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VALLÉE D'AOSTE

**DIPARTIMENTO DI SCIENZE UMANE E SOCIALI**  
**CORSO DI LAUREA IN SCIENZE E TECNICHE PSICOLOGICHE**

ANNO ACCADEMICO 2021/2022

TESI DI LAUREA

**SEXUALITY OF PEOPLE WITH DISABILITIES: IS IT OR NOT A SOCIAL ISSUE?**

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## Introduction

Even today, the issue of sexuality of people with disabilities (PWDs) often causes discomfort to most of the people and controversy in society (Callen, 2022). Research concerning disability have only recently begun bringing the sexual issues of PWDs into the political fore, as the access in public sexual health services, the development of a disabled identity policy and the way society consider people with physiological and psychological impairments (Oliver, 2013).

Dinah Radtke, counsellor for disabled people and a woman with disability, claims that the debate concerning PWDs and their sexuality is highlighted by the curiosity of scientists and therapists that write articles and books asserting what disabled people have the right to do and to do not, even though they do not have any disability (Addlakha et al., 2017; Campagna, 2012).

There are doctors, psychologists, scholars, who had the courage to discuss the topic of sexuality of PWDs in public. This helped the more sceptical people to understand that assisting the sexuality of people with intellectual and physical disabilities (I/PDs) is not about letting a “handful of perverts” to realize their fantasies or to live out their animal urges. Indeed, PWDs, just like the majority of the people, have sexual needs. However, the difference with most of the people is that, due to their impairments, they often do not have the same possibilities and opportunities to fulfil these desires (Campagna, 2012).

The society is still characterized by myths and common beliefs that everyone should absolutely remove, such as believing that an individual with I/PDs does not experience any sexual desires, or believing that sexual pleasure does not matter for them. Above all, another widespread assertion we should get rid of is that even if PWDs would experience sexual desires, since they are unable to satisfy them as the other people would do, they should give up such a pleasure (Campagna, 2012). Indeed, even if it is well known that PWDs have equal rights to sexual and reproductive desires as people without a disability, society has disregarded their sexual and reproductive interests, aspirations, and human rights. PWDs are considered eternal children; this leads to beliefs about their sexual interests such as being asexual or hypersexual, incapable of reproduction and unfit partners or parents.

Unfortunately, the sexual and reproductive health and rights of PWDs continue to be disputed and especially for women with disability (WWDs) the situation is alarming. Even nowadays

being a disabled woman still means exclusion from a life of femininity, partnership, active sexuality, and denial of opportunities for motherhood (Addlakha et al., 2017).

All of these convictions are associated to the widespread idea that sexuality of PWDs is something that does not concern people without a disability, and since it is not considered a social problem, the majority of people have difficulties to understand the reason why the community and the society should assist them to provide their own sexuality. However, does this issue not concern all of us?

Oliver (2013), a British academic and disability rights activist introduced in the early 1980s both individual and social models of disability. The idea behind the Social Model of Disability, conceived by the Fundamental Principles of Disability document, first published in the mid-1970s (UPIAS, 1976), is that PWDs are not disabled by their own impairments but by the disabling barriers they face in society. According to Oliver, people working with disabled people had an individual perspective and approach that should be re-oriented toward a social model in order to make the work with PWDs more pertinent to their needs. However, Oliver does not believe that the individual model should be completely abandoned, and neither that the social model is able to explain everything happening to disabled people. The Social Model of Disability helped the disabled movement, which had begun to emerge a decade earlier, to strengthen and to become the vehicle capable of developing a collective disability awareness.

Callen (2022) considers the Social Model of Disability of Oliver a new way to view disability from a social constructivist perspective, which had a profound impact on sociological approaches on disability and laid the foundation of disability studies as a field in itself. Indeed, compared to the medical model, which considers disability as an individual tragedy in which the individual must be “rehabilitated”, the social model discerns *impairment* from *disability*. It considers *impairment* as all the physiological and psychological effects associated with particular typologies of diseases and disorders; and *disability* as all the cultural and structural barriers, which cause PWDs’ exclusion from society’s standards of “abled-bodied”. The social model tends to focus on the economic and material exclusions of PWDs within modern capitalist society, fighting for things such as employment opportunities, accessibility in public places and improved government assistance to PWDs.

For those reasons, Shakespeare and colleagues (1996) have tried to extend such a social and constructivist perspective of disability into the domain of sexuality, creating the Social Model

of Disabled Sexuality. Shakespeare and colleagues (1996) claim that a combination of factors within the society has left the sexual marginalization of disabled people unaddressed and unchallenged. These factors are the beliefs of asexuality, sexual inadequacy or sexual deviancy, the exclusion from the sexual market and from debates, and the indifference of politics concerning their sexuality. Indeed, many forms of exclusion and discrimination leave PWDs undereducated about their sexuality and excluded from public places. This context deprives them from the opportunity of meeting potential partners, and consequently to acquire the resources and self-esteem necessary in order to engage in sexual relationships (Shakespeare, 2000).

Even though PWDs often experience difficulties regarding their sexual scope, sexual expression, including the right to develop relationships and have access to sexual health educational programs, it is important to point out that these are all necessary human rights (Hole, Schnellert, Cattle, 2021). Moreover, the World Health Organization (WHO) declares that sexual health necessitates a positive and respectful approach to sexuality and sexual relationships, along with the possibility of having pleasurable and safe sexual experiences (World Health Organization, 2015). During the Convention on the Right of Persons with Disabilities (CRPD), the United Nation (UN) declared: *“People 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 Article 1).

Replacing the focus from the rights of PWDs to society’s responsibility, the fundamental issue turns into society’s duty, in terms of what it should provide regarding the sexuality of PWDs and of which exact nature this duty is. Thus, does society has only the simple duty to make the sexuality legally possible by abolishing certain prohibitions, or it has the duty to make sexuality actually possible by making certain resources available for PWDs? Alternatively, in a long-term perspective, does the society has the duty to guarantee sexual expression promoting research studies to overcome some of the problems that arise in the vast issue of sexuality and disability? (Campagna, 2012)

Nevertheless, sexuality is worthy of attention as it forms a key part of being human and it impacts on the health and well-being of all human beings (Gomez, 2012).

# Chapter 1. Disability and sexuality

## 1.1 Disability

In 2011 for the World Report on Disability, WHO reported that more than 15% of the world's population live with several types of disabilities, including physical and sensory impairments; and developmental, intellectual and psychosocial disabilities (Addlakha, Price & Heidari, 2017; World Health Organization, 2011).

Disability is a significant functional limitation that reflects an inability in both personal functions and social performance associated to expected roles and tasks. It is a condition strongly related to a lack of physical and mental health outcomes and less participation in personal and socioeconomic decisions. Indeed, it represents a substantial disadvantage to the individual and it is influenced by contextual factors, thus it can be worsened by obstacles which preclude opportunities, equity and inclusion and it can be mitigated (reduced or alleviated) through interventions and supports (Luckasson & Schalock, 2013; Martinez Rios, 2013).

The UN Convention on the Rights of Persons with Disabilities assert that PWDs are people with long-term physical, mental, intellectual or sensory impairments, which the interaction with various barriers may impede their full and effective participation in society on an equal basis with others (United Nations 2006 Article 1).

Inside the vast domain of disability, it is possible to discern four different types of disability: Intellectual disability (ID), Developmental disability (DD), Developmental disabilities (DDs), Intellectual and Developmental disabilities (IDD) (Schalock, Luckasson, Tassé; 2019).

ID is characterized by significant limitations both in intellectual functioning and in adaptive behaviours as is showed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. The American Association of Intellectual and Developmental Disabilities defines ID as a group of disorders characterized by limited mental capacity and connected difficulties with adaptive behaviors such as managing schedules, routines and social interactions (American Association of Intellectual and Developmental Disabilities; Schalock et al., 2010).

DD is a severe and chronic disability that is due to a mental or physical impairment or a combination of both. It manifests before the age of 22 and is likely to continue indefinitely. In addition, it causes substantial functional limitations in three or more major life activity areas and consequently it leads the individual to require lifelong or extended duration support and assistance, which are individually planned and coordinated (Developmental Disabilities Assistance and Bill of Rights Act Amendments, 2000).

DDs refer to a group of conditions due to an impairment in physical, learning, language, or behavioral areas. These conditions arise during the developmental period, might affect day-to-day functioning, and usually last throughout a person's lifetime (Centers for Disease Control and Prevention, 2018). IDD is the term used to refer to the vast field of intellectual and developmental disabilities. IDD are state of decreased functioning associated with disease, disorder, injury or other health conditions, which are considered by the social context consider as impairments, activity limitations or participation restrictions (Leonardi, Bickenbach, Uston, Kostanjsek, Chatterji, 2006; Schalock, Luckasson, Tassé, Verdugo, 2018).

