g. by Ladd (2003) and Chang (2017)], thus the results here confirm the existence of this distinction as witnessed also by the participants themselves. There were other participants who mentioned friends and family in the social networks without stressing the primary role of family, whereas they were participant who did not mention family at all among the persons they feel close to, meaning their close social network.

On the **frequency and way of contact** with their social networks, the majority of participants expressed that they speak using text messages (mostly on WhatsApp) or video-calls with one or more of their close friends every day or almost every day, and meet often depending on their availability, such as during weekends, or two or four times per week, and they go for a coffee or a beer, but those who have friends who are not living in the same city in Italy or they live in another country they see them less often. Only two participants mentioned that they meet less often with their friends or sometimes.

The majority of participants reported that they do not **belong to an association or organised group**, although, almost all participants using the sign language were recruited in this study during a group meeting of an association for family psychophysical health, thus obviously they were belonging to this group, and others mentioned attending events of an association for deaf persons in Milan. Thus in reality it appears through the study that the vast majority of participants did belong to an association or organisation, despite stating that they did not. Only two participants expressed that they belonged to a theatrical group and the other one to a sports group of Olympic games for deaf persons (Deaflympics).

Despite the fact that on the topic of frequency of contact with social networks the vast majority of respondents expressed that they meet with their friends regularly, when asked about their **daily activities**, only half of them reported that they meet with their friends regularly. Apart meeting with friends indoors or outdoors, they also reported mostly taking care of their child or husband, doing housework, going shopping, going for walks, travelling to other Italian cities to meet friends, among others. The other half of the participants did not mention meeting with friends regularly, and two of the participants, mentioned they do not have a lot of free time during the day with all the activities they are doing, although they were both unemployed and living with their husband/partner.

Four of the participants had **homophilious social networks**, composed only by deaf persons. Three participants expressed that they within their close social network they had both persons with hearing difficulty and persons without hearing difficulty, but mainly the persons they were feeling closed to were deaf persons, while the other three participants also had social networks including both persons with and without hearing difficulty, but those with hearing difficulty were a small minority in their social networks, whereas one of the participants did not have any friends with hearing difficulty. All the participants who were using the sign language were found to have homophilious networks or heterophilious networks mainly consisting of other deaf persons too, whereas three of the speaking participants had heterophilious social networks consisting mainly of hearing persons. This is logical given the difficulty, reported previously, that deaf persons who use the sign language have to communicate with persons of the wider society. Furthermore, the evidence here show that deaf participants using the sign language demonstrate weaker bridging social capital (Putnam, 2000), thus are less integrated in wider society, whereas speaking deaf participants have more heterophilious social networks and stronger bridging social capital, thus are more integrated in the wider society. Based on previous evidence, there is a large positive effect on social participation and health-related quality of life of persons having cochlear implantation over a 6-month follow-up period (Hawthorne, et al., 2004); possibly indicating that deaf persons with cochlear implant or hearing aids have more chances becoming more integrated socially compared to deaf persons using only the sign language. Nevertheless, deaf participants using the sign language appeared to be to a much greater extent connected with other deaf persons, thus have stronger bonding social capital, contrary to deaf speaking participants who had very few or no deaf friends, thus demonstrating weaker or inexistent bonding social capital (Putnam, 2000).

Three participants reported having experienced **change of attitude of others** and/or prejudice due to their deafness. In particular, one of them mentioned she informs others from the start about her hearing difficulty and if others have difficulty accepting it then she takes her distance from them first. Another participant expressed that she does not say to others from the start that she is deaf and it depends from the person and the context whether she will tell them or not. Lastly, a participant specifically mentioned that she has experienced prejudice from her colleagues (she is a teacher) and this hurt her, but she overcame it. Given that she grew up in a small town with no other deaf children to interact with, she felt lonely, despite her parents supporting her, and reading books became her passion and all this made her develop a mechanism of resilience which helped her a lot in her life. As it has been suggested in another study, intelligence and desire to learn are two of the internal psychological characteristics and personality traits that can enable resilience and if we want to move towards a more sophisticated understanding of resilience in the context of deaf children, we should also include an understanding of both risk and resources within the domain of social relations and social policy (Young, Green, & Rogers, 2008). Therefore, resilience can be important for social relationships and deriving from solid social relationships too, apart from other factors such as intelligence and desire to learn.

The majority of participants reported **receiving social support** to deal with their hearing difficulty mainly from their family, as well as the State or municipality providing to them financial support mainly, or others, such as sign language interpreters. Respondents often referred to the fact that they ask from family members to make a phone call on their behalf in order to book an appointment for a medical visit. The Italian national health system requires medical visits to be done through phone calls and it often emerged within this study that participants considered it as a barrier or difficulty they have to deal with in their everyday lives. Therefore, the State or municipality could improve their booking system for medical visits so that service users do not have to book only through the phone or in person a medical visit, but can also write or select from an online booking system the date and time they want to attend a medical appointment. As it has been suggested elsewhere, there is technology, for example, which can be used in health care settings that allows texting communication with regular phones, so it enables deaf people to make initial contact by telephone (through voiced text messages) and continue any conversation by text messages on the phone (SMS) (Kuenburg, Fellinger, & Fellinger, 2016).

Technological advancement of the booking system and during consultations with physicians as well could advance the level of accessibility of national health systems that could be beneficial not only for persons with hearing difficulty, but also older people, foreigners, and others. Moreover, it has been previously found that deaf persons encounter significant challenges in terms of health care utilisation, mainly related to their communication with health care professionals (Kuenburg, Fellinger, & Fellinger, 2016). It has been also reported that deaf persons have lack of health knowledge and health literacy, while especially women, ethnic minorities and older people are at higher risk for disparate health care treatment (Kuenburg, Fellinger, & Fellinger, 2016), while lack of healthcare knowledge has been reported also in another study on deaf women, together with poor access to communication with healthcare providers, among other issues (Steinberg, Wiggins, Barmada, & Sullivan, 2002). Therefore, it is important to improve accessibility to health care services and improve communication within health care services for deaf persons too. Another issue mentioned by participants under the topic of social support, is that in case of emergencies they have to ask help from others to understand an announcement on a speaker, for example, or need to have an illuminated alarm for emergencies, as one of the participants was trying to do in the school at which she is teaching. Communication in case of emergency is a known long-lasting issue that deaf persons have been facing (Kuenburg, Fellinger, & Fellinger, 2016). One of the participants mentioned receiving psychological support from a psychologist during periods of her life that she confronts challenges living with deafness, as she put it, and mentioned that her parents chose her to grow up among hearing persons and integrate socially among them, but this caused difficulties for her which she tries to overcome. Based on another study, deaf persons spend their youth trying to understand who they are in relation to the hearing society and depending on the decision of their parents on which kind of school they will attend, so do not have the opportunity to learn the sign language or have contact with other deaf persons before they become young adults themselves (Singleton & Tittle, 2000). Therefore it is understandable that they may face challenges in terms of self-identity, as it has been noted in other parts of this thesis.

In terms of financial institutional support received by participants with hearing difficulty, the majority of them reported that they had received support – whether in the present or past –, such as from the municipality, provided with a place to stay and financial help, or from the social services, or the State benefit for persons with deafness (called in Italian *indennità di comunicazione*), and one participant mentioned also using the Law 104 (mentioned above also) for justified absences from her work to attend medical visits or maintenance of her hearing aids. Two participants received no financial support from the State, although they received some kind of social support from family, and there were two other participants who received no financial or social support of any kind, with one of them not receiving any financial support or other kind of social support because she mentioned she can manage living on her own independently. However, the three participants who mentioned that they received no financial support from the State, although they tried to, had countries of origin other than Italy, therefore it can be presumed that they were not entitled to the same benefits as their Italian deaf peers, possibly due to bureaucratic issues of citizenship or other reasons. In any case, in other European countries, such as the United Kingdom, all citizens whether coming from another country or not are entitled to disability benefits equally to native British citizens. Thus, in Italy it appears that there is more that could be done at State and/or municipality level for supporting financially all persons with deafness living in it equally.

Almost all participants, apart from two, reported that they have **provided social support**, such as helping non-Italians who come to Italy to go to offices of public services or other, and one of them was appointed from the municipality to offer this support. Others expressed that they have provided support to friends when dealing with challenges of deafness or discrimination from others or in terms of friendly relationships in general, or having provided support to young people with physical disability as part of volunteer work. Nevertheless, given that the majority of respondents had provided social support to others confirms previous argument, also expressed above, that persons with disability make contributions to society in terms of support or volunteer work, but these remain invisible and unrecorded so are not attributed to them (Chenoweth & Stehlik, 2004). However, invisible contributions of persons with disability should be revealed too in order for the wider society to change their perception on persons with disability as being weak and needy, and realise that they are actually an active, supportive and productive part of the population like everyone else.

About having **trust in general in others** in their community, most of the participants expressed that it depends on the person whether they would trust this person or not, or gradually can trust others, and at first they do not trust others but when they get to know them they might do, or were uncertain. Only two participants were affirmative that they do trust others in their community, whereas two other participants mentioned they had no trust towards other people. Therefore, it appears that overall participants with hearing difficulty had moderate to low trust towards others in their community. On **institutional trust**, participants appeared having more trust in the police and justice, and less trust in the parliament. In specific, none of the participants reported trusting the parliament, while only one participant had trust in the press and most of them mentioned that they assess the news they read before trusting them. There were also participants who mentioned that they had never any involvement with these Italian institutions so they cannot say whether they trust them or not, and particularly one participant using sign language seemed very uncomfortable asking her about trust in the police and justice so did not ask her about trust in the other two institutions. Thus it can be concluded that participants had overall moderate to low trust towards institutions as well. On the **opinion of participants on specific civic norms**, it emerged that the majority disagreed with tax evasion, claiming government benefit that one is not entitled to or accepting a bribe during work, whereas three participants differentiated on the opinion about tax evasion and mentioned that it depends on the situation, for example, paying for public television when it does not have subtitles for them, or when someone has financial difficulties should pay less taxes, or when taxes are being paid but the public services are of equivalent quality. There was also a participant who mentioned she does not know anything about these situations and cannot reply to them. The same participant was uncomfortable replying about trust in institutions, so it might be that because she was not an Italian native citizen she was afraid or uncomfortable disclosing her opinion about these issues related to institutions and civic norms. As mentioned previously, general and institutional trust together with opinion on civic norms was used in this study to explore the degree of trustworthiness of participants within their community, constituting also the cognitive component of social capital (Kaasa & Parts, 2008). Relevantly, it has been argued in another study that the pervasive societal, psychological, and physical barriers which deaf persons experience limit their incidental learning opportunities and particularly their opportunities to build social capital, and it is suggested that role models for deaf persons could contribute to how they build social capital (Cawthon, Johnson, Garberoglio, & Schoffstall, 2016). Therefore, given that here participants were found to have moderate to low degree of trustworthiness, apart from civic norms on which trustworthiness within their community appeared to be more moderate to higher, it seems that the social capital of deaf participants could be strengthened more.

All participants were **active voters**, whether in Italy or their country of origin. One of them mentioned that she would like to vote also in Italy but she did not have the right yet. Half of the participants had **participated at demonstrations and signed a petition** and the topics most of them were interested in were rights of gay persons and gay pride, animal rights, and rights of persons with deafness or disability, such as employment, recognition of sign language, and others. Higher voter turnout for deaf persons compared to other types of disability emerged also in another study in the USA – thus the findings of this study are confirming this – and, according to the same source, persons with hearing impairments were more likely to have contacted (within 2008) a public official compared to persons without disability (Schur & Adya, 2013). Consequently, it appears that deaf persons have a high degree of involvement in political activities.

In terms of **employment difficulties due to deafness** as experienced by participants, it was found that four of them were in paid employment, while five of them who were not in paid employment had experienced difficulty finding a job due to limited availability of employment opportunities for deaf persons compared to hearing persons or other reasons, as some of them were not certain if their difficulty finding a job was more related to their deafness or other reasons. Only one participant who was a university student and was not working at the time of the interview mentioned that she had never experienced any difficulty finding a job and when she did an internship she did not face any problems related to deafness. The participant who did not have a problem in employment related to deafness had a hearing aid, whereas the other participants who wanted to find a job and could not were using only sign language. As mentioned also previously, it has been found elsewhere that economic well-being is worse for deaf persons compared to hearing population, since persons with hearing loss had lower household income, greater difficulties making ends meets, and were less likely to work in paid jobs compared to hearing participants (Kim, Byrne, & Parisha, 2018). The same study suggested that there should be in policies an increasing investment in better employment opportunities for deaf persons (Kim, Byrne, & Parisha, 2018). About deaf women in specific, evidence from another study suggest that when deaf women have an education level lower than bachelor’s degree they experience high underemployment and unemployment compared to deaf men and hearing peers, due to a range of factors which intervene in their occupational patterns, such as: *“sex-role stereotyping; inadequate science curriculums and weak academic preparation generally; limited career education and guidance; a* *narrow range of career options; communication difficulties and the resulting isolation from information; and ultimately, job discrimination based on deafness."* (MacLeod-Gallinger, 1992, p. 323). These factors should be addressed in terms of public employment bodies, inclusive education, private employment sector, society gender stereotypes, and deaf persons, who should try to achieve a stronger academic knowledge for themselves.

The findings on **barriers for social participation** that participants with deafness had experienced, revealed that eight of the ten participants mentioned as barriers the lack of a sign language interpreter and/or accessibility at public places and/or avoiding socialisation due to deafness, mostly regarding the lack of: a sign language interpreter or subtitles at a theatre, direct subtitling (i.e. someone typing simultaneously what a person says) at conferences or seminars or book presentations, subtitles on films at the cinema, or a sign language interpreter (not paid privately) at museums, but also not being able to hear the speaker on the station informing people about a strike, or going to the planetarium with her son in the dark without an interpreter or socialising with hearing peers. Previous evidence has shown that one of the barriers that numerous deaf persons face daily is the *"overwhelming deprivation of their right of access to information"* whether in terms of the news or health care information (Munoz-Baell & Ruiz, 2000, p. 43). To confront most of these situations in which deaf participants experienced barriers for social participation, they expressed that they have to hire a sign language interpreter to help them participate in them or avoid participating in these situations altogether, thus these barriers restrict their social participation with others, as they find alternative solutions which isolate them from the general population. For example, one participant shared a childhood memory of being isolated from other children at parties watching them chat and play while she could not interact with them, and the participant mentioned she was not living well due to this fact. Another example was mentioned by a participants who had requested from a theatre to have with her a sign language interpreter during the play and they refused it to her saying that the light shed on the sign language interpreter would be annoying; thus for aesthetic reasons a person was excluded from being able to participate in this activity. Language is the essential tool for human socialisation, however for deaf persons communication breaks down since language fails (Munoz-Baell & Ruiz, 2000). As it has been argued elsewhere, hearing loss is a social issue and not just pathology, therefore there is pressing need to remove the stigma from deafness as a pathology, and health professionals should understand more the problems related to communication, low self-concept and social functioning that deaf persons might have (Munoz-Baell & Ruiz, 2000).

Another theme that emerged here among the reported barriers for social participation were limited choices for employment of deaf persons due to communication barriers, in the sense that deaf persons would have difficulty becoming lawyers, because they need to be able to hear everything mentioned, or surgeons, because if a person has their mouth covered it would be difficult for them to do lip-reading. So the same participant suggested that deaf persons, similarly to any person having a disability, should accept their limitations, however there are also limitations not due to personal or body functions but due to the lack of support from the State. This restriction of options for employment for deaf persons has been stressed also in a previous study reporting that deaf persons have been employed in a narrower range of occupations compared to hearing workers, and deaf women, in particular, were found to be employed twice as often in jobs considered unskilled or semiskilled and at 1/3 the rate in managerial and professional positions compared to the women of the USA national population (MacLeod-Gallinger, 1992). Moreover, deaf people with an educational level lower than bachelor's degree were employed in managerial and professional specialty occupations in relatively small percentages, whereas ¼ of the general population with the same level of education were employed in such employment positions (MacLeod-Gallinger, 1992). Consequently, there appears to be a difference among hearing and deaf persons in terms of employment prospects and highest level of educational attainment, which should be addressed.