During the Declaration of the Rights of People with Disabilities, Claude Hamonet defined disability as the restriction of both personal activities and/or the participation to social life, which emerges from the interactive contrast between the individual's abilities characterized by one or more lasting, physical, mental, sensory functional limitations and the physical and social impairments of his/her living environment. The definition highlights that disability is associated to two fundamental concepts: the individual and the environment, in which the individual lives and has or must perform certain tasks (Campagna, 2012).

According to this approach, if the individuals are able to perform tasks without particular difficulties comparing to the average, they are not considered disabled, otherwise if they do not achieve or if they do but only by putting additional effort, they would be considered PWDs. Hamonet underlines that these impairments might lead the individual to social isolation, especially when these tasks are essential for the social integration of his/her self. Indeed, a deaf person does not only have to deal with the incapability to carry out certain tasks but also with the inability to attend events such as a concert or a theatrical play (Campagna, 2012).

Two important and controversial models characterize the discussion concerning disability, the medical model and the social model. The medical model primarily considers disability as

a somatic dysfunction. Therefore, the medical model is based on specific norms, which determine the proper functioning of the organs and according to which it affirms the presence or absence of a disability in an individual. On the other hand, the social model, without neglecting the biological aspect, emphasizes the social environment and defines disability only in terms of realizable tasks. As an example, it considers an individual who has to go to an administration office in order to get an ID document. If both the individual using a wheelchair and the individual using his/her own legs can reach the task, without encountering any considerable obstacles, there is no need to talk about disability, at least not directly regarding that issue. This might be explained as the achievement of the same goal in two different ways (Campagna, 2012).

According to this approach, it might consider a case of disability an individual with wheelchair who would have the necessity to use public transportations, but which are not adequately arranged for PWDs and he/she might need the help of other people. In that case, the individual is considered disabled in that certain task only because the situation is invalidated. Therefore, if the social environment would be designed for PWDs, probably these people would not be considered as disabled, whereas people without disability would be (Classification Internationale du Fonctionnement, du Handicap et de la Santé, 2001; Campagna N, 2012).

The medical “solution” is to rehabilitate, thus, operate on the individual in order to compensate the organic dysfunction. Therefore, for the medical model the environment in which the person with disability is, it is not taken into consideration. The social model proposes a completely different approach. The social “solution” to the disability issue is an operation that primarily address the environment that consists to eliminate all the invalidated obstacles that complicate a certain portion of the population. Indeed, the social model believes that the problem on the accessibility for PWDs does not concern the individual’s inabilities; differently it concerns the inaccessibility of the social context (Campagna, 2012; Oliver, 2013).



## 1.2 Sexuality

Sexuality is a multifaceted construct, which includes sexual activity, behaviour, function, attitudes, motivation and partnership (Srinivasan et al., 2019). It is a very important part of the personality of each individual, a nature human need and it cannot be separated from any other life domains, including quality of life and life satisfaction (Chrastina & Vecerova, 2018).

Sexuality involves physical, physiological, psychological, social, emotional, cultural and ethical dimensions of the personality and gender. Moreover, it affects thinking process, interactions, feelings, activities and it has an impact on the mental and physical health (Gomez, 2012). Therefore, sexual expression, including the right to develop relationships and access to sexual health education, is an innate human right (Hole, Schnellert, Cante, 2021).

Indeed, already in 1975, the WHO, regarding sexual health, declared that sexuality is a fundamental part of everyone's personality (men, women and children) and it is a basic human being aspect that cannot be separated from any other human life's elements (Coleman, 2002). However, this definition of sexuality mentioned both adults and children's sexuality, but it could be more appropriate to mention also aged and disabled people. Indeed, the sexuality of these people has often been ignored or neglected. The definition also highlights the innate nature of the sexual and sexuality needs, suggesting that these needs are not related to the category of artificial needs, resulting from a certain type of socialization but they are an integral part of our human condition (Campagna, 2012).

Therefore, the impossibility to satisfy one's sexual need would affect other aspects of the person life, such as the physical and mental health. Similarly, while satisficing one's sexual needs, the individual should not neglect the satisfaction of other needs or constitutive dimensions, such as the need of respect, gratitude, love, intimacy. The sexual function does not have to be considered as a simple biological function, but it needs to include in social and cultural aspects (Campagna, 2012).

To conclude, every human being, independently by the age and the gender, should have the possibility to satisfy one's own sexual and sexuality needs, and this satisfaction should have the same importance of other individual needs (Campagna, 2012).

### **1.3 Sexuality of people with disabilities**

Historically, sexual promiscuity, mental illness and “idiocy” were inner and closely associated with crime, poverty and disease, thus the possibility of IDD people to have children was considered a main problem. Indeed, for a long time the sex lives of PWDs had to endure misconceptions, myths and stereotypes, which were related to the idea of asexuality or sexual deviance (Callen, 2020).

Within the society, several common beliefs are still present concerning PWDs’ sexuality such as asexuality, sexual inadequacy or dysfunction, sexual unattractiveness, child-like innocence or dangerous sexual deviancy. Disabled individuals often internalize these misconceptions, causing problems in the developments of their self-esteem and sexual expression (Callen, 2020). Consequently, for people with IDD the access to sexual expression and freedom is often denied (Stein & Dillenburger, 2017).

Milling and Neufeld reported that before the 1970s sex and disability were under researched and the few studies covering this topic were primarily focused on the biological and medical understanding of disability (Ebrahim, 2019).

However, in the last decades the concept of disability shifted from a medial and biological condition to a form of social oppression. According to Shakespeare (1996), disability is not due to a different body but to a society, that habitually subjects PWDs to devaluation and desexualisation (Ebrahim, 2019). Indeed, disability began to be seen under a sociological perspective and to be defined as a dynamic, interactive relationship between a person with an impairment and his/her social environment. Decisive for this changing of perspective was the disability right movement, which raised from some organizations during the 1970s and begun to demand that needs of PWDs must be respected and met (Stroman, 2003).

Looking at the society now, it is clearly noticeable that some group’s sexual scripts are normalized and manifested more than others, such as the heterosexual, non-disabled, monogamous couple. Thus, a couple where one or both partners have disability is rather invisible in these cultural contexts. Consequently, for PWDs it became hard to achieve their intrapsychic sexual scripts and have been denied from opportunities and access to sexual expression. In this context, all these aspects can be analysed in terms of social exclusion and powerless, where the majority of the population had advantage (Bahner, 2012). These beliefs and stereotypes put PWDs at a greater risk to sexual exploitation, disease and/or mental

health issue. Contrary to these myths, PWDs desire meaningful relationships, both friendships and sexual intimacy relationships (Brown & McCann, 2018; Kelly et al., 2009).

Unfortunately, PWDs have to confront themselves with the society's limited view based on prejudices, taboo and false beliefs, in which sexuality tends to be related to youth and full physical and mental capability (Franco, Cardoso, Neto, 2012).

Many factors affect sexuality of PWDs, such as biological (side effects of medications, type of disability, etc.), psychological (internalized stereotypes, body image, etc.), educational (provider competences) and sociocultural (access to relationships). These factors, which interfered with the sexual experience of disabled people, can be divided as direct and indirect factors. Direct factors are due to a physiologically consequence caused by injury or disease, instead indirect factors refer to physical condition which interfere with sexual experience (e.g., mobility) and the psychosocial variables associated with living with a disability (e.g., changes in body image) (Eisengber et al., 2015).

Indeed, when people with ID begin to discover their own sexuality, they have to deal with several problems (Chrastina & Vecerova, 2020). Therefore, people with ID still face discrimination and stigma while expressing their sexuality. They are often considered as having a lack of cognitive capacity for sexuality, instead of being recognized as sexual agents with different sexualities. Indeed, concerning sexuality, people with ID are seen as asexual, sexually inactive or conversely sexually deviant (Hole, Schnellert, Cattle, 2021).

Moreover, even people with PD are often considered by mainstream society as asexual and less attractive as, due their impairments, they do not fit in the widespread society normative standards (Sakairi, 2020). Many of them when they begin to discuss or express their sexuality, they still have to face prejudices and ignorance, which is just another way of delimitating sexual expression for PWDs through disciplinary power (Bahner, 2012). Society perceived sexuality as a privilege of the white, heterosexual, young, single, non-disabled and physically attractive people, thus specifically the male sexuality is seen in an exclusive, phallogentric and oppressive way commonly based on physical performance, and this may lead men with PD feeling castrated and emasculated (Callen, 2020). However, sexuality is not only based on physical performance; contrary is deeply connected with emotional closeness and pleasure, which can be achieved through any kind of practices (Sakellariou, 2006).