Finally, two participants expressed that they had never met any barriers for social participation due to deafness, with one of them reporting that when she finds any communication barriers she overcomes them by using applications (on the mobile phone) where she writes phrases she wants to say and uses a translator or interpretation through the mobile phone.

The **suggestions for removing barriers for social participation** for deaf persons included calling a sign language interpreter or requesting subtitling or cooperation from others for communication. An example of request of cooperation from others is when teachers have their back turned towards students during class, so the deaf student cannot read their lips, therefore she/he can ask them to turn around when they speak. It was suggested also that direct subtitling would be accessible by everyone. Similarly, participants also suggested that there should be sensitisation of the wider society and information to the wider society on diversity and deafness. In particular they suggested that sensitisation could begin from teaching school children that diversity is a positive thing, not a negative one, and adults should explain that to them, and this way the society would progress and they would become more open-minded. A campaign was also mentioned as a way to sensitise the public on deafness provided by companies and bodies that organise educational courses, because from the participant's experiences it appears that hearing persons do not know how to behave to a deaf person, and they get panicked and start shouting or making gestures or refuse communication with her. According to a previous study, hearing peers have varying attitudes toward deafness *"with negative attitudes centred on frustration, misinterpretation, communication breakdowns, fear, and lack of familiarity with deaf peers and an unwillingness to consider children who are 'different'"* (Batten, Oakes, & Alexander, 2014, p. 286). Therefore, the statements of participants here that there is need for sensitisation of children especially at schools as well as the communication breakdown as reaction to a deaf participant when trying to communicate with hearing persons emerged compliment these previous findings. Moreover, a review of relevant studies showed that communication and social competency are clearly related, but it is difficult to establish the way they interact and how they contribute to each other's development. Deaf children have been found to feel more rejected and neglected compared to their hearing peers, and also not having as many close friendships with hearing peers, while relationships with hearing peers are more sporadic for them too, but social interactions and relationships with peers is very important especially at young age (Batten, Oakes, & Alexander, 2014). Consequently, there could be initiatives at school or adult learning level, as suggested by participants here, regarding awareness of hearing persons on how to overcome communication barriers with deaf persons and have more positive attitudes towards deafness. Nevertheless, it has been also suggested that there is difference in attitudes between different kinds of disabilities, with parents and students been found to have a more positive attitude toward inclusion of physically and sensory disabled children in comparison to children with behavioural or intellectual disabilities (Stijn, Freriksen, & Vervloed, 2013). Therefore, it should be taken also into consideration that deaf respondents might believe that hearing people hold more negative attitudes towards deafness than is actually the case, as it has emerged in another study (Schroedel & Schiff, 1972). The remaining two participants, who were both using the sign language, seemed more passive in terms of dealing with barriers for social participation, as they expressed to avoid becoming involved in situations where they do not feel included or do not know what to do in order to remove the numerous barriers that exist.

Similarly to barriers for social participation, the vast majority of participants mentioned **barriers for living autonomously** related to their dependence from other persons for helping them with communication difficulties, such as a sign language interpreter (paid by public services or privately), family members (such as father, husband, partner or son), or others, such as colleagues at work. The common contexts in which they required assistance for communication were for making phone calls (such as in the case of emergency), booking medical visits, going to municipality offices, post office, train ticket desk, at the cinema or television (if there are no subtitles), or at work, when arranging with a colleague to be answering the phone instead of the participant. As expressed also above the issues of the dependency on sign language interpreters and family and others for communication, as well as lack of subtitling and difficulties making phone calls and booking medical visits have been repeatedly mentioned by participants. A previous study has highlighted the issue of communication of deaf people with emergency services, stating that getting in contact with emergency services has been challenging for deaf persons for many years (Kuenburg, Fellinger, & Fellinger, 2016).

Other barriers for living autonomously included limitations for deaf persons finding a job and variety of barriers among deaf persons. In terms of employment it was reported that for deaf persons it is easier finding a manual job than a job requiring communication with others. In addition, there are different categories, as the participant called them, among deaf persons, others communicating with sign language, others speak, and others can do both, with deaf persons only using the sign language having more difficulty finding a job. She also compared deaf persons with persons in a wheelchair and mentioned that deaf persons can live more autonomously compared to persons in wheelchair, however do not have homogeneous barriers to face such as persons in wheelchair do. Regarding the differences among deaf persons, it has been also expressed in a recent study that persons with hearing loss represent a very heterogeneous group and have different audiological and demographic characteristics among them (Goldblat & Most, 2018). Lastly, two participants mentioned that faced no barrier living autonomously, although one of them was still living with her parents so it is only her assumption that she would face no issues living autonomously, but if she did face any issues then she would live with a flatmate.

The other participant was indeed living autonomously and alone and when she was facing issues with communication she was using written language.

Regarding **suggestions for removing barriers for living autonomously**, participants suggested asking from someone to help them with communication issues, such as sign language interpreter or family member for making a phone call or going to municipality offices or attending medical/dentist visits with them. Regarding the issue of difficulty attending medical visits alone, deaf persons have been found elsewhere having substantial communication difficulties with physicians and experiencing considerable difficulties in terms of patient-physician relationship (Zazove, et al., 1993) (Munoz-Baell & Ruiz, 2000). However, they report higher physician utilisation and better health-related behaviours, such as less tobacco and alcohol consumption, but lower subjective health status (Zazove, et al., 1993). Physicians should be aware of and understand the issues deaf person face related to communication, as well as issues related to low self-concept and social functioning (Munoz-Baell & Ruiz, 2000).

Other suggestions by participants included more activities, priority, accessibility, attention and inclusion for deaf persons. For example, having equal education for children with and without hearing loss, putting on display at stations when there is a delay, on national television having more programmes with subtitles and the news during the whole day not just at specific times, while a participant mentioned that there should be greater attention to deaf persons because they are increasing in numbers in Italy, so this kind of support would make their life easier and feel included. Similarly, it has been expressed in a previous study that one of the barriers deaf persons face in everyday life is an overwhelming deprivation of their right to access of information, because mainly many of them cannot follow the news in television or read the newspaper (Munoz-Baell & Ruiz, 2000).

Finally, a suggestion from one of the participants with cochlear implant/hearing aid was to be more effort for personal growth and development from the part of deaf persons, because she was often meeting deaf persons who were slightly marginalised and cannot use the sign language, therefore she preferred to socialise with hearing persons with whom she could discuss more things. As the same participants reported, deaf persons have the instruments for personal growth, but they have to make extra effort compared to hearing persons for spiritual development too, while they have to deal also with frustration, feeling marginalised, processing these traumas and becoming stronger, so they have more difficulty in terms of personal growth. Therefore, deaf persons appear to experience difficulties for living autonomously related to marginalisation and lack of personal growth. Moreover, it has been reported elsewhere that despite documented gains in oral language, which persons with cochlear implant have, the issues with social competence remain and children with cochlear implant have been found to be delayed in terms of social competence in comparison with their hearing peers (Hoffman, Cejas, Quittner, & CDaCI Investigative Team, 2016). Consequently, there should be more interventions focusing on the social and behavioural skills of children with cochlear implant too (Hoffman, Cejas, Quittner, & CDaCI Investigative Team, 2016).

4.4 Findings across types of disability

In the subchapter above, findings were presented within each type of disability. Below are presented the findings across types of disability (i.e. mental, physical, and sensory), by Main Area and Core Themes.

Main Area 1: The body, self and disability

Core Theme 1. Biographical experience of physical health issue

1.1 Age of onset

Mental disability: Based on the findings by type of disability, it appears that the majority of participants with mental disability experienced the onset of their health issue during adolescence.

Physical disability: For physical disability the majority had congenital health issue and all of them had lost the ability to walk before the age of 18.

Sensory disability: The majority of participants with sensory disability had congenital hearing loss and all experienced it before the age of 3.

1.1 Cause of onset

Mental disability: The cause of onset for mental disability was related to difficulties with social and/or intimate relationships, related to family problems, or exhibited after an intense period of tiredness and work or within the work environment, or other undisclosed reasons.

Physical disability: Eight of the participants with physical disability had a congenital condition, with two of them stating as possible cause for their health issue, premature birth due to unexpected respiratory failure, and possibility of a virus infection during the last month of the pregnancy, while two participants with physical disability had an acquired condition due to traumatic injury (from car accident and fall on a mountain).

Sensory disability: Seven of the participants with sensory disability reported having congenital hearing loss, while three reported that their hearing loss occurred after a treatment for an illness or infection at infancy.

Core Theme 2. Coping mechanisms for disability and feelings of loneliness

Mental disability: Participants with mental disability were going outdoors or relaxing at home or turning to friends and family, relied on religious faith, or were reading or writing or waiting passively for the difficult moment to pass.

Physical disability: Those with physical disability all of them required practical assistance by family, friends and/or paid personal assistants to cope with the physical limitations for daily tasks, such as going to and returning from work, having a bath or going to the bathroom, and moving around the city in general.

Sensory disability: For participants with sensory disability it was challenging mainly trying to cope with difficulties related to communication with others, such as in order to book a medical visit or when the subway stops and cannot hear what the announcement on the speaker is about, or when there is an emergency and deaf persons cannot call for help, however, there were also participants with sensory disability who expressed that they face no difficulties coping their hearing loss.

Mental disability: Those with mental disability in **moments of loneliness** usually tried to distract themselves from negative thoughts by calling a friend and/or going out with friends, with their children or staying alone whether outdoors for a walk or indoors, crying, eating or reading something, while there were participants who were feeling comfortable with loneliness, when they did not have negative thoughts.

Physical disability: The majority of participants with physical disability preferred staying at home listening to music, watching a film, writing or drawing without mentioning any contact with others, while only four participants mentioned speaking with friends and/or going out with them when feeling lonely, and one participant mentioned that she would like to have more time alone to herself.

Sensory disability: The vast majority of the participants with sensory disability mentioned that there are moments that they are feeling lonely and at these times most of them read a book or go out alone or with their friends and try to react positively and do also other activities that cheer them up, such as hanging out with their children to chat or read a book with them, or go to an exhibition or watch a film. However, there were again those who reported seeking of being alone or need loneliness for self-reflection.

Core Theme 3. Perceived gender differences based on health issue

Mental disability: Half of the participants with mental disability reported that they had never met any man with a similar health issue before, while those who did, stated that the perceived gender differences were mostly related to men’s feelings of embarrassment due to health issue and aggressiveness as a coping mechanism to confront health issue and that it is considered more common to see a woman who is timid, than a man.

Physical disability: For participants with physical disability, they had noticed gender differences on the basis of sexual behaviour and intimate relationships, with men having more difficulty finding a partner and a steady relationship compared to women with physical disability, and have a different approach on sexuality, and others that it is easier for men to perform their toileting needs compared to women, due to the physiological differences between the male and female body. There were also participants who stated that they had never noticed any differences between men and women with physical disability.

Sensory disability: Almost all participants with sensory disability expressed that they had never noticed any gender differences among deaf persons and consider deaf men and deaf women equal. One participant expressed that there are gender differences, however more related to personality aspects.

Core Theme 4. Expectations of the future at individual level

Mental disability: The vast majority of participants with mental disability had positive expectations for the future (such as having a child, getting married, finding a job), whereas only one participant had negative thoughts when thinking about her future. Only one participant expressed expectations at country level about the State assisting more people living in it.

Physical disability: The majority of participants with physical disability reported making positive thoughts about their future (such as making a family, having stable job and travelling), but there were also those who did not have a positive outlook and were afraid of the future and what would happen to them if their informal carers (i.e. parents or partner) were not able to help them anymore. There were also some who expressed expectations at global level for a more inclusive world and helping other persons with disability through political action.

Sensory disability: The vast majority of participants with sensory disability referred to expectations related mainly to family life, companionship and work, but also some of them to hopes of improvement of the circumstances for deaf persons such as full accessibility and fewer barriers for inclusion, sign language recognition and being taught at every university, hoping, at personal level, not to have any complications with their hearing in their future. Only one participant with sensory disability mentioned she does not want to have great expectations for the future, because they might not become reality.

Main Area 2: Social relationships, social participation and disability

Core Theme 5. Social networks (structural aspects)

5.1 About size of social network and type of relationship

Mental disability: For participants with mental disability was discerned a variety on the **size of social networks**, from none to ten persons.

Physical disability: Participants with physical disability, the smallest number of ties reported was about 5 persons and the largest about 20 persons, with the majority of participants having about 10 people in their close social network.

Sensory disability: In terms of size of social network, overall, the majority of participants with sensory disability included about 5 to 10 persons in their social networks.

Mental disability: In terms of **types of social relationships**, the findings varied for participants with mental disability, with almost all participants including at least one friend, and then some also a family member or more, and partner, health professionals, neighbours, a faith tutor, and one participant mentioned God as her only friend.

Physical disability: Almost all participants with physical disability mentioned family and friends, who they had known since childhood, school, university or work. Some of the participants also referred to having friends through sports groups, such as hockey team, and from rehabilitation centre, and only one participant mentioned among her friends a health care provider.

Sensory disability: Six of the participants with sensory disability expressed that they were feeling very close to their family primarily and then to some friends, whether these friends were living also in Italy or other countries, then also other participants who also mentioned both family and friends and/or colleagues but without any difference in the degree of closeness, and one participant did not mention any family member in her social network.

5.2 Frequency and way of contact with ties of social network

Mental disability: The vast majority of participants with mental disability reported in terms of frequency of contact with social network having face-to-face contact or via texting or telephone at least once a week with their closest ties of their social network, while other participants reported having less frequent contact even with closest friends.

Physical disability: Most participants with physical disability were speaking with their close friends at least once a week, but were meeting them in person less often – the majority of them about once a month, colleagues they were seeing them every day, the most common way of contact used by participants was a mobile application (i.e. WhatsApp), and then less often they also used standard phone calls and social media (i.e. Facebook), whereas they reported having face-to-face contact the least often.

Sensory disability: The majority of participants with sensory disability expressed that they speak using text messages (mostly on WhatsApp) or video-calls with one or more of their close friends every day or almost every day, and meet often depending on their availability, but those who have friends who are not living in the same city in Italy or they live in another country they see them less often. Only two participants mentioned that they meet less often with their friends or sometimes.

5.3 Membership at organisation or volunteer groups (formal social networks)

Mental disability: The vast majority of participants with mental disability were not members of any group, such as organised or voluntary ones, and those who were members of a group, belonged to religious groups or a political party.

Physical disability: Half of the participants with physical disability stated that they have been members of associations for persons with disability and/or part of sports groups, such as hockey team, or mutual-help groups at a rehabilitation centre. One of them was a member of a trade union and the other one a political party she was a representative of. However, three participants did not belong currently to any organised or volunteer group.

Sensory disability: The majority of participants reported that they do not belong to an association or organised group, although, almost all participants using the sign language were recruited during a group meeting of an association for family psychophysical health. Only two participants expressed that they belonged to a theatrical group and the other one to a sports group of Olympic games for deaf persons (Deaflympics).

Core Theme 6. Daily activities

Mental disability: Most participants with mental disability reported doing daily activities which do not involve meeting with friends or colleagues socially, and these activities are mostly done indoors and by themselves, such as reading, watching television, drawing, and studying.

Physical disability: Participants with physical disability stated doing various daily activities and at leisure time the majority of them mentioned watching a film at home or at cinema, while housework was mainly done by their mother, partner, or care assistant, and six of them mentioned going out socially as part of their daily activities, whereas four of them did not. Only two of the participants stated that they were currently doing or planning to do a sports-related activity.

Sensory disability: Half of the participants with sensory disability reported meeting with their friends regularly, and mostly taking care of their child or husband, doing housework, going shopping, going for walks, travelling to other Italian cities to meet friends, among others. The other half of the participants did not mention meeting with friends regularly.