### **1.3.1 Sexual Rights and disability**

During the 1980s in Europe, the sexuality of PWDs came into view. At the time, several European organizations tried to spotlight PWDs' sexual needs and rights (Morales, Quattrini, Auger et al., 2020).

In 1993, the General Assembly of United Nations made the first international scientific reference concerning PWDs' sexual life, publishing, "the standard rules for the Equalization of opportunities for persons with disabilities" (United Nations, 1994).

In 1997, the World Association for Sexual Health (WAS, 2016) during the World Congress of Sexology held in Valencia brought the idea of drawing up a declaration of sexual rights. Their main aim was to assert the connection between physical and mental health and a full and health sexuality, which is a right of every human being (Mannino, Giunta, La Fiura, 2017).

Successively, in 2006 the UN approved the Convention on the Rights of Persons with Disabilities (United Nations, 2006) in which it indicated how the various countries should proceed to ensure equality and full inclusion of all citizens with disabilities (Nazioni Unite, 2016). In the Article 25 of this Convention, the sexual health is considered a state of emotional, social and mental wellbeing (World Health Organization, 2015) and it is focused on providing to PWDs the same range, quality and service standards as the other people (Nazioni Unite, 2016).

Only in 2008 the WAS published the Declaration of Sexual Rights with the goal to recognize, promote, ensure and protect sexual rights of all individuals (World Health Organization, 2015). During the same time, also the WHO was operating to protect the sexual rights of all individuals, both with and without disability (Mannino, Giunta, La Fiura, 2017).

More recently in 2014, the WAS referring to the charter of human rights in a more extended way, established a new declaration which resulted in the nowadays' one regarding the sexual rights of PWDs (WAS, 2016). With this declaration, sexual rights, which are grounded in universal human rights, are considered extremely important, in as much sexuality is a central aspect of the human beings and includes concepts as gender, sex, identities, roles, sexual orientation, eroticism, pleasure, intimacy and reproduction (Mannino, Giunta, La Fiura, 2017).

### **1.3.2 Representations of disabled sexuality: body image and the role of pornography**

In our society, the body has a central symbolic role in the context of sexuality. However, the body with disabilities for many non-disabled people is seen as unattractive, non-sexual and non-gendered. Thus, might also affect the self-image, identity and feelings of unattractiveness of PWDs (Bahner, 2012).

Already in 1988, Hahn claimed that it is not only the myth of asexuality or sexual deviancy that contributes to negative attitudes, but the role of what he defines as “aesthetic anxiety”. For Hahn, this term refers to the fear originated by an appearance that either deviates from the typical human physical aspect or one that include particular features which are considered unappealing. These fears turn into both avoiding behaviours to the detriment of people that are physically different and the pressure to attain “supernormal standards of bodily perfection” (Hahn, 1988).

However, despite experiences of sexual exclusion, many PWDs declare to have a satisfying sexual life. Moreover, individual stories concerning the sexuality of PWDs, even if predominantly of heterosexual white men, have moved the issue from the private sphere into the public domain in western nations such as UK and Australia. This improvement regarding the right to access into disabled sexuality and disability pornography may be seen as a way to promote sexual emancipation of PWDs, already started by the disability rights movement. Indeed, pornography has held the power to circumvent some of the barriers of PWDs (Ebrahim, 2019). Pornography for “saktevoerotophilia” (love for disabled sexuality) might be considered as a positive move towards the liberation and increased visibility of the sexuality of PWDs. Disability pornography not only embraces the disabled body, but also displays that it can be a source of physical pleasure. This is such an important step because it makes visible historically stigmatised sex representations, thus empowering a previously largely unrepresented and marginalised group (Ebrahim, 2019).

Furthermore, since sexual worth is deeply correlated to the degree of physical beauty and attractiveness, it could show imperfect or abject bodies performing sexual activities in pornography lead to the vitalising of the sex appeal of disabled bodies (March, Grieve & Marx, 2015; Ebrahim, 2019).

### **1.3.3 Social participation**

People with physical and communication disabilities might have limited opportunities to socialize and form friendships. Indeed, many older adults with lifelong disability encounter obstacles in communication including those with cerebral palsy. This might affect their ability to interact with others and to initiate or maintain friendships. Thus, PWDs have the risk to experience loneliness (Sellwood, Raghavendra, Jewell, 2017).

Indeed, much research (Ager et al., 2001; Cummins & Lau, 2003; Bigby et al., 2001) had shown that although many adults with lifelong disability are now more physically integrated in the community, they are often not truly part of it.

In the Ballin and Balandin study (2007) with people with cerebral palsy, the participants reported that all those public places such as bars, churches and social clubs, which can be places to socialize, they can turn to places of limited opportunities for people with complex communication needs due to disability.

### **1.3.4 Relationships and sexuality**

PWDs face many barriers in several different types of relationships (Gomez, 20127).

The most frequently difficult relationships reported are the one with caregivers, family members and/or workers, who support and help PWDs (Hole, Schnellert, Cante, 2021). According to Ulivieri (2015), an Italian activist and writer who is trying to introduce sexual assistance service in Italy and a person with PD its selves, one of the first things PWDs lose due to their disability is their own intimacy. Ulivieri explains how their dependency on their partner affect their inability to achieve the personal pleasure. Indeed, PWDs might address several obstacles due to their impairments and to the fact that most of them live with their parents or caregivers. In fact, some obstacles are caused by a lack of privacy due to the fact they do not live alone, such as the risk to be heard, whereas others are directly connected to their impairments such as the undressing and cleaning part subsequent to the practice, which forced them to ask help to their parents or caregivers.

Furthermore, many research studies (Hole, Schnellert, Cante, 2021) described cases where staff or parents chastised participants for physical intimacy, teased them when they were discussing sexual topics and were not allowed participants partners to stay overnight. This attitude of over control, suppression and lack of privacy can lead people with ID at many

dangerous behaviours, such as being sexually active in public or semi-private places (Hole, Schnellert, Cantle, 2021).

Unappropriated support from family members and professionals about sexuality also affect people with PD, whom without that assistance found very hard to avoid the internalization of ablest opinions received from the social context (Bahner, 2012).

Often, PWDs also have difficulties with intimacy relationships. According to the Social Model of Disabled Sexuality” of Shakespeare (Shakespeare, 2000) it has been created a gap between the public and the private spheres, which lead the sexual marginalization of PWDs undressed and unchallenged. This gap is originated by the combination of several factors such as societal assumptions amongst PWDs of asexuality, sexual inadequacy or sexual deviancy, and the exclusion and neglect of disabled people from sexual discourses and sexual politics (Callen, 2020). Consequently, all these forms of exclusion and discrimination within the society leave PWDs undereducated about sex, excluded by public places where they could meet potential partners and unable to acquire all the necessary resources and self-esteem in order to have a sexual relationship (Callen, 2020). Therefore, Shakespeare affirms *“The problem of disabled sexuality is not how to do it, but who to do it with...”*(Shakespeare, 2000, p.161). Through this statement, Shakespeare and colleagues tried to make sexuality and relationships of PWDs areas of struggles for societal change and inclusion, bringing them into the purview of disabled politics (Callen, 2020).

Moreover, other research studies (DeLoach, 1994) reported that many in the society are more comfortable with the idea to have a friendship or a co-worker's relationship with PWDs than to have a potential dating or marriage partners. Furthermore, those with a PD that were married reported lower levels of sexual well-being than those who had non-live-in partners. This is possibly caused by the burdens perceived by their non-disabled partners, due to their additional role in the couple as caregivers (Callen, 2020).

For all these reasons, PWDs and WWDs in particular are less likely to have intimate relationships than individuals without disabilities, due to several barriers such as fewer opportunities, physiological obstacles to engaging and the dual role partner-caregiver. However, not all PWDs view their disability negatively in terms of sexuality; some of them even noticed that due to their disability their partner had a more loving and sexually creative approach. Such a sex positive and adaption approach draws on strengths instead on focusing on the limitations of PWDs (Eisenberg et al., 2015).

In 2006 Sakellariou carried out a study concerning Greek men with spinal cord injuries, in which he reported that these men considered their lack of sexual satisfaction not necessarily originated from their impairments but rather from many social factors, such as negative social beliefs about disabled sexuality, lack of employment opportunities and issues with accessibility and assistance (Sakellariou, 2006). In another study carried out by Healy, McGuire and colleagues (2009), most of the participants claimed that they do not know why people with ID were prevented to establish relationships. Specifically, one participant reported that people with ID, including him, should not have relationships because according to people without disabilities they are not able to understand what they are doing. The results of their study also show that the social and sexual awareness of people with ID increase with age. Indeed, they express dissatisfaction with the unfair situation, especially because they are aware of the sexual and relationship autonomy provided to their siblings.

Furthermore, it also reported that the way sexual relationships with disabled people are considered and seen, extremely change from culture to culture. Indeed, many racial and ethnic communities themselves often feel more uncomfortable than others on the idea of having romantic and/or sexual relationships among disabled people (Callen, 2020). In a study that took place in the Southwestern part of United States with Hispanic and Caucasian undergraduates from two universities (Marini et al., 2012), Marini and colleagues found out that Hispanic students were less likely to be willing to date a wheelchair user than Caucasian students. On the other hand, they find out that females were more willing to both date and marry a wheelchair user compared to males.

All these studies prove how these discriminatory cultural and structural factors within the larger society deeply affect PWDs, who are consequently forced to face a variety of challenges in establishing sexual and other types of romantic relationships (Callen, 2020).

However, Hole, Schenellert and Cantle reported that, regarding what PWDs considered important to know and learn more about, the participants highlighted qualities of respect and parity within relationships (Hole, Schnellert, Cantle, 2021).



### **1.3.5 LGBTQ people with disabilities**

LGBTQ people with disabilities have to deal a sort of “double discrimination”, both for being disabled and for enacting non-normative sexualities and genders (Campbell, 2017; Duke, 2011; Martino, 2017).

Indeed, LGBTQ people face severe judgments concerning their gender and sexual expression as many in society see their sexual orientations as pathological deviance stemming from their impairments or resulting from an inability to attract heterosexual partners (Callen, 2020).

However, Smit-Rainey (2017) has asserted that in terms of communication across queer and disabled movements, both often marginalize those who are the most “dependent and queer” in order to appeal to the broader ableist, heteronormative society.

Furthermore, Egner (2019) found out that while the “neuro-queer” community embraces the deconstruction of normative definitions of gender, sexuality and disability, many in the community also distance themselves from LGBTQ, feminist and disabled activist communities, embracing a “fluid” sense of “intersectional selves”. Thus, the confusing identity politics, along with ableist and heteronormative beliefs in both disabled and non-disabled spaces, mainly complicate the dual dismantling of imposed able-bodied and heterosexuality values (Callen, 2020).

### **1.3.6 Gender differences in disabled sexualities**

Garland-Thompson (2017) and others (Ferri, Gregg, 1998; Morris, 1993) claim that by problematizing disability as a social construct as gender, it is possible to gain an even more complete understanding of both power dynamics and resistance points existing within issues of identity, intersectionality and embodiment. Both femaleness and disabled are considered by the dominant society as deficient and lacking by the standards of the male-dominated and ableist society (Callen, 2020).

Pearson and colloquies (2017) reported that having negative attitudes towards the sexuality of women with PD is associated with having a traditional view of gender roles. Indeed, Cheng (2009) highlighted that many within a society often see WWDs as not fulfilling the traditional roles of female, due to their assumed characteristics such as the inability to fulfil the natural mother role, asexuality if they are physically disabled or promiscuity if they are cognitively disabled.

The feminist theorizing on social issues such as disability, gender and sexuality can be seen not only aimed at the white, heterosexual, male bias, which often exist within the Social Model of Disability, but also as a critique to the male-centric conceptualization of independence, ability, strength, and power that exist within the larger ableist society (Cheng, 2009). Another study (Yoshida et al., 1999) carried out by Yoshida and colleagues in 1999, conducted with ten disabled women of colour from “ethno-cultural” communities in Ontario (South Asian and Indo-Caribbean), shows the effect of gender cultural beliefs into disabled sexuality, intimate-marital relationships and having a family. Indeed, Yoshida and colleagues (1999) found out that the traditional gender roles and the misconceptions concerning asexuality and undesirability beliefs to the detriment of disabled women within these communities, were limiting their opportunities to open discussions and to learn about sexuality, intimate relationships and the possibility to have children.

Some research studies analysed the differences between women with physical and intellectual disabilities in regard of sexuality (Callen, 2020). Certain studies, focused on the experiences of women with spinal cord injuries (Parker & Yau, 2012; Whipple et al., 1996), highlighted the several challenges that these women face such as sexual dissatisfaction immediately following the injury and a lack of sexual health information from doctors, due to the widespread belief of a presumed loss of sexual desire. The sensory loss is a debate issue; indeed many PWDs eventually reach a phase of “sexual rediscovery” characterized by a more open communication about sexual needs and the engagement with alternative forms of sexual arousal. Instead, regarding women with ID, Tilley and colleagues (2012) assert that the current debates and general uneasiness about their reproductive rights are a “continuation of eugenic practices”. In a study concerning women with ID carried out in 2013 (Bernert & Ogletree, 2013), most of the women reported to perceive sex negatively, to practice abstinence and to have exclusively monogamous and heterosexual experiences. Moreover, the majority of the stereotypes regarding ID are contradictory, such as the belief of sexual vulnerability and asexuality. Moreover, WWDs have also a high risk to experience sexual abuse, due to several factors such as isolation, proximity and dependency on caregivers, underreporting of victimization, cultural insensitivity and discrimination that can lead a lack of self-esteem and self-blame among abused disabled women (Callen, 2020).

Regarding disabled masculinities, less theorizing and empirical research has been carried out when compared the feminist disability studies, most of the studies theorizing on disabled masculinities focus on “the crises of masculinity”, particularly due to bodily limitations

associated with physical impairments. Within the society, disabled men are perceived as not fitting society's male standards because of their dependency and limitations due to their impairments, thus undermining their masculinity (Callen, 2020).

Furthermore, Shakespeare (1999) found out how the stereotypical focus on phallogentric function and the emphasis on the hegemonic masculine regarding physical performance, instead of emotional and relational intimacy, contributes to the sexual marginalization of men with disabilities (MWDs). However, Shakespeare also highlighted the case of many disabled men, whom through some creativeness they placed greater emphasis on relational and emotional intimacy, and they engaged in alternative forms of erotization, thereby expanding both their masculine and sexual repertoires (Callen, 2020).

However, Yoshida and colleagues (1999) interviewed several WWDs in South Asian communities, who declared that MWDs were not interested to become romantically involved with disabled women. Indeed, another study carried out by Addlakha (2007) with Indian college students who had visual or locomotor disabilities, reported that even though female students were probably more sexual marginalized, the male students were much more likely to internalize hegemonic masculine norms regarding sex and relationships, preferring a non-disabled partner (Callen, 2020).

### **1.3.7 Sexual health education service**

Historically, the role of sexual health education has been unheeded in the assessment and treatment of PWDs. This is probably due to feelings of discomfort and lack of competencies in discussing sexual health, and few assessment tools or treatment strategies designed specifically for PWDs (Eisenberg et al., 2015).

Dukes and McGuire (2009) found out that providing an individualized sex education to people with ID, directly improve their abilities to make independent decisions in their sexual relationships. Indeed, health education cannot be disregarded, as it is fundamental for the individual in order to have a save sex life (Hole, Schnellert, Cantle, 2021). Unfortunately, only half of PWDs are involved in sex education (Chrastina & Vecerova, 2018).

Wilkinson reported that people with ID encounter several obstacles when it comes to sexual health education (Wilkinson et al., 2015). In a qualitative study focused to explore experiences of sexual health education among adults with ID (Hole, Schnellert, Cantle, 2021), the scholars found out three main areas coming up from the majority of participants,

who declared their strongest memories they had concerning the sexual education they have received. The first area covered topics such as transmitted diseases, condom use and pregnancy. Consequently, this focus led people with ID to internalize that sexuality is associated to risky and dangerous practices. The second type of strongly emphasized information that they reported are about human anatomy and sexual reproduction, through a focus on body parts and the mechanism of sex. This emphasis limits the vast domain of sexuality, shutting down any other richer way to consider an intercourse through its numerous nuances. The third central topic regarded the importance of safety and consent. However, the topic was principally transmitted to disabled people through conversation focused on the risks of having sex. Thus, the participants have internalized that was better to avoid sexual experiences in order to not risk any non-consensual experience. Regarding what is considered important to know and learn, the participants highlighted qualities of respect and parity within relationships (Hole, Schnellert, Cantle, 2021).

In conclusion, sexual health education cannot be disregarded, thus a lack of sexual knowledge may increase the risk of sexual abuse and sexually transmitted diseases (McDaniels & Fleming, 2016).