Core Theme 7. Disability-based homophilious or heterophilious social networks

Mental disability: The vast majority of participants with mental disability had heterophilious social networks, in terms of disability, in other words that their social networks were mainly heterogeneous since they were not composed primarily by persons with a mental health issue as well, thus demonstrating stronger bridging social capital and weaker bonding social capital.

Physical disability: The majority of participants with physical disability stated that they had both friends with and without disability within their social networks, and the other participants that they had only one or no friends with disability. Thus, all participants with physical disability had heterophilious social networks, indicating stronger bridging social capital, whereas weaker bonding social capital.

Sensory disability: For participants with sensory disability, all of those who were using the sign language and one of the speaking participants were found to have homophilious networks or heterophilious networks mainly consisting of other deaf persons too, whereas three of the speaking participants had heterophilious social networks consisting mainly of hearing persons. Thus, deaf participants using the sign language demonstrated weaker bridging social capital and stronger bonding social capital, whereas the majority of speaking deaf participants had more heterophilious social networks, with stronger bridging social capital, and weaker bonding social capital.

Core Theme 8. Change of attitudes of social network due to disability

Mental disability: The majority of participants with mental disability reported having received negative change of attitude from others and therefore ended the relationship with them or avoided social contact due to their health issue or their difficulty with social relationships, two others reported that at the beginning their social network had a negative change of attitude, such as fear, due to their mental health issue, but with time overcame it and one participant had not received any negative change of attitude because she was straightforward with her relationships from the start about her mental health issue.

Physical disability: Among the participants with physical disability there were those who stated that they had never experienced any change of attitude from others, because their health issue developed too early in their life, whereas others had experienced negative change of attitude from others when they realised that the participant had a physical disability, or when presented to a group of people who do not know how to react towards them, and possibly someone becoming distant after realising the participant has a disability.

Sensory disability: Three participants with sensory disability reported having experienced change of attitude of others and/or prejudice due to their deafness.

Core Theme 9. Social support (received and provided)

9.1 Received social support

Mental disability: The vast majority of participants with mental disability reported having received social support from health and care professionals, such as from the CPS, psychiatrists, psychologists, and care worker, while two participants reported seeking first to resolve any difficult moments on their own, and receiving support from family member or flatmate and health professionals. Only two of the participants mentioned family as a source of provision of social support, and one participant stated that she does not receive any social support from anyone. In terms of financial support received from the State, four participants were receiving disability benefit or financial support from social assistants, while six of them did not receive any financial support, for fear they might lose their driving licence or have difficulty finding a job, or because the price of medication is quite low, or for other undisclosed reasons.

Physical disability: The majority of participants with physical disability received social support mainly from their mother or partner and their friends (i.e. informal support), for performing everyday tasks. The rest of the participants were more independent, at least financially, from their family and some of them did not receive disability benefit or only a carer's allowance or neither. These participants received support partly in order to perform daily tasks from parents or partner, and mainly from care assistants and/or health professionals or other persons (i.e. formal support) under payment – privately or through institutional support. All participants received institutional financial support, whether disability benefit or carer's allowance or both, apart from one participant, who due to having a well-paid job she was not eligible for any financial support from the State.

Sensory disability: The majority of participants with sensory disability reported having received social support to deal with their hearing difficulty mainly from their family, as well as the State or municipality providing to them financial support mainly, or others, such as sign language interpreters. Another issue mentioned was that in case of emergencies they have to ask help from others to understand an announcement on a speaker, for example, or need to have an illuminated alarm for emergencies, as one of the participants was trying to do in the school at which she is teaching. One of the participants mentioned receiving psychological support from a psychologist during periods of her life that she confronts challenges living with deafness. The majority of them also received formal support, for example from the municipality, social services, or the State the benefit for persons with deafness (called in Italian *indennità di comunicazione*), and one participant mentioned also using the Law 104. Two participants received no financial support from the State.

9.2 Provided social support

Mental disability: Participants with mental disability stated that most of them provided volunteer moral (to clients during employment as beautician, or in terms of reciprocity within interpersonal relationships) and/or practical support to others (through their paid employment or volunteer work, such as assisting in housework other family members, or making packages or cakes for people in need, and giving money to beggars), and only one participant stated that had never provided any support to others.

Physical disability: Many of the participants with physical disability stated that they also provided social support to others, whether a more formal support, such as within the framework of associations/organisation of persons with disability and/or through political activity, for example to promote issues on accessibility at municipality level and practical assistance at national and international events of a sport group. There were also participants who reported that they provided more informal support, in terms of psychological support to others and encouragement, mainly to young persons and others with the same health issue, such as giving a talk or just chatting with them at a hospital or rehabilitation centre.

Sensory disability: Almost all participants with sensory disability, apart from two, reported that they had provided social support, such as helping non-Italians who come to Italy to go to offices of public services or other, while some expressed that they have provided support to friends when dealing with challenges of deafness or discrimination from others or in terms of friendly relationships in general, or having provided support to young people with physical disability as part of volunteer work.

Core Theme 10. Trust

10.1 General trust

Mental disability: Six of the participants with mental disability reported having little or no trust towards other people in general within their community, and four that they do trust others, however, only one of them reported having a lot of trust in other people, thus could be assumed that participants reported a moderate to low overall level of trust towards others in general.

Physical disability: Seven out of the ten participants with physical disability reported that they trust other people in their community in general, whereas only three participants stated that they do not trust others at all, or not always, or it depends from time to time. Thus it can be assumed that overall participants with physical disability showed moderate to high levels of general trust.

Sensory disability: Most of the participants with sensory disability expressed that it depends on the person whether they would trust this person or not, or gradually can trust others, and at first they do not trust others but when they get to know them they might do, or were uncertain. Only two participants expressed that they do trust others in their community, whereas two other participants mentioned they had no trust towards other people. Consequently, overall participants had moderate to low trust towards others in their community.

10.2 Institutional trust

Mental disability: Participants with mental disability had moderate to low overall level of institutional trust, with most of them reporting trust in the police whereas only one trusting the press and parliament, and parliament was the institution they trusted the least. Two of the respondents stated that they had no trust in any of the four institutions.

Physical disability: Overall participants with physical disability trusted the most the police, and the least the parliament, while for the justice and the press they seemed more divided in their responses. It can be concluded that they had moderate to high level of trust.

Sensory disability: Participants with sensory disability appeared having more trust in the police and justice, and less trust in the parliament. In specific, none of the participants reported trusting the parliament, while only one participant had trust in the press and most of them mentioned that they assess the news they read before trusting them. There were also participants who mentioned that they had never any involvement with these Italian institutions so they cannot say whether they trust them or not. Overall participants had moderate to low trust towards institutions.

Core Theme 11. Opinion on specific civic norms

Mental disability: Participants with mental disability were found to have similar opinion on civic norms, apart from two participants who stated that for two of the civic norms it would depend from the circumstances whether they would agree with them or not.

Physical disability: The vast majority of participants with physical disability disagreed about claiming government benefit if one is not entitled to it and avoiding paying taxes in total, while about accepting a bribe during the course of one's duties, all participants disagreed with this statement. The only different opinions on civic norms emerged from two participants, with one of them agreeing initially on claiming benefits one is not entitled to and another saying that it depends for her on tax evasion.

Sensory disability: The majority of participants with sensory disability disagreed with tax evasion, claiming government benefit that one is not entitled to or accepting a bribe during work, whereas three participants differentiated on the opinion about tax evasion and mentioned that it depends on the situation. There was also a participant who mentioned she does not know anything about these situations and cannot reply to them.

Core Theme 12. Political participation

12.1 Voting at elections

Mental disability: Seven participants with mental disability were active voters.

Physical disability: Almost all participants with physical disability stated that they are active voters, apart from one who did not reply to this question.

Sensory disability: All participants with sensory disability were active voters, whether in Italy or their country of origin. One of them mentioned that she would like to vote also in Italy but she did not have the right yet.

12.2 Participation at demonstration or signed a petition

Mental disability: Half of the respondents reported that they have never participated at any demonstration and have never signed a petition. Three reported that they have both participated at demonstrations and signed petitions, whereas two participants stated that they signed petitions but never participated in a demonstration. The petitions they had signed were relevant to environment, animals, the rights of persons at international level, the rights of women, or children with health problems due to war, or persons who become evicted, or employment in general.

Physical disability: For participants with physical disability, it emerged that all of them had signed a petition and half of them had participated at a demonstration. The topics they were more interested in were relevant to the rights of persons with disability, environment/ecology/climate change, animals, and bio-tests/experiments, but participants were also interested in issues related to autonomy, mobility, violence against women, same-sex marriage, human rights, politics – in general –, and one participant mentioned protesting against the pollution of a town from asbestos.

Sensory disability: Half of the participants with sensory disability had participated at demonstrations and signed a petition and the topics most of them were interested in were rights of gay persons and gay pride, animal rights, and rights of persons with deafness or disability, such as employment, recognition of sign language, and others. Three participants reported that they had signed a petition, but never participated at a demonstration, and two participants, both using sign language, had never participated at a demonstration or signed a petition.

Core Theme 13. Employment difficulty due to health issue

Mental disability: Four of the participants with mental disability had a full-time job, whereas six participants did not have a job in their field, with three of them having faced difficulties due to their mental health issue during their employment or for finding employment, and the rest of participants, who did not have a job in their field, were not looking for a job (for example due to pregnancy) or could not find a job due to non-health-related reasons.

Physical disability: For participants with physical disability, eight of them were employed and the other two were university students – not actively looking for a job in their field yet. Both of them reported that they had experienced difficulty finding a job mainly due to inaccessibility of the workplace for wheelchair users.

Sensory disability: Four participants with sensory disability were working in paid employment, while five of the participants who were not in paid employment had experienced difficulty finding a job due to limited availability of employment opportunities for deaf persons compared to hearing persons or for other reasons, as some of them were not certain if their difficulty finding a job was more related to their deafness or other reasons. On the other hand, a participant who was a student mentioned that she had never experienced any difficulty finding a job and when she did an internship she did not face any problems related to deafness.

Core Theme 14. Barriers for social participation and suggestions for removing them

Mental disability: In terms of **barriers for social participation**, four of the participants with mental disability had never experienced any discrimination due to their mental health issue, whereas the remaining six participants had experienced prejudice, discrimination, stigmatisation, and/or lack of empathy towards them from others, on the basis of their mental health issue, within their informal and formal networks, but also from the wider social network, and there were also participants that it was their choice to avoid social participation due to the nature of their mental health issue.

Physical disability: All participants with physical disability mentioned barriers for social participation which were related to physical environment and accessibility issues, while almost all of them – apart from two – mentioned also respective barriers related to social environment. All participants reported barriers they have encountered within public spaces of the physical environment of the city of Milan, making it difficult for persons in a wheelchair to move around the city, mainly concerning inaccessible public transport services, inaccessible public (such as public services, museums) or private (such as company offices, cinemas, bars) buildings, inaccessible public restrooms, pavements without dropped kerbs/inclinations, and lack of appropriate elevators or stairlifts for wheelchair users within buildings and the subway. In terms of barriers related to the social environment, participants mainly referred to prejudice and mentality barriers that people of the wider society have against persons with disability.

Sensory disability: Eight of the ten participants with sensory disability mentioned as barriers the lack of a sign language interpreter and/or accessibility at public places and/or avoiding socialisation due to deafness, mostly regarding the lack of: a sign language interpreter or subtitles at a theatre, direct subtitling (i.e. someone typing simultaneously what a person says) at conferences or seminars or book presentations, subtitles on films at the cinema, or a sign language interpreter (not paid privately) at museums, but also not being able to hear the speaker on the station informing people about a strike, or going to the planetarium with her son in the dark without an interpreter or socialising with hearing peers. Participants using the sign language suggested that they often need a sign language interpreter, whereas speaking participants focused more on the lack of subtitling. Another theme that emerged here among the reported barriers for social participation were limited choices for employment of deaf persons due to communication barriers, in the sense that deaf persons would have difficulty becoming lawyers, because they need to be able to hear everything mentioned, or surgeons, because if a person has their mouth covered it would be difficult for them to do lip-reading. Finally, two participants expressed that they had never met any barriers for social participation related to deafness.

Mental disability: The **suggestions on removing barriers for social participation** as reported by participants with mental disability, were mostly public-oriented, such as education, campaigns, understanding, and change of mentality of wider social networks on mental health issues, as well as implementation of more projects for enhancement of social life of persons with mental health issues, but also individual-oriented suggestions, such as self-confidence, self-worth and self-acceptance of mental health issue by the person experiencing it.

Physical disability: Suggestions for removing barriers related to social participation as reported by participants with physical disability included implementation of existing laws on accessibility and denouncement of accessibility problems to institutions, as well as change of mentality of the public, more public visibility of and communication about persons with disability, education of the public, and life projects for persons with disability.

Sensory disability: By participants with sensory disability the suggestions for removing barriers for social participation reported were calling a sign language interpreter or requesting subtitling or cooperation from others for communication. Participants also suggested that there should be sensitisation of the wider society and information to the wider society on diversity and deafness. Lastly, two participants, who were both using the sign language, seemed more passive in terms of dealing with barriers for social participation, as they expressed to avoid becoming involved in situations where they do not feel included or do not know what to do in order to remove the numerous barriers that exist.

Core Theme 15. Barriers for independent/autonomous living and suggestions for removing them

Mental disability: In terms of **barriers for living autonomously/independently**, three participants with mental disability reported no barrier for living autonomously, while four other participants could live autonomously if they had a job or financially were able to sustain their expenses independently, but two of them had difficulty finding a job due to their mental health issue. The other three participants did not have homogeneity in their responses regarding barriers for autonomous living, which were related to their mental health issue, such as being institutionalised or lack of right to have a driving licence, or due to other reasons, such as bureaucratic difficulty for having meal for children at school being a foreigner or disliking doing housework or not being allowed to live alone yet by a family member. Overall participants experienced barriers of autonomy due to lack of a job in their field or adequate financial resources, and they expressed or hinted that they would prefer living autonomously without their family of origin, but were not certain if they would be able to do that due to their mental health issue or for other reasons.

Physical disability: The majority of participants with physical disability reported as barriers for autonomous living the fact that they had to depend on their family and/or partner for support with daily tasks and/or needed more financial support to be able to cope with the expenses of care assistance due to their disability without the help of their family or partner. Physical environment and accessibility barriers also emerged as barriers for autonomous living, as well as the lack of a common national law in Italy on the distribution of funds for persons with disability, and the fact that independent living for persons with disability is not adequately considered in Italy as in other countries, plus, there are bureaucratic barriers in Italy for getting things done. Cultural barriers mentioned included that others are not aware that persons with disability can also live independently have a partner and a life like everyone else.

Sensory disability: The barriers for autonomous living mentioned by the vast majority of participants with sensory disability related to their dependence from other persons for helping them with communication difficulties, such as a sign language interpreter (paid by public services or privately), family members (such as father, husband, partner or son), or others, such as colleagues at work. The common contexts in which they required assistance for communication were for making phone calls (such as in the case of emergency), booking medical visits, going to municipality offices, post office, train ticket desk, at the cinema or television (if there are no subtitles), or at work, when arranging with a colleague to be answering the phone instead of the participant. Other barriers for living autonomously included limitations for deaf persons finding a job and variety of barriers among deaf persons. Lastly, two participants mentioned that faced no barrier living autonomously.

Mental disability: About **suggestions on removing barriers for autonomous/independent living** by participants with mental disability, two of them who had experienced barriers for living autonomously suggested that these barriers could be removed by change of attitude of others towards them, such as with more openness and understanding by others, but also with a change of attitude of themselves regarding circumstances in their own lives, such as overcoming fear to live alone or finding alternative solutions to barriers. The other two participants who faced barriers for living autonomously suggested that these barriers could be removed by more support from the State in terms of the amount of the disability benefit and the protection of the rights of vulnerable groups in practice within the employment sector, since in practice the laws are not being implemented.