### **1.3.8 Sexual abuse**

The American Association on Intellectual and Developmental Disability (AAIDD) defines sexual abuse as unwanted sexual contact obtained by forcing, threatening, coercing, tricking, or manipulating another person, who is unable to consent to (Stein, Dillenburger, 2017).

For people with ID, this risk to be sexually violated is even higher (Hole, Schnellert, Cantle, 2021). Tomsa and colleagues (2021) claim that one in three adults with ID experience sexual abuse. Another study (Smit, Scheffers, Emck et al., 2019) reported that people with ID have between 7 and 34% risk to be abused.

Moreover, several recent studies highlight that people with IDD have much higher rates to endure non-consensual sexual experiences than non-disabled individuals do, specifically the worldwide incidence in IDD's children ranging around 44% and in IDD's adults around 83% (Stein, Dillenburger, 2017).

## **Chapter 2. The invisible needs of women with disabilities**

### **2.1 The changes in the ideology of sexuality of women with disabilities through the centuries**

In the early 20<sup>th</sup> century, the violent eugenic practices of institutionalisation and compulsory sterilisation, to the detriment of WWDs, were caused especially by the fear concerning their sexuality and their reproductive capability, since at the time disability was considered as a transmitted disease (McCarthy, 2014; Campagna, 2012). Indeed, the prestigious psychologist of the time Goddard declared, concerning ID in which he called “feeble-mindedness”, that it was highly hereditary, asserting that at least two-thirds of all the cases were children or grandchildren of other people with ID (Stein & Dillenburger, 2017).

Only during the latter decades of the 20<sup>th</sup> century, it began to emerge detailed evidence on the way women with ID experience their sexual lives, especially concerning their vulnerability to sexual abuse and exploitation (Fitzgerald & Withers, 2013; Kempton, 1972; Lowes, 1977). At that time, the research studies were particularly focused on how women with ID were experiencing relationships and sexual life. One study on marriages involving women with ID presented evidence showing that husbands, with or without disabilities, were typically more intellectually able than their wives and were often the dominant and abusive partner. Other studies suggested that, in general, sex was conceived as a negative experience for the women with ID, especially for two main reasons, a lack of sexual agency and a high level of sexual abuse (McCarthy, 2014).

At that time, the social inclusion and health developments generally began to improve in USA for individuals with ID and PD, due to state and federal protections such as the “Rehabilitation Act” of 1973 and the “Americans with Disabilities Act” (ADA) of 1990. Furthermore, the decision of the U.S. Supreme Court’s landmark *Olmstead* in 1999, promoted the delivery of health care services in communities for PWDs and established legal protection against the forced or coerced sterilization of women with I/IDD (Chou, Lu, & Lin, 2018; Verlenden et al., 2019).

In 1993 the United Nations and the ministries responsible for women’s issues from different member states, were committed to eliminate violence against any women from any nationality, conditions (both physical and psychological), social class and sexual orientation.

Yet, only in 2006 PWDs began to be considered more likely to be victim of violence and it has been acknowledged the necessity to insure or increase their protection (Fitzgerald & Withers, 2013; Parsons et al., 2017).

## **2.2 The difficulties that women with disabilities face nowadays**

Unfortunately, still now WWDs endure several obstacles concerning their sexuality, especially in a social context that hardly understand their sexual needs. The barriers that women with PD face the most, are related to their sexuality and sexual- reproductive health. In particular regarding the access to sexual-reproductive health services and the social attitudes that define disability as de-sexualising, which results in the undermining of the women rights to be considered and treated as sexual beings (Hunt, van der Merwe, Xakayi, Du Toit, Hartmann, & Hamilton, 2021).

The reproductive health care for women with I/PDs has always been a practice of segregation, institutionalization, and stigmatization. Indeed, WWDs claim to experience sexual reproductive health disparities, in terms of unintended pregnancy, victim of sexual abuse, and limited access to reproductive health care (Verlenden et al., 2019).

Concerning social attitudes which refers to sexuality, WWDs are more likely to be ignored by their parents, professionals, and the community they are involved in, than their peers (Chou et al., 2018). These attitudes are the consequence of a social context, in which women with I/PDs are in, that is often characterized by many widespread misconceptions about the sexuality of WWDs, supported by most of the people. Consequently, when a WWD attempts to express her sexuality is often a victim of misunderstanding, fear and prejudice, and is considered as “deviant” or “asexual” (Parsons et al., 2017).

In 2011, a UK study concerning how women with ID consider their sexuality or develop a sexual identity was conducted. Many of the women reported that they do not consider themselves as sexual beings and hardly think or talk about sex and their sexuality with other people, since they deemed it as “dirty and disgusting” or they associated it with diseases and infections (Fitzgerald & Withers, 2013). Regarding PD, in 2016 a qualitative Canadian study interviewed 8 women with PDs, specifically 3 women with cerebral palsy who always use wheelchairs and five with motor disabilities in their upper limbs or no arms. The participants declared that a common belief of the majority of people is that WWDs are asexual and that

they do not masturbate, this misconception promotes an attitude of silence and incomprehension about any abuse they might experience (Parsons et al., 2017).

The society also has an effect on the way women with I/PD accept and consider themselves as sexually interesting to others. Indeed, society's beauty standards are often in contrast with their physical aspect, and thus some of them create a negative body image and a lack of confidence. Regrettably, this negative consideration of themselves let them feel lucky when someone is interested in them, therefore these women are more likely to have an unhealthy and violent relationship (Vaughn et al., 2015).

In addition, the society forms and imposes gender roles and responsibilities, such as the capability to be sexually active and the reproductive capacity for a woman. This leads WWDs to be in secondary positions of power and consequently forced to depend on men for status and resources, and to be more vulnerable to violence. Especially, when women experience financial dependency, social isolation, difficulties on their physical self-defence, exclusion from violence prevention programs (Hunt et al., 2021). In a sexuality research study conducted in San Francisco (USA) in 2014 with WWDs, from 28 to 52 years old, one participant pointed out that her incapability to have an intimate relationship with men was due to the lack of trust she had about them concerning safe sex and remain faithful in the relationship (Vaughn et al., 2015).

Adolescence, a life phase already problematic, became for women with I/PDs even more difficult and complex. Indeed, in adolescence many of these women live with excessively protecting caregivers, who nether encourage, emphasize nor normalize their sexuality. Consequently I/PD women have a lack of relationship and sexual knowledge and many of them consider sexuality as a negative experience, even though they have a strong desire to learn more about it (Parsons et al., 2017). Furthermore, teenagers and young WWDs may experience additional challenges with emotional regulation and behavioural during menses, such as excessive fatigue, crying, sadness, anxiety, and cramps, as well as increases in behaviour symptoms associated with some DDs (Verlenden et al., 2019). Women with disabilities are also generally highly vulnerable to depression, because their condition may cause them a limited mobility, which lead them to be isolated and have less opportunity to meet new people.

Masturbation is a practice of sexual exploration, which gives women the opportunity to learn more about their bodies, desires and sensations, thus it is important since it promotes

women's sexual empowerment (Tiefer, 1996). It is common between all the women, especially those with a disability, when it is physically possible (Herbenick, Reece, Schick, Sanders, Dodge, Fortenberry, 2010; Bowman, 2014). Unfortunately, masturbation has always been socially undervalued and discredited due to fear and taboo, which resulted from religious and cultural beliefs and that leads women to feel contradictory feelings such as desire and shame (Browne & Russell, 2005).

Unfortunately, for some PWDs this activity is impossible to achieve for many reasons, among which their inability to touch their own body, lack of neurological sensations, incapability to be left totally alone and their impossibility to have an adapted sexual education which properly teaches them how to satisfy their own desires (Sevène, 2014). These difficulties not only sometimes complicate or even do not allow the achievement of this practice, but often also increase their dependence on other people, causing a lack of intimacy (Taleporos & McCabe, 2001). Since they are unable to provide for their own personal pleasure, it might be easier for them to use erotic objects as sex toys. However, regarding the use of erotic objects it should be reminded that PWDs, especially those with a PD in their upper or lower limbs, are not always able to behave and response fast and independently to their necessities. Thus, it can be very dangerous to insert objects into their body since in case of any complications it might be hard for them to take them out. In addition, these objects need to be cleaned often and properly, to avoid diseases or infections, and women with PD could face difficulties to do that too, thus they might need to ask the help of their parents or caregivers and this could turn masturbation in an extremely embarrassing experience (Bailar-Heath, Hough, Kassioukov, MacHattie, Naphtali, Miller, Elliott, 2010). Moreover, WWDs that begin to initiate masturbation express feeling of guilt while doing it and in some cases it is related to religion because they consider themselves as sinners who should be punished (Morales, Gauthier, Edwards, Courtois, 2016).