Physical disability: By participants with physical disability it was suggested that there should be change of mentality of the wider society towards persons with disability so that people would understand that they are only seated and have a difficulty, they are not a problem, and start thinking of them in a different way. Removing barriers related to accessibility would help them move around the city calmly and more autonomously, such as by improving problematic accessibility to public transport, removing architectural barriers in new constructions, and designing buildings and spaces being both accessible and pleasant to the eye for persons without disability too, with cultural education of the project designers. It was a also suggested that they should be provided with financial support to be able to live autonomously, and seriously invest on employment of persons with disability because work is dignity, as well as young persons with disability to have advanced level of education that would help them live independently. At the same time, persons with disability should denounce issues to institutions and there should be institutional support for accessibility as well as a team at municipality level including persons with disability for trying to find ways to improve accessibility in the city. Suggestions were also directed to their peers for self-empowerment and finding the resources to reach autonomy and not be focusing only on disability.

Sensory disability: Participants with sensory disability suggested asking from someone to help them with communication issues, such as sign language interpreter or family member for making a phone call or going to municipality offices or attending medical/dentist visits with them. Other suggestions included more activities, priority, accessibility, attention and inclusion for deaf persons, for example, having equal education for children with and without hearing loss, putting on display at stations when there is a delay, on national television having more programmes with subtitles and on the news during the whole day not just at specific times. Finally, a suggestion from one of the participants was to be more effort for personal growth and development from the part of deaf persons, because some of them are slightly marginalised. However, deaf persons have the instruments for personal growth like everyone else, but they have to make extra effort compared to hearing persons for personal growth and spiritual development too, as they have to deal also with frustration, feelings of marginalisation, and processing these traumas and becoming stronger.

4.5 Patterns within and across types of disability

4.5.1 Ideal types of participants

As mentioned in the Methodology chapter above, the Weberian ideal type (Weber, 1949) was employed here to facilitate the interpretation of findings in terms of comparisons across and within the types of disability. The ideal types were formed based on the common characteristics and elements found within the data in respect to the main concepts of the aim of this study, meaning, social relationships and social participation. In specific, the ideal types were based on the size of social networks and frequency of interactions with the ties of their social networks, similarly to previous research using these two aspects in order to measure social participation (Sparling, Stutts, Sanner, & Eijkholt, 2017). Based on that, the most evident patterns within and across the types of disability explored here were:

Socially high-active persons: in terms of engagement with social networks, thus having more friends and being often involved in various social, cultural and/or political activities with others and communicating with more than one friend often (outside work or university or rehabilitation centre). The participants who were included in this ideal type were: six with physical disability [Diana (P), Penny (P), Phoebe (P), Janet (P), Christine (P), Rebecca (P)]; three with sensory disability [Monica (S), Claire (S), Shirley (S)]; and two with mental disability [Lily (M) and Elizabeth (M)].

Socially low-active persons: in terms of engagement with social networks, thus having a small number or no friends and not being often involved in various social, cultural and/or political activities with others and communicating with more than one friend often (outside work or university or rehabilitation centre). The participants who were included into this ideal type were: three with mental disability [Mary (M), Amelia (M), and Jennifer (M)]; one with physical disability [Amy (P)]; and one with sensory disability [Nancy (S)].

These two ideal types provide some sense of the level of the main aspects of social relationships and social participation. Participants with physical disability were the ones across the three types of disability who were the most within the socially high-active ideal type, in contrast to participants with mental disability who were the most that belonged to the socially low-active ideal type across the types of disability. This finding indicates that potentially persons with mental disability encounter greater difficulties in social relationships and social participation due to their health issue possibly in interaction with factors of the social environment and personal factors, as mentioned also by the participants with mental disability in this study.

It has to be noted that based on the inclusion criteria of this study were recruited only participants who already had a role of relative autonomy, for this reason none of the participants was socially inactive or completely isolated from the wider society, thus participants did not have any major differences in terms of social participation to extremes, but to a moderate extent, again, according to the inclusion criteria.

4.5.2 Sociodemographic characteristics

The data were also explored in terms of similarities of sociodemographic characteristics within and across types of disability as well, based on the patterns discerned on sociodemographic characteristics under each theme and across types of disability. The comparison of the sociodemographic characteristics of respondents across types of disability was based on the patterns discerned within each type of disability. In particular, the following patterns were discerned across types of disability for the following themes, based on the sociodemographic characteristics of respondents:

- **Core Theme 4.** ***Expectations of the future at individual level:*** Participants with mental and physical disabilities, who expressed fear or negative thinking about their future, were living with their parent(s). The fear and negative thinking reported here was expressed because participants with physical disability stated that they were feeling afraid that they would not be able to cope with daily challenges without the help of their parents, due to financial and practical difficulties for completing daily tasks on their own. For the participant with mental disability who stated that she has negative thinking about the future, it was because currently she said that she has no solid base to say what she will be doing in 10 years, so can only think of it in a negative way and prefers not to programme anything. Nevertheless, it appears that it is not common for Italian young adults in general to leave their parental home in early adulthood. Data at European level from 2017 (Eurostat, 2018) reveal that in the EU Nordic Member States young people leave the parental household in their early 20s [Sweden (21.0 years), Denmark (21.1 years) and Finland (21.9 years)], whereas in Italy young adults leave their parental household at the age of 30, on average. Therefore, one of the reasons that these participants felt fear or negativity about their future could be also due to the fact that they were still living with their parents, possibly because apart from their financial and practical worries for daily tasks, they were also insecure about leaving the parental nest and becoming independent – which apparently is not uncommon for young adults in Italy, compared to young adults living in Northern Europe, who seem to become more independent at an earlier age.
- **Core Theme 5.** ***Social networks (structural aspects):*** On the size of social network, participants with mental and physical disabilities, who reported the largest number of persons within their close social networks, were never married. This finding is not in line with a recent meta-analysis on social network changes and life events across the life span (Wrzus, Hänel, Wagner, & Neyer, 2013), according to which two of the selected studies reported that married participants had larger social networks compared to single participants, whereas only one study was found to report the opposite effect.

Regarding formal social networks, in terms of membership to volunteer or organisation groups, all participants from all three types of disability, who belonged to such groups (i.e. trade union or political, sport, theatre, or religious groups), were working – in paid employment. This finding confirms previous evidence that group membership is higher amongst Europeans who have a higher education and household income, and who are employed – compared to those being unemployed (Christoforou, 2011). Additionally, individuals facing unemployment appear to have a strong disincentive to participate in social groups, therefore expansion of education and employment opportunities could increase their incentive to participate in groups and enhance the stock of social capital (Christoforou, 2011).

- **Core Theme 8. *Change of attitudes of social network due to disability:*** Participants with physical disability, who experienced negative attitudes from others, and participants with mental disability, who had experienced negative change of attitude from others and did not have contact with these people anymore, had never been married. This could have emerged possibly because unmarried women might be less self-confident or have less patience with other people who demonstrate negative change of attitudes towards them due to their disability, or for other reasons. However, the aspects of self-confidence and patience with other people were not explored in this study.
- **Core Theme 9. *Social support (received):*** Participants with mental and physical disabilities who received formal and/or financial support from the State were older than 32 and 30 years old, respectively. The reason for younger participants with mental and physical disability not having received formal and/or financial support from the State, could be related to the fact that younger participants rely more on informal support (from family members/partner/friends), whereas older participants might be more independent from their families (e.g. through work or education) and thus require more formal support from the State and less informal support. For younger participants with mental disability, it might also be that they choose to conceal their mental health issue – as it emerged in this study too – and avoid declaring to formal institutions their mental disability either for finding employment or for keeping their driving licence or for other undisclosed reasons.
- **Core Theme 10. *Trust:*** Participants with mental and physical disabilities, who reported having trust towards other people in general, were older than 33 and 30,

respectively. Previous research has shown that there is a universal positive association between age and five types of trust (i.e. generalised; family; friends; neighbours; and strangers) across 38 countries (including Italy) (Li & Fung , 2013). One explanation for this could be that age differences in trust may be mediated by future time perspective, in the sense that emotional meaningful goals are essential in later adulthood because of older adults' limited future time perspective (Li & Fung , 2013). Another explanation could be that later adulthood is accompanied by inevitable physical and cognitive decline, therefore older adults rely more on other people's help through enhanced trust toward others, instead of struggling to accomplish all tasks by themselves (Li & Fung , 2013).

- **Core Theme 14.** ***Barriers for social participation:*** Participants with mental and sensory disabilities, who reported that they had never experienced barriers for social participation, had an upper or post-secondary school certificate as highest level of education. Given that the upper or post-secondary school certificate was the intermediate level of education reported here, and not the lowest (i.e. lower secondary school certificate) or the highest (i.e. Bachelor's or Master's degree) one, no justified assumptions can be made in relation to this finding.

To summarise, from the above patterns discerned across types of disability based on sociodemographic characteristics of respondents, it can be concluded that, for all three types of disability, those who belonged to a formal social network were all working. In addition, for participants with mental and physical disabilities, those who had received formal support and trusted other people in general were older than 30, those who had larger social networks and experienced negative attitudes from others due to their health issue were never married, and those who expressed fear or negative thinking about their future were living with their parent(s). A pattern was also discerned among participants with mental and sensory disabilities, on that those who had never experienced any barriers for social participation had an upper or post-secondary school as highest education level.

4.5.3 Visible versus invisible disability

The fact of concealing one's health issue emerged mostly by participants with mental disability, and fewer participants with sensory disability mentioned that they do not always disclose from the beginning to others that they have a hearing difficulty, whereas persons with physical disability did not mention concealing their health issue from others. However, this can be attributed to the fact that physical disability is a visible disability, whereas mental disability is an invisible one, thus the persons can conceal it more easily and choose whether to disclose it or not, even in long-term social relationships. Hearing loss is not always an invisible disability as it can be also visible if the deaf person has a hearing aid visible to others, so it can be both an invisible or visible disability depending on the context too, but in any case cannot remain invisible in a long-term social relationship. From the findings here it appears that participants with a visible physical disability were far more socially high-active compared to participants with an invisible mental disability, whereas persons with sensory disability belonged somewhere in the middle in terms of level of social participation. Nevertheless, it seems contradicting and unexpected the finding that persons with a visible disability were more socially active compared to persons with an invisible disability, who were less socially active, since all persons with physical disability mentioned a lot more barriers for social participation – both in terms of physical and social environment – compared to persons with mental disability, who mentioned fewer barriers for social participation and four of them mentioned that they do not experience any barrier for social participation at all. Although this finding was unexpected, it partly confirms previous findings from a study on women with physical and sensory disability, which found that the meaning of leisure and the constraints women with physical disability had in respect to leisure activities, such as time, money, ethic of care, and safety, were broadly similar to those of women without disability, but only sometimes women with physical disability had to do things differently because their constraints were magnified (Henderson, Bedini, Hecht, & Schuler, 1995).

Moreover, differences among invisible and visible disability were also discerned in respect to informal versus formal social networks as sources of social support, as perceived by participants. In particular, family was reported by participants with physical and sensory disability as the main source of the social support they received, whereas for participants with mental disability the main source was health professionals, as only two of the participants with mental disability mentioned family as a source of social support. This could be attributed to the fact that, as some of them reported, their mental distress could have roots in issues related to their family relationships. Therefore, it emerged that participants with physical and sensory disability relied more on their informal social network, whereas persons with mental disability relied more on their formal social network for support. This finding partly confirms previous evidence (Magliano, et al., 2002) showing that in Northern Italy (including Milan) the burden of families of persons with severe mental distress is lower, whereas in Southern Italy it appears that there is a larger and more supportive social network for persons with severe mental distress, thus the burden for families is higher. According to this evidence, persons living in Milan can be expected to receive lower social support, compared to other parts of the country, however having access to more professional resources for supporting patients' relatives, compared to the Southern parts where these resources have been found to be poor (Magliano, et al., 2002).

Despite the above differences discerned among participants with physical and mental disability mainly, similarities emerged as well, such as that almost all participants with physical and mental disability – apart from one participant with mental disability [i.e. Rachel (M)] – had heterophilious social networks, whereas the majority of participants with sensory disability had homophilious social networks or heterophilious social networks including mainly other deaf persons.

Furthermore, some of the participants with mental and physical disability referred to prejudice from the wider society. Those with mental disability faced prejudice due to their mental health issue being considered as 'dangerous' or 'crazy' by others or others being afraid of their health issue or felt discriminated from co-members of a group (e.g. a religious group). As previous evidence has shown, it appears that many people of the wider population have difficulty understanding that invisible disability can be as debilitating as visible disability (Banks & Kaschak, 2003). Participants with physical disability faced prejudice from others such as people looking at them badly when asking for their help, being considered as handicapped by others which hurts them, people thinking of them as 'poor ones', needy and not being able, people being ignorant about persons with disability, for example that they can have a baby as well, and was also mentioned as an example the incident of bullying of a child with physical disability that a participant had heard in the news. Not only in terms of prejudice, but also discrimination was mentioned by both participants with mental and physical disability, such as that they experienced discrimination in the workplace due to their mental or physical health issues.

To conclude, on the issue of concealing one's disability, it has been previously argued that it is not unusual for persons with invisible disabilities to keep their disability *"entirely secret from everyone else apart from their closest friends"* (Wendell, 2006), while women with visible disability have previously reported that other people ask them more often about their medical diagnosis, physical appearance and sexual and intimate aspects of their life than people are willing to listen to them and try to understand their experience of disability (Wendell, 2006).

4.5.4 Politically active versus politically inactive participants

Other patterns were discerned among types of disability as well, such as that participants with physical disability were the ones mostly politically active, whether directly by a position of political authority or an association for persons with disability or a trade union, or by having participated in demonstrations and/or signed petitions on the rights of persons with disability. Then they were followed by participants with sensory disability who some of them had also participated in actions in favour of their rights, whereas only one participant with mental disability [i.e. Lily (M)] mentioned active political participation and providing support to other persons with mental disability. This finding partly contradicts previous evidence from a study on persons with visual, hearing, mobility, and mental disabilities, according to which persons with physical mobility issues were the ones having the lowest voter turnout, whereas persons with hearing difficulty were the only disability group that did not have lower voter turnout compared to persons without disability (Schur & Adya, 2013). In this thesis as well, all participants with hearing difficulty were active voters, but also all of the participants with physical disability were active voters, whereas three participants with mental disability were not active voters. In any case, participants with physical disability were also more actively involved in other political actions apart from voting, compared to participants with sensory and mental disability. As it has been argued elsewhere, although there is an obvious interrelationship between social participation and civic participation, those who have most to gain from civic and community participation seem to be the ones most isolated from it, as social inequalities exist between persons with disability and persons without any disability in terms of social participation and other life areas too (Barnes & Mercer, 2010).

4.5.5 Speaking versus signing deaf participants

There were no major differences discerned among participants with sensory disability who had a hearing aid and those who were using sign language to communicate with others. One of the differences discerned was that under the theme of ‘Disability-based homophilious or heterophilious social networks’ all participants using the sign language were found to have homophilious networks or heterophilious networks mainly consisting of other deaf persons too, whereas speaking participants (with hearing aid) had entirely heterophilious social networks, consisting of hearing persons of the wider population.

The other difference discerned among speaking and signing deaf persons was under the theme of ‘Employment difficulty due to health issue’ where all participants who experienced difficulty finding a job were using sign language and Italy was not their country of origin, whereas the only speaking deaf participant who did not have a job mentioned that she had never experienced any employment difficulties. This could be due to the fact that many jobs require verbal communication with others, and as one of the participants pointed out [i.e. Monica (S)] deaf persons have limited choice of employment due to their hearing difficulty.

4.5.6 Social media usage for communication

A common aspect of social networks across the three types of disability was that the vast majority of participants reported using social media resources to communicate with the ties of their social network, apart from traditional phone calls, whether a specific mobile texting application (i.e. WhatsApp) or online social media platform (i.e. Facebook) both commonly used for communication by young people in Italy nowadays. This confirms findings of a previous study on young adults with disabilities as well, according to which most of their participants used social media in order to connect with their friends too (Schneider & Hattie, 2016). Nevertheless, this finding of the thesis matches previous evidence on young people’s social media usage, of the wider population, that predominant users of social networking sites are young adults, with ¾ of adult internet users of below the age of 25 having a profile on a social media site (Correa, Hinsley, & de Zúñiga, 2010).

4.5.7 Comparisons based on social capital components

In this subchapter are summarised and compared the main findings which were specifically considered in this thesis as aspects of social capital – given that it was used as a sensitizing concept in this thesis, as mentioned above.

4.5.7.1 Structural aspects of social networks

i) Size of social network

Participants with physical disability had the largest size of reported social networks (5-20 persons), followed by participants with sensory disability (5-10 persons) and the smallest size of social networks were reported by participants with mental disability (0-10 persons).

ii) Type of relationship with social network ties

Almost all participants mentioned both family and friends within their social networks, who they had known since childhood, school, university, work, religious or sports or rehabilitation groups, and the minority included health professionals and health care providers in their social network, and one person mentioned God within her social network. No particular differences were discerned across types of disability.

iii) Frequency and way of communication with social network ties

The vast majority of participants with mental disability reported in terms of frequency of contact with social network having contact at least once a week, most participants with physical disability were speaking with their close friends at least once a week too, while the majority of participants with sensory disability expressed that they speak with one or more of their close friends every day or almost every day.

The most commonly way of communication used by participants was face-to-face contact or via telephone, WhatsApp and/or Facebook.

iv) Membership at organisation or volunteer groups (formal social networks)

The vast majority of participants with mental disability were not members of any group, such as organised or voluntary ones, and those who were members of a group, belonged to religious groups or a political party. On the contrary, the vast majority of participants with physical disability were members of associations for persons with disability and/or part of sports groups, such as hockey team, or mutual-help groups at a rehabilitation centre, one of them was a member of a trade union, and another one member of a political party she was a representative of. The majority of participants with sensory disability reported that they do not belong to an association or organised group, and only two expressed that they belonged to a theatrical group and the other one to a sport group of Olympic games for deaf persons (Deaflympics); however, as mentioned above, the majority of deaf participants were recruited through associations of persons of disability of which they were attending group meetings.

4.5.7.2 Cognitive aspects of social networks

i) General trust

Most of the participants with mental disability stated that they had little or not trust towards other people in general, most of the participants with physical disability said that they had trust in other people in general, while most of the participants with sensory disability expressed that it depends on the person whether they would trust this person or not, or gradually can trust others.

ii) Institutional trust

All participants across all three types of disability had more trust towards the police and trusted the least the parliament.

iii) Civic norms

Participants with mental disability were found to have similar opinion on civic norms, apart from two participants. Similarly the vast majority of participants with physical disability had the same opinion on the civic norms apart from two participants, while the majority of participants with sensory disability had the same opinion on civic norms too apart from three participants who differentiated on the opinion about some of the civic norms and one who had no opinion on the civic norms.

Based from all evidence above on structural and cognitive aspects of social networks of the participants, it can be concluded that participants with physical disability had higher level of social capital overall compared to the other two types of disability, followed by sensory disability participants and the lowest level of social capital can be attributed to participant with mental disability, mainly due to their moderate to low degree of trust towards other people in the community. Nevertheless, it appears that across types of disability there were also several similarities in terms of social capital components, thus the differences across types of disability were not major in terms of social capital.

4.5.7.3 Bonding and bridging social capital

Regarding bonding and bridging social capital (Putnam, 2000) – based on having homophilious or heterophilious social networks – it emerged that participants with mental and physical disability both had stronger bridging social capital and weaker bonding social capital (meaning more heterophilious and less homophilious social networks), whereas participants with sensory disability were divided on this, since those using sign language had weaker bridging social capital and stronger bonding social capital, whereas the majority of speaking deaf participants had stronger bridging social capital and weaker bonding social capital as well.

Therefore, it can be assumed that participants using sign language for communication were not included in the wider society as the rest of the participants from all three types of disability did. This could be due to the fact that it is difficult for them to communicate with others who do not know the sign language or might feel that others do not understand their Deaf culture so they choose not to socialise with persons of the wider population, especially if they are not family members of a deaf person or theirs – as I was told by experts on the topic too. This is evident also from the fact that deaf participants using the sign language came to the interviews together, in twos or threes, and only one participant using the sign language came alone – the one who was also living alone [i.e. Claire (S)]. For this reason it seems that there is a sense of belonging, attachment and possibly safety that deaf persons using the sign language feel when they are in company of other deaf persons, which did not emerge for the rest of the participants of this study.

Consequently, apart from participants with sensory disability who were using the sign language to communicate, all other participants of this study had stronger bridging social capital and weaker bonding social capital, confirming also the fact that in this study were not included participants who were socially marginalised or isolated from the wider society.

CHAPTER FIVE: CONCLUSIONS & RECOMMENDATIONS

5.1 Recommendations

The findings presented above highlighted issues related to social relationships and social participation of women with disability in their everyday life as well as the barriers they encounter within their social and physical environment. In specific, it was found that women with mental disability have faced prejudice, discrimination, stigmatisation, and/or lack of empathy towards them from other people of the wider population which hinder their social participation. All women with physical disability have faced barriers to social participation related to numerous accessibility hindrances of the physical environment, and most of them have also faced prejudice and mentality barriers towards them from persons of the wider population. Women with sensory disability have encountered mostly barriers for social participation related to lack of resources for communication with people of the general population, whether in private or public places, when there is no sign language interpreter or subtitles provided, while they have also limited opportunities for employment compared to hearing persons. These barriers could be overcome with a series of public-oriented and individual-oriented suggestions made by participants, showing that there is a two-fold interaction of both personal and environmental factors hindering their social participation and autonomous living.

Accordingly, in this subchapter are presented recommendations, based on the issues for social participation that emerged in this study, which future researchers, educators, health and social care professionals, and policy-makers can consider when aiming to explore and/or promote inclusion of persons with disability at clinical, rehabilitation, educational, cultural and societal levels.

5.1.1 The viewpoint of participants

To begin with, recommendations were made by participants when I asked them to tell me their opinion on how barriers for social participation and autonomous living could be overcome for themselves and other persons with the same type of disability. I did this because I consider that needs assessment is fundamental to any research or intervention focusing on the better understanding of the needs of a target group of the population, as an outsider’s eye may be too distant from the experience of an insider, especially on personal experiences related to health issues and social relationships. In that sense, an outsider might not be able to grasp all the problems which might be hindering or helpful to the persons with disability and based on these issues to suggest ways to facilitate their social inclusion. In addition, it has been argued that *“to understand the social world, it is necessary to explore people’s subjective ‘definition of the situation’ and their attempts to navigate its inherent uncertainties and dilemmas”* (Barnes & Mercer, 2010, p. 5). Therefore, the subjective viewpoint of the participants was primarily considered in terms of suggestions for overcoming barriers for social participation and autonomous living.

5.1.1.1 Suggestions for removing barriers for social participation

On removing barriers for social participation (as it has been already presented in detail in the previous chapter of this thesis), respondents with **mental disability** made mostly public-oriented suggestions for overcoming social participation barriers, such as education, campaigns, understanding, and change of mentality of wider social networks on mental health issues, implementation of more projects for enhancement of social life of persons with mental health issues, but also made individual-oriented suggestions, such as self-confidence, self-worth and self-acceptance of mental health issue by the person experiencing it.

Respective suggestions by participants with **physical disability** included implementation of existing laws on accessibility and denouncement of accessibility problems to institutions, as well as change of mentality of the public, more public visibility of and communication about persons with disability, education of the public, and life projects for persons with disability.

Participants with **sensory disability** suggested calling a sign language interpreter or requesting subtitling or cooperation from others for communication and sensitisation of the wider society and information to the wider society on diversity and deafness.

5.1.1.2 Suggestions for removing barriers for autonomous living

Similarly, participants made the following suggestions for removing barriers for autonomous living.

Participants with **mental disability** in their majority suggested that these barriers could be removed by change of attitude of others towards them, but also with a change of attitude of themselves regarding circumstances in their own lives, as well as suggested more support from the State in practice within the employment sector.

Respondents with **physical disability** suggested that there should be change of mentality of the wider society on persons with disability and/or removing architectural barriers, there should also be provided financial support, employment opportunities and advanced education for persons with disability, institutional support at municipality level, less dependency on family support, the need for a unique legislation across regions of Italy for allocation of funds, while persons with physical disability should denounce barriers to institutions and could use self-empowerment, while finding the resources to reach autonomy, and not focusing on disability.

Participants with **sensory disability** suggested asking a sign language interpreter or family member to help them overcome communication difficulties, more activities for them, priority, accessibility, attention and inclusion for deaf persons, as well as more effort for personal growth and development from persons with sensory disability.

Consequently, it appears that participants from all three types of disability explored here made suggestions oriented towards the wider society or professionals, but participants from all three types of disability made also suggestions oriented towards themselves and their peers with the same type of disability, indicating a two-fold interaction of both personal and environmental factors hindering their social participation and autonomous living.

5.1.2 Elimination of prejudice, discrimination, stigma and abuse

The issues of prejudice, discrimination, stigma and abuse emerged in this study as participants reported having experienced them personally or they knew other persons with the same type of disability that had experienced these issues. Sexual abuse in young age was mentioned by two participants with mental disability [i.e. Jennifer (M) and Amelia (M)] and physical abuse by one of them [i.e. Jennifer (M)]. Evidence shows that there is a reciprocal relationship between violence and disability, with women and girls being at increased risk of experiencing violence, while violence can lead to severe disability, and the perpetrators of their abuse can be persons of whom they are physically, financially, or socially dependent, and because they may rely on these people for help they are more likely to stay in abusive situations for longer time (Dunkle, Van der Heijden, Stern, &

Chirwa, 2018). Women with disabilities are uniquely able to identify ways to tackle violence against other women and girls with disability, therefore it is essential to support and foster the leadership of women with disabilities (Dunkle, Van der Heijden, Stern, & Chirwa, 2018). Additionally, the rights of women and girls with disabilities have been one of the main areas of the work of the European Disability Forum (EDS), since *"women with disabilities are three times more likely than women without disabilities to be victims of violence in Europe, including forced sterilisation"* (European Disability Forum, Annual Report 2016-2017 [Nothing about us without us], 2018, p. 40). In particular, active progress has been made towards promoting the rights of women and girls with disabilities, through campaigns by the EDS together with the European Women's Lobby for the European Union in order to ratify the Council of Europe Convention on preventing and combatting violence against women and domestic violence too (European Disability Forum, Annual Report 2016-2017 [Nothing about us without us], 2018).

Furthermore, one of the participants with sensory disability [i.e. Kylie (S)], who had experienced prejudice due to her deafness by her colleagues as a teacher, referred to the fact that she developed resilience which helped her to a great extent in her life. As it has been suggested elsewhere, resilience can be useful for persons with physical disability in terms of improved functional outcomes as resilience has been found to have strong negative association with depression and strong positive association with social role participation, thus social participation could be an important aspect through which resilience helps to stabilise quality of life; a relationship which can be explored further in future research too (Silverman, Molton, Alschuler, Ehde, & Jensen, 2015).

Moreover, prejudice, discrimination and stigma due to health issue were mentioned mostly by participants with physical and mental disability as barriers for their social participation and autonomy. Stigma has been proven to have an impact on various levels and depends on the context, so there is no on-size-fits-all approach to combat stigma, thus relevant programmes should influence policies and communities to reflect local interests and needs in order to tackle prejudice and discrimination (Corrigan, Druss, & Perlick, 2014). Advocates of such programmes include persons who have lived experiences of prejudice and discrimination of mental illness stigma, for example, and how it has had an impact on work and independent living, but also can include family members, care providers, and community and government leaders (Corrigan, Druss, & Perlick, 2014). To combat stigma of mental illnesses, in specific, there have been suggested the following six approaches to stigma reduction:

> The first – *education* – attempts to replace myths and misinformation with accurate conceptions about the nature and prevalence of mental illnesses, thereby improving mental health knowledge and overall mental health literacy. (…) The second – *protest* – tries to suppress negative representations by openly objecting to situations that portray people with a mental illness in a negative or stereotypical way. (…) The third – *contact-based education* – facilitates interactions between members of the public and people who are successfully managing a mental illness, usually with opportunities for active discussion. (…) The fourth strategy – *legislative reform* – is designed to prohibit discrimination on any grounds, improve protections for people with a mental illness, and offer accommodations in such areas as employment, education, and housing. (…) The fifth strategy – *advocacy* – is designed to ensure that people with a mental illness actually enjoy the rights and freedoms offered by legislation, and provides avenues of redress for inequitable policies and procedures. (…) The sixth strategy – *stigma self-management* – is consistent with recovery literature that encourages services and supports that empower people with a mental illness to overcome their illness identities and move beyond the illness experience to find new personal meanings and valued social roles. (Arboleda-Flórez & Stuart, 2012, pp. 461-462).

These approaches could be applicable also for stigma reduction of other types of disability, since all of these approaches emerged also in this thesis through the suggestions of participants with physical disability, such as education of the public, to denounce barriers of the physical environment, implementation of legislation at public places, advocacy by persons with physical disability to promote change of mentality of others towards them, and regarding self-empowerment of persons with physical disability in terms of finding the resources to reach autonomy and not be focusing only on their disability. Furthermore, social scientists and psychologists need to partner with advocates in order to identify the most appropriate strategies for eliminating stigma (Corrigan P. , 2004).

In Italy, in particular, it has been found that the areas that persons with schizophrenia have most frequently experienced discrimination have been: discrimination by family members (44%), making and maintaining friendships (33%), maintaining a job (36%), finding a job (34%), and getting or keeping a driving licence (32%) (Maggiolo, et al., 2010); which all emerged in this study as well, not only for persons with schizophrenia, but persons with psychoses in general; however, mainly reported here as barriers of social relationships and social participation, not explicitly mentioned as forms of perceived discrimination. Keeping all above in mind and in conjunction with the fact that in this study it emerged that participants with mental disability faced prejudice due to their mental health issue being considered as ‘dangerous’ or ‘crazy’ by others or others being afraid of their health issue or felt discriminated from co-members of a group, a recent study (Magliano, Punzo, Strino, Acone, & Affuso, 2017) found that beliefs about discriminatory treatment for persons with schizophrenia in hospitals are common among Italian general practitioners (GPs). These beliefs were found to be related to perceptions of ‘dangerousness’, social distance, and scepticism about the ability of persons with schizophrenia to report their own health issues accurately, as well as the need for medication for life (Magliano, Punzo, Strino, Acone, & Affuso, 2017). As presented in previous parts of this thesis, the use of medication for treatment of persons with psychoses has been criticised by scholars in the field. Despite that, in this previous study mentioned here, 18.4% of the GPs reported that they firmly believed that persons with schizophrenia should be separated from other patients at hospitals and 31.4% that they should be supervised, as well as that 42% were fully convinced that persons with schizophrenia should take psychiatric drugs for life, which based on the same source, could be related to the adherence of some GPs to a biogenetic model of mental disorders (Magliano, Punzo, Strino, Acone, & Affuso, 2017). Given that in Italy GPs and hospital physicians collaborate, the beliefs of GPs on how their clients should be treated may significantly influence the decisions that their hospital colleagues make about the treatment of persons with schizophrenia (Magliano, Punzo, Strino, Acone, & Affuso, 2017). Therefore, in order to reduce discriminatory treatment of persons with schizophrenia based on ‘dangerousness’, it has been suggested provision of education to GPs on successful treatments, positive prognosis in schizophrenia, and countering non-evidence-based stereotypes about ‘dangerousness’, and in this way could possibly reduce the proportion of GPs who believe in discriminatory behaviour towards people on the basis of a diagnosis of schizophrenia (Magliano, Punzo, Strino, Acone, & Affuso, 2017), and in turn contribute to the elimination of prejudice against persons with schizophrenia and psychotic disorders, in general, in the wider society as well.