As many studies showed, WWDs have also a higher risk to experience sexual abuse, even from their family members (Fitzgerald & Withers, 2013; Parsons et al., 2017). An experience of abuse influences the way these women consider masturbation; some women see masturbation as a way to deal with their violent experiences, others instead decrease masturbation successively to their negative episodes, which might not only be sexual abuse but also accidents or decreased sensitivity. It is interesting to highlight how, even with these negative experiences, WWDs did not stop to desire sexual intercourse and relationships (Morales, Gauthier, Edwards, Courtois, 2016). Research highlights the high probability for



WWDs to be abused. Some studies point out that a woman with PD is two to four times more likely to be physically and sexually violated, while a woman with ID have twice that risk than women without disabilities (Hunt et al., 2021). In addition, Horner-Johnson and Drum (2006) studying the sexual abuse of adults with IDs, discovered prevalence rates of 25-50% (Fitzgerald & Withers, 2013).

### **2.3 The issue of sterilization of women with disabilities**

Sterilization is defined as a process or act that renders individuals permanently unable to have a sexual intercourse and getting pregnant. Multiple types of this practice exist, such as tubal ligation or hysterectomy, which it stops women's menses (National Women's Law Center, 2021). In 2004 and 2006 social justice and women's protection movements have considered reproductive justice as the claim to the fully realization and protection of women's human rights, which include not only the physical, mental, spiritual, political, social and economic well-being but also the right to become a parent and to be free from any judgments about one's capability to become one.

Even so, in the United States sterilization is still one of the most used contraceptive methods, indeed it represents the 50% of all contraceptive use in the continent among all the population. From 2011 to 2013 1,2 million of American women with P/IDs (almost one-third of the entire population) used sterilization as primary contraceptive practice and 9,4 million have been sterilized (Wu et al., 2017).

Reproductive justice also supports the right not to be a parent; this implies that a WWD, which desires to be sterilized, should have the same access to this service as woman without disability. However, it is important to inform these women about non-surgical alternatives to sterilization, such as intrauterine device (IUD) and the sub-dermal implant, since they are related to fewer complications than sterilization and are fully reversible upon removal. A comparison study conducted in 2016 in USA (Wu et al., 2017) between women with and without disability from 15 to 44 years old concerning female sterilization has highlighted that WWDs are more likely to be sterilized. This is due to several possible reasons, such as the fact that WWDs are more likely to have health problems, and that is why they might try to avoid a possible pregnancy more than women without disabilities do. Furthermore, they are more likely to have complications during childbirth, including premature delivery and low birth weight. However, WWDs might not feel supported when it comes to their right or ability to be a parent (Wu et al., 2017).

Indeed, the crucial point of this issue does not concern sterilization practice, which regards both women with and without disabilities, but rather the fact that every woman should have the right to decide what to do with her own body.

Unfortunately, until now many states, such as 31 USA states and Washington D.C, also some countries with a repressive government (North Korea and Uzbekistan) and those with a legacy of population policies consisting mainly of birth rate reducing measures (China and India) allow and practice forced sterilization to the detriment of disabled women (Rowlands, 2017). Forced sterilization, means that the doctor is allowed to sterilize a woman with P/IDs, even without her consensus. This might lead to episodes where judges, along with the family members or caregivers, can decide for someone, who may not even be aware of the situation. As for any issue, there are people who agree with this forced practice, because they claim it is a way to help these women to not worry anymore about getting pregnant, but nevertheless it is necessary to come up with new laws since every individual should have the control of his/her own body (National Women's Law Center, 2021).

#### **2.4 The thorny situation of women with disabilities in African countries**

South Africa is a deeply patriarchal society, in which women are frequently underprivileged and overpowered, especially those with a disability, since the presence of high social inequalities. Indeed, the country is characterized by different forms of violence and discrimination to the detriment of women, such as the violation of their sexual and reproductive rights. South African research shows that, women with PD are more likely to be with a violent partner and to endure economic and sexual abuses, due to the widespread negative stereotypes concerning PWDs (Hunt et al., 2021).

A study carried out by Chappell (2017) in KwaZulu Natal, South Africa, with young men and women with physical and visual disabilities, points out how the masculinity patriarchal society prevails, and defines gender roles and relationships. In this context women are forced to be in subordinate positions, under the authority of men, and they are supposed to satisfy men sexually, take care of the children and accept men "superiority", dominance and violence (Chappell, 2017; Leclerc-Madlala, 2003).

Reviews concerning African countries highlight the experiences of sexual abuse that WWDs often face in their families, communities and rehabilitation centres. In 2017, Peta carried out a study in Zimbabwe, in which she reported that family members, such as stepfathers, often

sexually violate girls with ID. In a context where disability and poverty are directly connected to abusive experiences, some mothers, even if they might know about the abuse, may decide to choose silence, driven by the fear of losing who provide their economic stability. Some women, due their disability, may not be aware of what they have experienced and because of insufficient sexual education, they may not even have the proper terminology and knowledge to grasp the differences between an act of love and an experience of abuse, probably leading the victim to marry her executioner (Peta, 2017). A qualitative study in South Africa (Phasha and Nyokangi, 2012) analysed the experiences of sexual abuses by young adults with ID at two special schools in Gauteng Province. The study shows that sexual abuses happening in the schools were not declared at all or they were declared as “misconduct”, because the school preferred to save its name, instead of reporting them.

Furthermore, young women with ID claimed to be intimidated by men after their rejection, fearing violence and sexist insults, thus they felt humiliated (Peta, 2017). In a study conducted in South Africa in 2021, with 18 women with PD, reported significant emotional abuse and manipulation received from their partners. A woman reported “*I was just a useless person...he was saying to me...there is no one else that can fall in love with me again*” and another participant shared “*I got an emotional abuse because he was abusing my children, because when he is abusing my children and does not want them while he is married to me and he lives in my home, that meant that he was abusing me*” (Hunt et al., 2021, p. 652). A participant claimed that her partner blamed her because of her disability. Indeed, after she was injured, her partner started to say he was in pain and always drunk because of her disability.

To conclude, many participants affirmed that their disability influence their relationships negatively since their partners are ashamed of them; whilst on the other hand, few women reported that having a disability affected positively their romantic relationship. One participant said that she felt her partner more attentive and loving than before she was in a wheelchair. Another woman, describing the empathy and understanding she gained from her partner, said “*...I can say the reason for that it is because he knows this condition. He was once in a wheelchair for 3 years because he was shot, but he got well again*” (Hunt et al., 2021, p. 654).

The complex situation of WWDs in the African context is characterized also by traditional beliefs, which associates disability with witchcrafts, breaking of traditional taboos and evil

spirits. Thus, it might lead men without disabilities and their family to believe that marrying a woman with disability could bring bad luck into the male spouse's family or that the woman might deliver children with disabilities (Peta, 2017; Peta et al., 2015). Other studies, undertaken in African countries such as Ghana, Zimbabwe, South Africa and Zambia, highlight that women with disabilities are commonly considered as "damaged", asexual, ugly and unacceptable, and who do not deserve relationships and therefore should be grateful to have a partner and a sexual life. Barriga (2004) pointed out that Zambia is characterized by the strong and widespread common stereotype that women with disabilities are asexual. He reported the statements of a single mother with disability who said: *"People think that people with disabilities can't have...girlfriends...They can't feel sex...They must be just staying at home as a disabled"* (Peta & Ned, 2019 p.18). These misconceptions, concerning the beliefs that women with disabilities are not sexual and they cannot have sex, are common in many other African countries. In Kenya, a woman with disability described her trauma regarding the use of public transportation. While she was assisted to help her get in and out from the bus, some men took advantage of the situation to touch her inappropriately, with the declared purpose to "test" if she was sexually sensitive and respondent since she is disabled (Okello, 2018). In a qualitative study in Zimbabwe, Peta et al. (2015) reported the experience of a woman with PD, which claimed that a man without disabilities had the intent to take off her clothes in order to check if she had a vagina (Peta et al., 2015). Another study conducted in South Africa (Peta, 2017) shows how, due to prejudices and misconceptions, disability alters concepts of gender and sexuality. In this study women and men were asked to write down on papers whatever comes in their minds concerning the sentence "woman with disability". Most of the participants reported that nothing came to their minds, so they didn't write anything; the others described women with disabilities as passive, weak and dependent, using words like lonely, sorry, old, wheelchair, crippled, grey, pity and lifeless. It is interesting to notice that when the participants were asked to conduct the same task but concerning the word "woman", the answers the researchers got were very different, indeed themes as heterosexual relationships, motherhood and work emerged.

Moreover, African women with disabilities must face other significant obstacles, associated for example to the health care service, which is already deficient in some African countries, in terms of insufficient capacity to fill the demand of all the people who need it. A study carried out in Lusaka, Zambia (2014), analysing the obstacles that women with disabilities

encounter using the health service, found out that women experience several attitudinal, social and physical barriers to access safe motherhood and reproductive health care.

Stereotypes and negative beliefs surrounding disability deeply affect the quality of health care services that women with disabilities receive, as the one assisting motherhood. Indeed, negative suspicions such as the conviction that evil spirits possess women with disabilities might spread the belief that something would go wrong during their delivery. This might encourage midwives to send these women to tertiary maternity centres, even when it is not necessary, which may be placed far from the community where these women live, thereby creating additional difficulties to the detriment of people with a limited mobility (Peta, 2017). In a study conducted in South Africa (2021) few participants reported experiencing difficulties becoming a mother after acquiring a disability; some women said, “*They said they were not sure if I can have a child again so I stopped prevention*”, “*They told me that I will never be able to get a child*” (Hunt et al., 2021, p. 654). This notice had a profound negative impact on the women who received it. Moreover, women reported that they did not receive a proper explanation for the reason why they could not bear a child. However, some participants did not lose hope to carry a child, due to several positive declaration of other women, such as a woman asserting that with a good doctor there might be the possibility to have a baby, while another added that a friend of her had a baby even though her disability (Hunt et al., 2021).

Diseases prevention programs also exclude women with disabilities, thus leading them be more likely to risk contracting Human Immunodeficiency Virus (HIV). Indeed, women with disabilities, compared with women without disabilities, are more vulnerable to HIV infections. This might be caused by their temporary intimate relationships, as the result of a hard compromise due to the limited opportunity originated from the sexual context which surround them (Peta, 2017). Zimbabwe is the African country in which women with disabilities face the most thorn situation concerning HIV. Peta (2017) found out that, in Zimbabwe, traditional healers advise people to pursuing an intercourse with a disabled woman as a cure to many diseases, like HIV and epilepsy, and because it would give them healthiness. Another study (Choruma, 2007) in Zimbabwe highlights a similar situation, where traditional healers were prescribing coitus with a virgin woman as a cure for HIV. However, in Zimbabwe, disabled women are associated to asexuality myth and so the community is convinced that all disabled women are virgin. Consequently, these women turn to be the most “ideal candidates” for HIV cleansing. This not only makes women with

disabilities extremely vulnerable to HIV, but it also proves how their bodies are considered as mere objects, which turn to be “useful” only when they can be “consumed” by men for their own benefits. Moreover, in Zimbabwe sexual knowledges, such as HIV prevention and treatment strategies, are generally denied to women with disabilities, due the conviction they are asexual and so immune to HIV infection (Peta, 2017). In Zimbabwe HIV information and services for women are enough widespread, but there are not service, and education specifically dedicate to women with disabilities. This is demonstrated by the difficulties these women have to face even to reach the HIV centres, often located in unreachable buildings for women with a limited mobility. Another study carried out in Cameroon (De Beudrap, Beninguisse, Pasquier, Tchoumkeu, Touko, Essomba, Mac-Seing, 2017) reports that women with disabilities, compared to women without disabilities, are more likely to be involved in transactional sexual relationships and to experience sexual violence (Woman Disabilities Africa, 2019). Due to the exclusion of African women with disabilities from health prevention programs some of them still do not have any knowledge and awareness concerning HIV diffusion and the presence of prevention and treatment programs (Peta, 2017), even though countries as Zimbabwe present a high rate of HIV and AIDS awareness programmes (Living Zimbabwe, 2008). Indeed, surveys undertaken in African countries reported in a systematic review of disability and HIV literature (Hanass-Hancock, 2009), highlight that disabled people, compared to people without disabilities, have limited information about HIV, even if they have the same or even higher risk to contract the disease (De Beudrap et al., 2017; Peta 2017; Okello 2018).

In conclusion, Hanass-Hancock (2009), referring to South African context, claims that the difficult access to the HIV services and knowledges is not a stand-alone issue but it concerns the vast national health care system, which unfortunately leave out people with disabilities (Hanass-Hancock, 2009).

## **Chapter 3. Love-Ability: The erotic and sexual assistance for people with disabilities**

### **3.1 Sexual Assistance**

In the wake of the major social movements that occurred in the 1970s with the recognition of the universal right to equality, the issue of the sexual assistance also emerged for the first time (Chatton, 2008; Rosenbaum, Aloni, Heruti, 2013).

The sexual assistance is a sexual accompaniment service for people with disabilities, which provide educational knowledge and support, regarding both sexual practices and sexual activities, with the aim of meeting sensual and sexual clients' necessities depending on their disability (Chatton, 2008; Morales, Quattrini, Auger et al., 2020).

Moreover, this type of assistance should include an environment that provides a vast range of activities for disabled sexuality, such as providing accessible information, allowing and supporting intimacy and privacy, encouraging social interaction, providing sexual goods, arranging paid sexual services, facilitating masturbation or sexual intercourse, helping to address and supporting sexual surrogacy (Reale 2022).

A team of specialists such as psychologists, sexologists, and sexual assistants (Mannino et al., 2017; Reale, 2022) form this service. The team, along with the disabled individual, settle a personalized sexual service after a series of meetings in which they discuss about practical topics such as the amount of sessions (maximum 12) and the type of sexual activities (Mannino et al., 2017). Specifically, the sexual assistant may perform one or more of the following sexual activities: erotic massage, conversation about sexuality, masturbation, oral sex, appropriate use of sex toys and a complete sexual intercourse (Limoncin, Galli, Ciocca, Gravina, Carosa, Mollaioli et al., 2014). However, during these sessions most of the time (as much as 90%) is devoted to preparatory exercises to sexuality such as relaxation exercises and sex education. In fact, the physical contact between the sexual assistant and the client can begin after the fifth session (Casalini, 2013).

### **3.1.1 Sexual Assistance from the perspective of disabled people and their family**

Ulivieri (2015) in his book “Love-Ability” presented several testimonies of PWD and their family members, which represent the difficulties they must address in the matter of sexuality due to the lack of a proper sexual assistance.

First, some testimonies received were from women who opened themselves, describing their necessities of having a complete sexual relationship with someone, and to be willing to even pay someone in order to achieve it. Indeed, contrary to the common thinking, women are strongly interested on finding solutions to satisfy their sexual needs, but their voice is simply more neglected than the men’s due to all the prejudices still present in nowadays society (Ulivieri, 2015).

For example, a father of a 19-year-old boy with Down syndrome affirmed that he found extremely difficult to talk about sexuality with his son, since he does not know when it would be the perfect period to do it, thus in their family the topic was not discussed at all. This testimony highlights the differences existing between the sexual needs of PWD and the ones of the family projected on them. In other cases, PWD’s families, to protect them, instead of understanding and supporting their sexual needs, they seek to remove or obstacle them. As already mentioned by the social model, situations like the latter one show how the difficulties that PWD address while trying to fulfil their sexual needs are not always connected only to their impairments. This is the case of a young couple in love, of thirty years old with a cognitive deficit living in a small mountain village in the North of Italy. Unfortunately, their family considered their love as something dangerous and not real since, according to them, Alessio and Giulia are two eternal children. Instead, the psychologist, which they decided to consult, suggested them to let them to love each other, also because sometimes, especially for people with a cognitive deficit, the concept of love is not considered in a physical perspective but rather as a practice of caresses and cuddles. Furthermore, most of the times these families are left by their own, without no one to guide them, totally relying on a psychologist or a therapist who, according to his/her personal opinion, decides if a disabled individual can love and be loved. Instead, PWDs need a real and professional help, who can teach them how to love and be loved properly (Ulivieri, 2015).

The difficulties parents might address with the sexuality of their children can be also related to medical necessities. Regarding this case, Ulivieri (2015) reported the testimony of the father of a 20-year-old boy affected by spastic-dystonic tetra paresis, who for a couple of



months has gotten prostatitis. The doctor, after failed attempts with medicines, suggested the family to induce him to ejaculation, but the person is not able to masturbate himself by his own due to his physical impairments. The dad explained that in Italy, in the place where they live there is not any type of sexual service besides prostitution. This is a clear example of the complex situations the PWD and their family might have to face where the only remaining solutions are prostitution or the family's help, without even imagining a decision as the latter can provoke in terms of roles confusion and frustration. In these cases, sexual assistance would help the person not only to achieve the doctor's suggestion, but also to explore with him the possibility to achieve it by his own.