5.1.3 Increasing political participation

Political and civic participation is important aspect of social participation, as persons who engage in community affairs can promote also the interests of their own group. The most active participants politically were those with physical disability, followed by one participant with mental disability and another with sensory disability, who mentioned being involved actively in common affairs, such as supporting others with mental disability or participating in events for promoting the rights of persons with sensory disability. Therefore, it appears that the majority of persons with mental and sensory disability were not actively involved in political actions either at individual level or related to the welfare of other persons with the same type of disability. However, persons with sensory disability were members of an association of persons with the same type of disability (as observed during the recruitment phase). None of the persons with mental disability mentioned belonging actively to an association of persons with mental disability or participating in demonstrations or protests for the rights of persons with mental disability, possibly because many of them stated that they were concealing their mental health issue even from persons of their close social network, thus they would not be expected to demonstrate about it publicly.

It has been stressed in a recent study that there should be more opportunities for persons with disability to participate in public and political life more widely, since many persons with disabilities become marginalised from public life, and although the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) stresses the importance of political awareness of disability rights, focused action still needs to be put in place for the implementation of persons' with disability political participation rights, accessibility and representation (Priestley, et al., 2016). To conclude, it has been suggested that disability should be considered as a socio-economic variable within national and cross-country surveys to be able to monitor any factors of exclusion in terms of political participation – and not only – given that currently *"there is a notable absence of disability as a socio-economic variable in political participation research"* (Priestley, et al., 2016, p. 7).

5.1.4 Alleviation of loneliness and depression

Any person faces moments of loneliness, and similarly to participants here, others view loneliness as a positive state while others have negative thoughts when they are feeling lonely and try to contact other people to overcome loneliness. However, some of them did not have many or any other person(s) to turn to for psychological support in difficult times, especially those with mental disability. As it has been found elsewhere, poor skills/social withdrawal is possibly the most clearly established factor on the development of loneliness (Heinrich & Gullone, 2006). Moreover, humans are inherently social beings with a need to belong, and when this fails to happen for them, disturbances, such as loneliness, may arise which can have severe consequences for mental health and well-being, therefore alleviation of loneliness should be a main focus in the practice of clinicians (Heinrich & Gullone, 2006). Nevertheless, loneliness was also perceived as relaxing and private time to oneself by participants of this study, thus not always considered a negative state. For this reason, researchers and practitioners should not presume that loneliness reported by participants/patients should necessarily be a negative state and should explore the individual's preferences and subjective perception on this.

In addition, it was mentioned by participants that persons with physical disability experience prejudice from others which hurt their feelings, so clinicians should closely attend to issues related to pain such as social support, social isolation, and abuse among women with physical disabilities, and to this can contribute pain self-management, social networking and social skills development, as well as safety and abuse prevention training, particularly for the design of depression intervention programs for persons with physical disability (Robinson-Whelen, Taylor, Hughes, & Nosek, 2013). Regarding ways to combat depression among women with physical impairments, it has been also suggested that the enhancement of their social networks holds potential for intervention, but although literature recommends this direction – both for persons with disabilities and the wider population – the interventions aiming at enhancing social networks and social support are very limited, as mentioned also above, while women with physical disabilities are at particular risk of social isolation, therefore more research is required in this population group too (Robinson-Whelen, Taylor, Hughes, & Nosek, 2013). Lastly, based on a recent systematic review (Tough, Siegrist, & Fekete, 2017), it appears that studies have shown that there is an association between social networks and depression, which compliments the suggestion above that more research and interventions should focus on the enhancement of social networks, therefore more efforts should be made in this direction.

5.1.5 Addressing accessibility barriers of the physical environment

As it emerged, all participants with physical disability referred to accessibility barriers of the physical environment regarding mainly the metropolitan area of Milan, whether about public open spaces, offices, restrooms, companies, bars, restaurants or houses, including any elements of these spaces which can be hindering, such as lack of slopes/ramps in buildings and pavements and lack of functioning and appropriate-in-size elevators and stairlifts. One tool which can be useful for identifying and addressing barriers of the physical environment is the biopsychosocial model of the ICF (World Health Organization, International Classification of Functioning, Disability and Health, 2001), through which environmental factors can be assessed to discern positive features of the physical environment, such as by adaptations of elements which improve usability of spaces (Koutsogeorgou, Quintas, Raggi, Bucciarelli, Cerniauskaite, & Leonardi, 2012). Therefore, according to the biopsychosocial model, the experience of the person interacting with her/his physical environment should be taken into consideration for addressing barriers of the physical environment and not only the existence of elements of the physical environment *per se* (Koutsogeorgou, Quintas, Raggi, Bucciarelli, Cerniauskaite, & Leonardi, 2012). Accordingly, as one of the participants suggested, there should be a project to record any barriers for accessibility in each neighbourhood of the city of Milan. The individuals principally involved in this kind of projects should be persons with disability, as they are the most adequate to identify these barriers based on their own experiences and interaction with the urban environment. In any case, as participants suggested, for overcoming accessibility barriers in public and private spaces there should be actual implementation of accessibility legislation, which already exists officially but is not implemented properly in practice, not even in the subway of Milan which is a main mean of public transportation for the majority of the city population.

According to the findings of this thesis, it was reported by participants that there is lack of implementation of existing legislation and policies relevant to accessibility issues of persons with disabilities in public and private spaces, which in Italy becomes even more complicated due to the lack of a unique legislation for all regions of Italy, with each region allocating the State funds as they wish, as it was reported by participants, leading to inequalities across Italian regions. Moreover, in the final months of 2018 it was published a provisional agreement of the EU institutions on the European Accessibility Act (Council of the European Union, 2018) including a Directive for Member States, the purpose of which was:

> to contribute to the proper functioning of the internal market by approximating laws, regulations and administrative provisions of the Member States as regards accessibility requirements for certain products and services, by, in particular, eliminating and preventing barriers arising from divergent accessibility requirements in the Member States to the free movement of certain accessible products and services (Council of the European Union, 2018, p. 2) .

However, this Directive was criticised by the European Disability Forum (EDS) who in a news release stated that the European Accessibility Act only covers digital accessibility and omits the real world environment where persons with disabilities live, and lacks essential aspects, such as regarding transport, microenterprises that provide services, household appliances, as well as any obligation on accessible buildings and infrastructure (European Disability Forum, Disappointing compromise on EU Accessibility Act, 2018). This latter issue on obligation about accessible buildings and infrastructure, as well as transport accessibility issues, emerged in this thesis as well. It should be highlighted that all participants mentioned that they had experienced accessibility issues in terms of the physical environment, in particular in relation to accessibility to public buildings and transport, while it also emerged here that relevant laws should be better defined and oblige all public spaces to pay attention to accessibility, without this attention being optional as it is currently, but to be obligatory by law.

5.1.6 Overcoming communication issues for deaf persons

Based on the findings above, participants with sensory disability also suggested for removing barriers for social participation providing information to the wider society on diversity and deafness, and for removing barriers of autonomous living they suggested more effort for personal growth and development for persons with sensory disability themselves. These suggestions could find application in the field of education, for example, by both providing information to hearing students and teachers on inclusion of deaf students, and from the part of deaf students there could be more effort with the proper resources provided to them in order to attain the highest education level possible which can help them in terms of personal growth and development.

A similar suggestion has been made also recently, directed to the Italian context for deaf persons, and in particular it has been suggested that the Italian language is the greatest problem an Italian deaf student encounters during her/his education path, so the school should develop targeted teaching strategies, create suitable materials, and use appropriate technologies as instruments in order to make the educational content accessible from an inclusive point of view (Dolza, 2017, p. 29). Such technologies could include simultaneous interpretation to LIS or direct subtitling, as the participants of this study with hearing loss suggested as well. In rehabilitation of persons with hearing difficulties it is helpful to understand the conditions that negatively influence their daily life, and future research could focus on the internal relationship between social participation and activity limitation (Helvik, Jacobsen, & Hallberg, 2006). Moreover, it has been suggested elsewhere that medical professionals should review and question the traditional medical model of deafness, which emphasises on pathology and treatment but not on the deaf persons' definitions of their needs (Munoz-Baell & Ruiz, 2000). Lastly, it is imperative for researchers in the field of deafness to consider that: *"because of its strong cultural bearing, medical research on deafness should no longer disregard research findings on non-medical areas when planning their research agenda and study designs"* (Munoz-Baell & Ruiz, 2000, p. 44).

5.1.7 Reducing financial and employment difficulties

Based on the present findings, the majority of participants from all three types of disability, especially physical and sensory disability, referred to their lack of financial resources whether due to lack of adequate financial support from the State or municipality that could allow them to lead an independent life without the social support by their parents or partner/husband, or the lack of or limited employment opportunities for them due to their health issue. As already mentioned, participants with mental disability concealed their health issue thus not even claimed disability benefits they were entitled to, but one of them [i.e. Lily (M)] mentioned that even if one receives the disability benefit, the amount of the benefit would not allow them to live independently anyway. In addition, participants with mental disability were the only ones who referred to renouncing their right to claim disability benefit for fear of the ‘label’ of a persons with mental health issue and the difficulty this might create for them for finding a job or maintaining a driving licence, as due to mental health issue they were not allowed to have a driving licence. According to data from Eurostat, people with activity limitation are more likely to struggle to make ends meet, as in 2013, 34% of adults with activity limitation living in the EU had difficulties in making ends meet, compared to 26% of adult population without any activity limitation (Eurostat, 2015). Moreover, it has been argued that there is significant degree of social exclusion encountered by disabled women in the labour market, thus, women with disability experience disadvantages that distinguish them from men with disabilities or women without disability, economically, socially, and psychologically (Barnes & Mercer, 2010).

Consequently, persons with disability should receive more financial support from institutions in order to be able to make ends meet and tackle this issue of social inequality among persons with disability and without disability. As it emerged also from the findings, the majority of participants appeared to provide also social support to others which remains unrecorded, apart from their contribution to the society as working persons, and in particular participants with physical disability who all were working or studying during this research. However, most of them were struggling financially despite the disability benefits they received, as a full-time care of a person in a wheelchair is too expensive for them to cover this cost on their own or even if they can cover it on their own without receiving disability benefit, there is no reduction in taxes for them to pay for having personal care assistants, as one of the participants with physical disability pointed out [i.e. Janet (P)]. Also many of the women with mental and sensory disability seem to have encountered difficulties finding a job, and some of them coming from other countries than Italy had difficulty receiving disability benefits too. Therefore, more systematic monitoring of the financial needs of persons with disability should occur from institutions which would help distribute funds and resources more appropriately among persons with disability and regardless of whether they were born in Italy or not or how long they have lived in the country, all residents in Italy should be treated equally in terms of health care, as it happens in the United Kingdom, for example. Institutions should support more actively persons with disability in finding a job while ensuring that employers implement legislation for inclusion of persons with disability and accessibility in the workplace by removing any architectural barriers and educating employers and employees on inclusion of persons with disability in the workplace. This could contribute in eliminating prejudice and discrimination. Finally, institutions should inform more systematically persons with mental disability about the benefits and support they are missing out by not declaring their mental health issue officially.

Furthermore, as it has been stated elsewhere, only 16% of persons with disabilities in Italy had a job in 2012, thus it is has been recommended that there needs to be carried out a structural reorganisation for the relationship between companies and employment agencies in order to avoid the risk that companies would consider persons with disabilities as an obstacle, rather than as a resource (Iudici & Renzi, 2015). This latter perception by companies could be reduced in this field by addressing the lack of communication between the involved parties and the lack of support in the employment process (Iudici & Renzi, 2015). Moreover, a study on the inclusion of persons with disabilities in the Italian labour market (Agovino & Rapposelli, 2013) has shown that the sheer presence of potential employers and employment offices is not enough for Italian regions to implement the Law 68/1999, while it has been suggested that both environmental and socio-welfare factors should be considered per region to determine the provision of employment for persons with disability. In addition, for policy actions it has been stressed by the same study that in order to promote integration of persons with disability in the labour market *"environmental and social capital variables ought to be included as policy instruments within the context of law 68/1999, but with targeted and different interventions depending on the context"* (Agovino & Rapposelli, 2013, p. 1587). Thus, it is recommended that social capital variables can be used by policy makers as a source of information on the context and thus construct more targeted implementation of any laws or policies focusing on the inclusion of persons with disability in the employment sector; and not only.

5.1.8 Strengthening social participation

As mentioned previously, based on the current findings, participants with a visible disability (i.e. physical) were far more socially high-active compared to participants with an invisible disability (i.e. mental), whereas persons with sensory disability belonged somewhere in the middle in terms of level of social participation. This indicates that there is need for more opportunities for social participation and building meaningful social relationships with others in the wider community for persons with mental disability, as they were also the ones who reported the least having received social support from their informal social networks (i.e. family and friends), among the participants of this study, as they relied more on their formal social networks (i.e. health professionals) for support. Overall, participants of this study were not socially excluded or marginalised, as already mentioned, however this was attributed to the inclusion criteria of the study.

Relevantly, a previous research on young adults with disabilities too has found that their participants had a very active social participation in their social networks as well, with 84% of them spending time with their friends at least several times per month and 76% engaging in leisure activities at least several times per month (Schneider & Hattie, 2016); similarly to this thesis that showed that the vast majority of participants met with their friends often and the majority of them engaged in social activities. However, based on the same previous study, frequency of social contact *per se* is not necessarily a reliable indicator of high quality of social integration, and exploring the experiences of participants through interviews and focus groups would provide a more meaningful idea of participants' social lives (Schneider & Hattie, 2016); as it was performed in this thesis too. In any case, it has been suggested that professionals in the field have the important role to enhance social participation of young adults with disability, opening up communities and creating opportunities for persons with disability to interact with others as well (Schneider & Hattie, 2016).

Furthermore, it has been also suggested that there is need for the scientific understanding of societal participation of persons with disability at a more general level, using a broad perspective, as social participation is related to many areas of life, thus can contribute to the understanding of how public and political attitudes towards political participation can be enhanced, as well as how future disability policies and studies can enable equal opportunities for persons with disability in terms of social participation (Hästbacka, Nygård, & Nyqvist, 2016). It has been also suggested that legislation and disability policies were reported by persons with disability most often as facilitators for societal participation, thus it is crucial that decision-makers and professionals implement such legislation and policies for them (Hästbacka, Nygård, & Nyqvist, 2016).

5.1.9 The usefulness of the biopsychosocial model

As it emerged, there were participants who did not participate in work and other daily activities as much as the rest of participants did. To this could contribute health-promoting practices relevant to health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management as these have been found to be related to mental health and less limitation in participation in work and other daily activities, with the frequency of engaging in positive interpersonal relationships being related to increased role participation (Tyszka & Farber, 2010). Thus, health-promoting practices could contribute to improving social participation and social relationships too.

What is more, as research has shown, women with disability are more prone to negatively perceive their quality of life (Estrella-Castillo & Gómez-de-Regil, 2016). Therefore, it is important for ultimate functioning of women with disability to include social support and assistive technology that will help them be as independent as possible whilst remaining socially connected to other people (Scherer & DiCowden, 2008). Moreover, more research and intervention needs to focus on the impact of gender differences on disability and rehabilitation, since, for example, rehabilitation settings may be responsive to the physical needs of women with disability, but less attention is given to their psychological and social concerns (Scherer & DiCowden, 2008). Thus, using the biopsychosocial model of the ICF (World Health Organization, 2001) as the framework of these actions, could be valuable for identifying and monitoring relevant issues to the ICF's Activities and Participation domain and possibly improve these issues too (Scherer & DiCowden, 2008).

Additionally, it has been found that social and community participation of wheelchair users is complex and has been associated with factors from all the domains of the ICF, meaning body functions and body structures, activities and participation, environmental factors, and personal factors (Smith, Sakakibara, & Miller, 2016); thus showing that social participation of persons with disability is a multi-faceted topic for which the biopsychosocial model could be proven valuable with its ecological approach to health and disability. Similarly to this study's finding that all participants with physical disability reported barriers related to the physical environment and accessibility issues, it has been reported that wheelchair factors and accessibility are the most frequently reported factors by wheelchair users in terms of participation (Smith, Sakakibara, &

Miller, 2016). Based on all above it appears necessary to focus future intervention-based research on accessibility issues (Smith, Sakakibara, & Miller, 2016) from an ecological perspective.

Furthermore, it has been argued that in clinical practice the physician's first source of information is the patient and this includes data of feelings, opinions and memories as well as reported observable and reported behaviour of the patient, and while some claim that the biopsychosocial model imposes an impossible demand on the physician, it actually does not add anything that is not already there in patient care (Engel, 1980). The biopsychosocial model provides, among others, a conceptual framework to the physician to act rationally in areas that were excluded from rational approach, as it motivates the physician to become more informed and skilful on psychosocial areas, which have been neglected by the biomedical model, thus the biopsychosocial model extents this knowledge (Engel, 1980). This suggestion was made almost four decades ago by George L. Engel (1980), pioneer of the biopsychosocial model, but still nowadays it appears crucial to repeat it as the majority of physicians still apply the purely biomedical model in their practice and continue to treat with arrogance – or ignorance – psychosocial factors and other contextual factors which have been proven by numerous studies to impact on health and well-being.

Finally, it has been argued that both mental health professionals and persons in mental distress are called upon to take into consideration the biopsychosocial model of mental distress, including the role of *"biological, psychological and social processes regarding the causes, triggering and course of each person's mental health difficulties and to intervene at all levels"* (Georgaca & Zissi, 2017, p. 15). Accordingly, for psychotic disorders the pharmaceutical treatment is deemed necessary – usually –, however, persons in distress are encouraged to deal with the psychological and social parameters of their case as contributing to their mental health issue, such as by constructing social support networks (Georgaca & Zissi, 2017). Relevantly, assisting young persons with psychosis to rebuild their social relationships beyond the recovery phase may require psychological interventions in order to improve the young persons' social functioning and reduce stigmatising attitudes by people of their social networks (MacDonald, Sauer, Howie, & Albiston, 2005). In practice, this could involve youth activity groups with the support of other peers who have experienced psychosis as well, which can facilitate recovery for young persons with early psychosis and at the same time enhance their experiences of social relationships (MacDonald, Sauer, Howie, & Albiston, 2005).

5.2 Conclusions

This study explored various aspects of social relationships and social participation of women with mental, physical and sensory disability, within each type of disability and across them, thus provided an in-depth insight on the topic under question. One of the main objectives of this thesis was to discern barriers and facilitators of social inclusion for persons with disabilities through patterns of their reported experiences, which can potentially influence policy-making and improve personal experiences of persons with disabilities in terms of their social relationships and social participation.

Based on the findings presented above, it appears that women with mental disability seem to have the lowest social participation, whereas women with physical disability the highest social participation, across the three types of disability explored. Various issues in respect to their social relationships emerged, however some of them were in common across types of disability, thus patterns were discerned too in terms of sociodemographic characteristics, visible and invisible disabilities, politically active and inactive women with disability, among deaf participants using the sign language and among deaf participants with hearing aid, social media usage for communication, and in terms of aspects/components of social capital (such as social networks and trust) which was used as a sensitising concept in this study.

As mentioned above, it appears from the previous scientific literature that there has been a need for future research to advance our understanding of social isolation experienced particularly by women with physical disabilities, who are at high risk of social isolation (Robinson-Whelen, Taylor, Hughes, & Nosek, 2013), to explore whether essential components of phenomena of social relationships are common for young adults with psychosis or other long-term illnesses (MacDonald, Sauer, Howie, & Albiston, 2005), as well as to address a gap in the number of studies on intersection of disability and gender (Mohamed & Shefer, 2015). All these issues were addressed in this thesis, by exploring various aspects of social relationships and social participation and barriers experienced by persons with disability related to these aspects. The comparisons within and across the three different types of disability provided also novel ground for future exploration of the relevant issues persons with different types of disability face. In any case, the importance of looking deeper into the social relationships and social participation of persons with disability and helping them to address any potential relevant issues could possibly be a valuable way for reducing prejudice, stigma, and other barriers they have reported in this study too.

From the present findings it appears compelling to focus within research and practices also on the exploration of the various aspects of the social relationships and social participation of persons with disability as the barriers they face in relation to these aspects are numerous and multi-faceted as well as related to their personal and social development having an impact on their health and psychological well-being too. Prejudice and discrimination against women with disability are issues which have been addressed in this study, and could be potentially diminished by employing a less biomedical and more biopsychosocial approach in health care, employment, education, public services, and all life domains, not only related to health and disability, whilst acknowledging the proven impact that social relationships and social participation have on health and well-being. It is time to move beyond the perception of ‘fixing’ the person with disability, towards creating a more facilitating social and physical environments that may enable persons’ with disability full inclusion into society, through the elimination of their barriers for social participation and autonomous living, together with the strengthening of their social relationships.

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APPENDICES

Appendix A: Interview and sociodemographic information

Below is presented the form used for collecting interview information and sociodemographic information of participants, which was filled in by the researcher before each interview started.

***Participant No.* ________**

***Date of interview**: __ __ /__ __/ __ __ [Day / Month / Year]*

1. **Name**: ____________________________ (only first name).

2. **Age**: __________

3. **District of residence**: _________________________________ (not specific address)

4. **Level of education**: ___________________________________

5. **Current Marital Status**:
   - 5.a Single/Never married [ ]
   - 5.b Currently Married [ ]
   - 5.c Separated [ ]
   - 5.d Divorced [ ]
   - 5.e Widowed [ ]
   - 5.f Cohabiting with partner [ ]

6. **Current Employment Status**:
   - 6.a Paid employment [ ]
   - 6.b Self-employed/freelance [ ]
   - 6.c Non-paid work, such as volunteer/charity [ ]
   - 6.d Student [ ]
   - 6.e Keeping house/House-maker [ ]
   - 6.f Retired [ ]
   - 6.g Unemployed (health reason) [ ]
   - 6.h Unemployed (other reason) [ ]
   - 6.i Other [ ] *(please specify)* ____________

7. **Type of disability/diagnosis**:____________________________________

8. **Current living arrangements** (living alone or with others):
____

9. **Societal role of relative autonomy**:
   - 9.a Worker [ ]
   - 9.b Student [ ]
   - 9.c Partner/Wife [ ]
   - 9.d Mother [ ]

Appendix B: Interview guide (list of topics/questions)

Below is presented the interview guide which includes a list of self-developed topics for discussion based on the aim of this study and research questions, and was used by the researcher as a guide during interviews with participants.

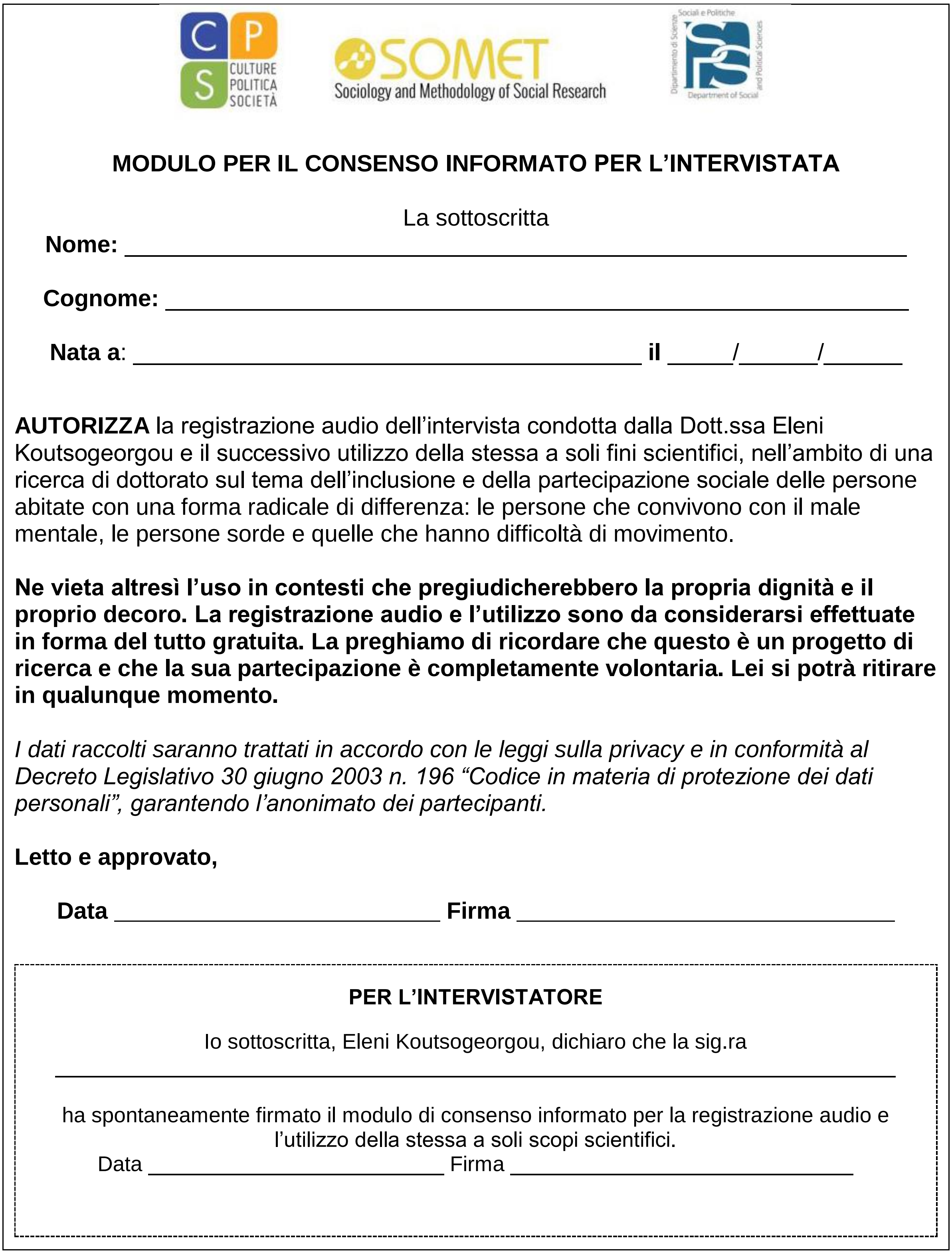
1. **Biographical experience of disability** (time and cause of onset of disability).
2. **Coping mechanisms** for disability in everyday life.
3. **Social networks:** Experience about social relationships and group membership:
    - Within family, intimate relationships, relationships with neighbours, health/social care professionals
    - Members of organised or volunteer groups (church, associations, sports clubs, etc.)
    - About size of social network, about how many people they would say that they feel close to.
    - Type of relationships, frequency of contact, and usual way of communication between them.
4. **Disability-based homophily or heterophily of social networks:** Most of the persons belonging to their social networks are persons with disability too (homophilious) or without any disability (heterophilious).
    - If so, have they ever reached out to persons outside their usual social networks and got rejected. Or do not want to be involved with other persons since they feel that they cannot understand them.
5. **Social support received or provided:**
    - If they receive support from others. If so, for which reason (emotional or practical support) and how often. And by what type of relationship (e.g. family members, friends, etc.)
    - If they provide any support to other persons.
6. If they receive **institutional support** from national or local authorities (e.g. or everyday tasks, or any health/social care benefits, disability benefits, etc.) or from advocacy organisations (e.g. companion for outdoor activities who are volunteers in disability associations, etc.)
7. Any **changes in experience of relationships** with others or received support after the onset of their disorder/disease/injury.
8. **Trust:**
    - towards people in general.
    - towards institutions (such as police, justice, parliament, and the press).
9. **Political participation**:
    - If they vote regularly.
    - If they are members of associations or advocates for persons with disability.

    - About their participation at a demonstration or petition regarding issues of political life in general.

10. Perceived **gender differences**. If they have observed any differences between men and women having the same health issue.
11. **Feelings of loneliness** and coping mechanisms about it.
12. **Daily activities** and during weekend (about their routine).
13. **Leisure time** preferences, hobbies, indoor or outdoor activities, with other or alone, etc.
14. If they are **not working**, if they would like to find a job but they cannot due to their health condition.
15. Opinion about specific **civic norms**. If they agree or disagree with these statements [based on (Kaasa & Parts, 2008)]:
    - Cheating on taxes if one has the chance
    - Claiming government benefits to which one is not entitled to
    - Someone accepting a bribe in the course of one's duties.
16. If they have experienced any **barriers for social participation** (both physical environment and social-related).
17. Suggestions for removing barriers regarding social participation.
18. If they have experienced any **barriers for independent/autonomous living**.
19. Suggestions for removing barriers regarding independent/autonomous living.
20. How do they see their **future in the next ten years** (at personal and/or professional level). [Expectations about their future might reveal personal attitudes or additional barriers for social relationships.]

Appendix C: Informed Consent Form

Below is presented the original informed consent form (in Italian) used in this study. Both the researcher and each participant signed two copies of this form prior to each interview (one copy was retained by the researcher and the other copy was given to the participant).



MODULO PER IL CONSENSO INFORMATO PER L'INTERVISTATA

La sottoscritta

Nome: ____

Cognome: ____

Nata a: ______________________________ **il** ____/_____/_____

AUTORIZZA la registrazione audio dell'intervista condotta dalla Dott.ssa Eleni Koutsogeorgou e il successivo utilizzo della stessa a soli fini scientifici, nell'ambito di una ricerca di dottorato sul tema dell'inclusione e della partecipazione sociale delle persone abitate con una forma radicale di differenza: le persone che convivono con il male mentale, le persone sorde e quelle che hanno difficoltà di movimento.

Ne vieta altresì l'uso in contesti che pregiudicherebbero la propria dignità e il proprio decoro. La registrazione audio e l'utilizzo sono da considerarsi effettuate in forma del tutto gratuita. La preghiamo di ricordare che questo è un progetto di ricerca e che la sua partecipazione è completamente volontaria. Lei si potrà ritirare in qualunque momento.

I dati raccolti saranno trattati in accordo con le leggi sulla privacy e in conformità al Decreto Legislativo 30 giugno 2003 n. 196 "Codice in materia di protezione dei dati personali", garantendo l'anonimato dei partecipanti.

Letto e approvato,

Data ____________________ **Firma** ______________________

PER L'INTERVISTATORE

Io sottoscritta, Eleni Koutsogeorgou, dichiaro che la sig.ra

____

ha spontaneamente firmato il modulo di consenso informato per la registrazione audio e l'utilizzo della stessa a soli scopi scientifici.

Data ____________________ Firma ______________________

Appendix D: Sample of interview in original language

In Table 5 below are presented extracts from one of the interviews conducted for this study in the original language that interviews were held (i.e. Italian) including their English translation, as example for proving the accuracy of the translation from Italian to English of the quoted text extracted within the main body of this thesis. The extracts are from the interview conducted with Shirley, one of the speaking participants with sensory disability. The extracts of this interview found below correspond to the text extracted from this particular interview and used as quotes within the Empirical Results chapter of this thesis. Please note that I have not included here the whole interview to protect the anonymity of the participant.

Table 5. Extracts from an interview in original language and translated in English.

Extract in Italian	Extract in English
Io sono nata sorda, ma i miei genitori se ne sono accorti tardi, mi hanno diagnosticato la sordità che avevo due anni e mezzo. A tre anni sono stata protesizzata... e ho iniziato nell'educazione.	I was born deaf, but my parents realised it late, they diagnosed me with deafness when I was two and a half years old. At the age of three I got prosthesis… and then I started the training.
No, me la cavo da sola, me la sono sempre cavata da sola. Interagisco con tutti, comunicazione verbale, con la lettura labiale naturalmente, non conosco la lingua dei segni, quindi la comunicazione attraverso verbale, labiale.	No, I manage to get by on my own, I have always managed by myself. I interact with everyone, verbal communication, of course with lip reading, I do not know the sign language, so the verbal and lip-reading communication.
Io spero che ci siano sempre meno barriere. Faccio anche l'esempio dei cellulari, 25 anni fa ancora non c'erano ed era un grosso passo avanti, è decisamente migliorato negli ultimi anni con l'avvento di social network, ha permesso, è stato più facile, inserirsi, conoscere. Io spero che anche nei prossimi 10 anni ci sia qualcosa di più.	I hope that there are always fewer barriers. I make also the example of mobile phones, 25 years ago they did not exist and it was a big step forward, it really got better in the past few years with the arrival of social media, it allowed… it became easier to integrate, to get to know other people. I hope that also in next 10 years there is something more than that.
La mia compagna e alcuni amici. E la mia mamma. (...) no, non sono rimasta in contatto con nessuno della scuola. I miei sono amici più recenti, neanche un collega. Però sono amici come tutti da adulta.	My partner and some friends. And my mum (...) no, I have not remained in contact with anyone from school. My friends are more recent, not even one colleague. But they are friends that I made as an adult.
Mediamente. Allora ho diversi amici, ne ho tanti, non riesco ad incontrarli tutti frequentemente, però	Moderately. So I have various friends, I have many, I cannot manage to meet with all of them frequently,

mediamente due volte a settimana, dipende anche dai periodi. (...) Faccia -faccia. Poi gli altri li sento magari più spesso tramite whatsapp, quasi ogni giorno sento sempre qualcuno. Però incontrarsi dal vivo dipende anche da gli impegni, non avere una casa, una serie di cose.	but on average twice a week, it depends also on the periods. (…) Face to face. Then the others I talk to them maybe more often via WhatsApp, almost every day I am always talking with someone. But to meet in person it depends also on commitments, not having a house, a number of things.
No, al momento no.	No, at this moment no.
Lavoro, torno a casa, dipende dalla giornata. Il giorno in cui sistemo casa, ogni tanto anche di cani come dog-sitter. dipende. O sennò cucino, faccio la spesa, preparo la cena, leggo quando riesco, mi documento in generale e guardo film. (...) sì.. Io lavoro per un gruppo bancario. Ma ogni tanto mi chiamano come dog-sitter. (...) attualmente non sto facendo sport, niente. Ho sempre fatto sport. Ultimamente no, ho tante spese di affrontare e poi non ho tempo. Mi sto organizzando, quando sarò più libera riprendo sport. (...) incontrare amici. Incontrarsi a cena con amici.	I work, then I go back home, it depends on the day. Some days I clean my house, sometimes also the dogs as a dog-sitter. It depends. If not, then I cook, do the shopping, prepare dinner, I read when I can, I keep up with the news in general and watch a film. (…) yes, I work for a bank group. But every now and then they call me as a dog-sitter (...) Now I am not doing any sports, nothing. I was always into sports. Lately no, I have a lot of expenses and I don't have time. I will get things resolved and then when I have more time I will get back into sports. (…) meeting friends. Meeting with friends for dinner.
Tutti i miei amici sono, due vere persone non udenti, che sento, sono due. Poi quelli che frequento più spesso sono udenti, anche la mia compagna è udente.	All of my friends are [hearing persons], I only have two deaf persons, with whom I am in touch, they are two. Then the people that I meet more often are hearing people, also my partner is a hearing person.
Mi è capitato sì. (...) In qualunque ambito. Tutto dipende di una persona, di capirla di inquadrarla, e magari di pormi. Magari non lo dico all'inizio, ma lo dico subito, dipende dal contesto, capire quando è il contesto giusto per dirlo, anche per non mettere la persona che ho davanti, in condizione di essere prevenuta nei miei confronti. Mettere la persona in condizione di capire, e tranquillizzarla, allora io spiego anche, per spiegare che per me è fondamentale la natura labiale, altrimenti non potrei comprenderla, dipende dal contesto, da fattori.	It has happened to me, yes. (…) In any setting. It all depends on the person, to understand her/him, to identify her/him, and maybe to ask myself. Maybe in the beginning I don't say it, but I say it immediately, it depends on the context, to understand when the context is right to say it, also to not put the person that I have in front of me in a condition to be biased towards me. To put the person in a condition to understand, and to calm her/him, so I also explain, to explain that for me it is fundamental the lip-reading nature, otherwise I would not be able to understand her/him, it depends on the context, on factors.
Allora si, io ciclicamente, chiedo supporto da una psicologa, quello si, a periodi si, perché insomma mi aiuta... ogni tanto mi affido, chiedo aiuto per	So, yes, I cyclically ask support from a psychologist, that yes, periodically, because she helps me... sometimes I confide in, I ask help to

elaborare anche... come puoi convivere con una sordità, non è facile. Non è facile. (...) è una domanda che apre tante domande, è complesso, non saprei da dove cominciare, non si può riassumere in due righe, in due parole. Allora faccio una premessa, i miei genitori hanno fatto questa scelta di farmi crescere tra persone udenti e quindi di non insegnarmi, hanno fatto in modo che io non imparassi la LIS, affinché rimanessi appunto il più possibilmente integrata tra persone normo udenti, integrata anche dal punto sociale. (...) Quindi è un motivo per cui io ogni tanto chiedo un supporto psicologico per lavorare anche su la mia persona interiore su una capacità di fare fronte insomma per riflessare a me proprio. (...) ricevo un'indennità di comunicazione.	elaborate also... how you can live with deafness, it is not easy. It is not easy (…) it is a question that opens a lot of questions, it is complex, I wouldn't know where to start from, it is not possible to summarise in two lines, in two words. So I making a premise, my parents made this choice to raise me among hearing people and so not to teach me, they did it in a way so that I would not learn the Italian sign language, so that I would remain the most possibly integrated among hearing persons, integrated also socially. (…) So this is a reason for which I sometimes ask for psychological support to work also on my inner person, on my capacity to deal with, to reflect on myself really. (…) I receive a communication benefit.
Allora, la fiducia ...insomma.. persona che si fida facilmente. Diciamo che cerco di essere prudente, per gradi. Ma intendi nei confronti delle persone? (...) vado per gradi. Vedere cosa succede e man mano.	So, the trust... so… person who trusts easily. Let's say that I try to be prudent, gradually. But do you mean in respect to people? (...) I go gradually. To see what happens and little by little.
lo dicevo prima, quello delle barriere architettoniche, un tema che meriterebbe più attenzione. (...) i sottotitoli. Allora io di recente ho partecipato ad un convegno organizzato dalla società per cui lavoro eravamo circa 250-300 persone, abbiamo riempito una sala di un albergo, avevano contattato tre interpreti della LIS, e naturalmente non ho compreso nulla, ma è impossibile riuscire a seguire una conversazione per diverse variabili, per diversi fattori, la persona che mette la mano davanti, lo schermo dietro la persona non mi permettono di mettere a fuoco il labiale, comunque mantenere la stessa alta attenzione per diverse ore è impossibile, per me fisicamente mi stanca molto, mi piacerebbe essere aiutata con un supporto di una sottotitolazione diretta, leggere sottotitoli. Questo mi permette di essere, di sentirmi inserita, di essere informata, di sapere cosa succede, al di fare della mia sordità. Avere anche il potere di elaborare una	I was saying before about architectural barriers, an issue that would merit more attention. (…) the subtitles. So recently I have participated at a conference organised by the corporation for which I am working. We were about 250-300 people, we filled in a whole conference room of a hotel. They had contacted three Italian sign language interpreters, and of course I did not understand anything, but it is impossible to follow a conversation for different reasons, different factors, the person who puts her/his hand in front of the mouth, the screen behind the person, do not let me focus on lip-reading. Anyway, to maintain the same high level of attention for many hours, it is impossible, I get very tired, I would like to be helped with a support of direct subtitling, to read subtitles. This allows me to be, to feel integrated, to be informed, to know what is happening, despite my deafness. To have also the power to elaborate an

mia opinione, dovrebbe essere una portata di tutti, un diritto di tutti, un diritto per la persona, anche per convivere meglio con la propria sordità, che già è difficile. Di me sarebbe interessante una piu ambia sensibilità.	opinion of mine, it should be in everyone’s reach, a person’s right, also to live better with one’s own deafness, which is already difficult. For me it would be interesting to have a broader sensitivity.
Perché la comunicazione per me è più facile quando ci sono poche persone, se non ci sono meno persone, è chiaro che diventa più difficile. C'è un corso su una qualsiasi cosa, faccio un esempio assurdo, ti spiega e mi piacerebbe seguire tutta la lezione in qualche modo una sottotitolazione sarebbe una cosa fantastica. (...) Allora, un'interprete come dicevo prima, no, perché non conosco la LIS, quindi.. Però mi piacerebbe molto che venisse diffusa, fare conoscere diffusa, mettere a disposizione la sottotitolazione in diretta, se io partecipo a un convegno per motivi di lavoro, o anche per il mio tempo libero. Spesso potrebbe un interprete LIS, ma questo non mi è di aiuto. Mi piacerebbe trovare invece una persona addetta alla sottotitolazione, e permettere di seguire il convegno, questo purtroppo non c'è. (...) Ma secondo me sarebbe anche più utile, perché è più accessibile a tutti. Al giorno d'oggi secondo me meriterebbe un po' di attenzione in più.	Because communication for me is easier when there are few people, if there aren’t fewer people, it is clear that it becomes more difficult. There is a course on whichever thing, I am making an absurd example, she/he explains it to you and I would like to attend the whole lesson somehow subtitling would be a fantastic thing. (…) So, an interpreter, as I was saying before, no, because I don’t know the Italian sign language, so… But I would like it a lot if it became spread, made known, widespread, to make available direct subtitling, if I participate in a conference for work reasons, or also at my leisure time. Often there could be an Italian sign language interpreter, but that does not help me. I would like to find instead a person assigned for subtitling, and allow me to follow the conference, but unfortunately that does not exist. (…) But I think it would even be more useful, because it is more accessible for everyone. Nowadays I think that it would deserve a bit more attention.
L'informazione, mi viene in mente anche le società, gruppi multinazionali, un ambito delle risorse umane, sono principalmente difficili, risorse umane che si occupano anche banalmente del corso dell'amministratore delegato, che due o tre volte l'anno a cui tutti partecipano, anche lì è importante, quindi per sensibilizzare la gente sicuramente, una campagna di informazione. Poi magari si fanno una pubblicità, non so.. se dedicassero uno spot alla sordità. Perché la sordità è un handicap che non si vede, è una disabilità che spesso, quasi sempre non vedi. Io mi ricordo di episodi qualche volta imbarazzanti in cui comunicavo con un udente, andavano nel panico, cominciavano a gesticolare a urlare, rifiutando la comunicazione con me. Questo	Information, also to my mind comes corporations, multinational groups, the field of human resources, they are mainly difficult, human resources that are dealing commonly with the course of the managing director, in which two or three times per year everyone participates, also there it is important, so to sensitise people, surely an information campaign. Then maybe they will do an advertisement, I do not know… if they dedicated a [commercial] spot on deafness. Because deafness is a handicap that cannot be seen, it is a disability that often, almost always you do not see it. I remember some embarrassing incidents when I was communicating with a hearing person, they were getting panicked, started making gestures and shouting, refusing

perché non sanno come comportarsi. Ad esempio una persona non vedente, è più facile sai come comportarsi, una persona in carrozzina anche sai come comportarti, una persona non udente, ci sono diverse sfumature.. ci vorrebbe più informazione e sensibilizzazione. (...) dappertutto, ho fatto l'esempio della azienda, ma può essere proposta a quegli enti che forniscono corsi di formazione, mi viene in mente corsi di 24 ore, o corsi per il tempo libero, corsi di formazione, di qualunque tipo.	communication with me. This is because they do not know how to behave. For example, a person who does not see, it is easier you know how to behave, a person in a wheelchair also you know how to behave, a non-hearing person , there are various shades... more information and more sensitization would be needed. (…) everywhere, I made the example of the organization, but it can be proposed to those institutions that provide training courses, it comes to mind courses of 24 hours [24Ore], or courses for leisure time, training courses, of any type.
Sì, quotidianamente. (...) no, io vivo lo stesso, ci riesco.. Ci sono ogni giorno delle barriere architettoniche, a volte ci riesco a volte meno, è una vita indipendente sì. Però sicuramente mi piacerebbe avere più indipendenza, avvertire i miei limiti che possono essere superati con il supporto, e l'aiuto. (...) della società. La sottotitolazione anche in maniera più adeguata, scandendo di più il labiale, e non mettendo la mano davanti.	Yes, daily (...) no, I live anyway, I manage... Every day there are architectural barriers, sometimes I manage, sometime less, it is an independent life, yes. But surely I would like to have more independence, to feel my limits that can be overcome with support and help. (…) [help] of the society. The subtitles also more adequately, enunciating more the lip-reading, and not putting the hand in front [of the mouth].
Spesso mi è capitato di conoscere persone non udenti, che magari vivono un po' più ai margini, non sanno ancora la lingua dei segni. Io come persona cresciuta tra persone udenti, mi sono trovata in difficoltà con queste persone, preferisco frequentare persone udenti, perché ho più possibilità di confronto, di scambio, personale culturale ed intellettuale. Mentre con persone che hanno preferito per vari motivi, per difficoltà, per comodità, hanno preferito tra virgolette ‘fermarsi’ lì, è un po' come se fossero messi indietro, che non so come dire. Quindi io penso che sia anche loro come anche ‘noi’ diciamo, sempre tra virgolette, avessimo tutti gli stessi strumenti delle persone udenti. Sarebbe anche più giusto, sarebbe anche più facile. È un valore importante, se tutti avessimo gli stessi strumenti, tutti potremmo evolvere e anche crescere come persone, spiritualmente. Ma spesso nel momento in cui non si trova a poter evolvere, prima	It has often happened to me to meet non-hearing persons, who maybe live a little bit more marginalised, they do not know yet the sign language. Me as a person who grew up among hearing persons, I found difficulties with these people, I prefer hanging out with hearing people, because I have more possibilities of discussion, of exchange, personal, cultural, and intellectual. While with people who preferred for various reasons, due to difficulty, due to convenience, have preferred to in quotation marks ‘stop there’, it is a bit as if they were put backwards, I don’t know how to say it. So I think that it is them like ‘us’, let’s say, always in quotation marks, we have had the same instruments like hearing people. It would have been more right, it would have been also easier. It is an important value, if we all had the same instruments, we could all evolve and also grow up as persons, spiritually. But often in the moment in which we find that we

affrontare e superare le frustrazioni, fare un lavoro grandissimo su sé stessi. Insomma ci sono più problemi da affrontare rispetto ad una persona udente, come se facesse un doppio o triplo o quadruplo lavoro. Non so se mi sono riuscita a spiegarmi. Una persona udente fa la sua vita, il suo percorso, con problemi, chi più chi meno. Una persona non udente anche qui ci sono diverse sfumature, sono diversi tipi di non udenti, c'è chi penso come me vuole andare avanti e vuole evolvere, ma deve fare conti anche con loro problematica dal punto di integra... vuol dire quello che dicevo prima, frustrazione, sentirsi emarginato e riuscire a elaborare questi traumi ed a fortificarsi, che spetterebbe ad ogni essere umano. Si fa più fatica. Permettere anche loro una crescita, tutti abbiamo il diritto di crescere, e spesso ci viene negato anche.	cannot evolve, first to deal with and overcome the frustrations, to do a lot of work with ourselves. To conclude, there are more problems to deal with compared to a hearing person, as if we were working a double or triple or quadruple work. I don’t know if I have managed to explain myself. A hearing person does her/his life, his course, with problems, some with more, some with less. A non-hearing person, also here there are diverse shades, various types of non-hearing persons, there is the one who I think like me wants to go forward and wants to evolve, but has to deal with also with their issues in terms of integra… it means what I was saying earlier, frustration, feeling marginalised, and being able to process these traumas and to fortify themselves which would be up to everyone being human. It is more difficult. To allow also to them a growth, all of us have the right to grow, and it is often denied to us as well.