Another difficulty gathered from the next testimony is the mix up of the professionals' role. An Italian masseuse declared that once she has been contacted by a mother of a 25-year-old who had a serious physical disability due to a motorcycle accident. She explained she started to work with him since he was in coma but after years and with the help of different specialists such as psychologists, physiotherapists, and speech therapists they were able to let him sit independently on the wheelchair. She affirmed that through the years, they build a strong and deep bond and since he started to be able to communicate again, he expressed the desires of touching her. After reporting that desire to his mother, she asked her if she was willing to give him something more, but she was not ready for that. Indeed, whoever is taking care of a disabled individual has the right to not feel compelled of crossing the boundary of one's profession with the risk of losing its professionalism and to commit in the intimate care (Ulivieri, 2015).

### **3.1.2 The differences between Sexual Assistance and Prostitution**

In the academic literature and in public discourses, it is still debated whether sexual assistance corresponds or not with prostitution. Geymonat (2019) highlighted how biases play an important role on the way this issue is approached. Indeed, people who do not advocate the idea of sexual assistance are usually against prostitution and consequently they consider them similar, whereas on the other hand the supporters of sexual assistance tend to insist on the differences, especially to allow sexual assistance to be legitimized (Geymonat, 2019).

The "Comité Consultatif de Bioéthique de Belgique", affirmed in its document regarding sexual assistance, that prostitution and sexual assistance can be distinguished on four main reasons. Firstly, from the fact that specialized operators are properly trained to provide sexual assistance. Secondly, sexual assistance is strictly and legally defined in order to ensure a

quality service as it is proved by the fixed and moderate price. In addition, this fixed amount of money is not the salary of the sexual assistants, in fact sexual assistance is not a paid job and not even their main activity. To conclude, what significantly differentiates prostitution from sexual assistance is the intimacy and the emotional connection provided by sexual assistance (Reale, 2021).

On the other hand, according to the French “Comité Consultatif National d’Ethique pour les Sciences de la Vie et de la Santé”, as expressed in 2012 in their document on the sexual and affective life of PWD, there are no substantial differences between sexual assistance and prostitution. Indeed, they believe that the exploitation of one’s body cannot be dismissed for the personal satisfaction of another, even if the operator is consented to, remunerated, or satisfied (Reale, 2021).

In the field of medical ethics, some scholars support the ideology that PWD should have the right to benefit from sexual services even in a system that condemn prostitution. On the other hand, other scholars are against the idea of supporting a right to sexual pleasure, a state-funded service, and a legal exception from prostitution, even if they consider themselves with the concept of aiding PWD to achieve their sexual necessities (Reale, 2021).

### **3.1.3 The difference between Sexual Assistance and Sexual surrogacy**

Often, sexual assistance is also confused with sexual surrogacy. However, sexual practices spreading nowadays in Europe differ from any type of therapy, especially from the sexual surrogacy therapy (Reale 2021; Ulivieri, 2015).

Sexual partner surrogacy, which is usually considered as the origin of sexual assistance, is a specific medical therapy originated by Masters and Johnson during the 1970s for people addressing physical and emotional intimacy issues, characterized by a professional assistant who works individually with the client. Unlike sexual assistance, sexual surrogacy consists in a triadic relationship where the sexologist controls and guides the sex surrogate partner’s performance according to the sexual necessities of the client (Reale 2021; Ulivieri, 2015; Geymonat, 2019).

Thus, psychologists or therapists dictate the terms and condition of this medical relationship between the patient and the sex surrogate partner, who must follow their instructions and report to them the meetings that take place with the clients (Reale 2021; Geymonat, 2019).

Due to the presence of a third part and the establishment of a medical plan, sexual surrogacy has been particularly criticised. BodyUnity, a not-for-profit organization promoting sexual assistance based in Switzerland, takes the distance from sexual surrogacy approach, affirming that the relationship with the client should be personal and personalised. Moreover, the disability rights movement, taking the distance from the “Medical model” which considers PWDs only according to their impairments, declared that the PWDs sexuality is not their disability (Geymonat, 2019).

In conclusion, sexual assistance and sexual surrogacy differ for four main reasons: the type of relationship built, the actors involved, the instrument used and the goals they want to achieve (Reale, 2021).

### **3.2 Sexual Assistance in Europe**

The concept of sexual assistance was born in the Anglo-Saxon culture (Ulivieri, 2015).

Several European countries sought to respond to PWD’s sexual necessities through the professional figure of the Sexual Assistant (Mannino, Giunta, La Fiura, 2017). Particularly, Germany, Denmark, Netherlands and Spain recognize the role of the Sexual Assistant, proving Sexual Assistance services on payment for PWDs (Casalini, 2013; Limoncin, Galli, Ciocca, Gravina, Carosa, Mollaioli et al., 2014).

However, no country in Europe has still established an official and specific legislation concerning sexual assistance; even in those where sexual assistance is a well-established service. This is probably because of the approach towards the service is highly dependent on the regulation of the trade of sexual services, such as prostitution. Indeed, in countries where sexual assistance is well introduced, prostitution is efficiently decriminalized and, on the contrary, in countries supporting an abolitionist or neo-abolitionist position towards prostitution, sexual assistance is struggling to be recognized both on the legal and social sides (Reale, 2021).

From this perspective, European countries can be divided into two different models (positive and negative) according to their position on the topic of sexual assistance and sexual services in general (Reale, 2021).

Nevertheless, the positive assimilation model does not provide any specific legislation for sexual assistance, and it considers sexual assistance as prostitution, which is regulated and

disciplined by law. Germany, Netherlands, Switzerland and Denmark support this type of model approach (Reale, 2021).

In 1982, the Netherlands was the first country to establish Sexual Assistance on behalf of PWD, by establishing the “Stichting Alternatieve Relatiebemiddeling” (Foundation of alternatives relationships), an association that offers help with the sexual life, sexual information and sexual education, accompanying PWD to discover their sexuality (Reale, 2022; Ulivieri, 2015).

Initially, the Foundation of Alternatives relationships (SAR) was a feminine association, with the mission to promote an alternative kind of prostitution and with 12 trained operators in total (10 women and 2 men). Until 1998, the SAR helped more than 1500 individuals, of which the 95% were male. In 2012, the team grew from 12 to 15 Sexual Assistants (10 women and 5 men); in which three of them have a homosexual orientation. Additionally, in Mook city (Netherlands) there is a “brothel” specialized for PWD where people in wheelchair can access autonomously (Ulivieri, 2015).

The only country in Europe who has tried to regulate sexual assistance is Denmark. The Danish Ministry of Social Affairs, through a non-binding document, at first a Guideline and successively a Handbook, sought to set out good-practice instructions in order to guide the service offered by the sex workers towards PWD. Indeed, since 1987 Denmark sexual assistants have been asking to eliminate all the obstacles set on Sexual Assistance from the Penal Code, to avoid any accusations of prostitution (Bahner, 2012; Reale 2021).

In 1959, Germany established the “Interessengemeinschaft Fur Behinderte” (IFB), an organization with the registered office in Wiesbaden, which in 1995 founded a service providing physical contacts named “SENSIS”. The service offered sessions of a maximum of 45 minutes where the client did not benefit from any sexual intercourse’s rights, and the workers were obliged to take part of specialized training that takes place throughout a certain period (Ulivieri, 2015).

However, between the 90s and the 2000s, Denmark, Netherlands and Germany have legalized prostitution, considering it as any other job and protecting the sex worker’s free will and the ability to be financially independent. During that period, sexual assistance has also been promoted and practised by local organizations (Reale, 2021). In fact, in countries such as the Netherlands and Germany, legal recognition of prostitution came even before the one concerning sexual assistance (Mannino, Giunta, La Fiura, 2017). The experiences of these

three European countries have provided an important example on Sexual Assistance, which is primarily based on a caring and respecting environment rather than the mere sexual intercourse practice (Ulivieri, 2015).

Twenty years after Denmark and Germany, Switzerland has recognized the necessity of having a certificate of competencies for their sex workers, and since 2008, it began to legitimize Sexual Assistance. Indeed, in the German Switzerland the “Pro Infirmis Zurich and Pro Infirmis Suisse” have decided to organize a specific training course for sexual assistants, following the previous footsteps of the neighbouring countries. In the country, sexual workers are men and women with heterosexual and homosexual orientation, which are professionally trained, and provide both “classic” sexual services and other type of service such as “service of tenderness”. Moreover, the application for the training courses is characterized by particularly severe requirements such as being over thirty years old and being in a stable marital situation (Mannino, Giunta, La Fiura, 2017; Ulivieri, 2015).

Nevertheless, other European countries did not legally legitimize Sexual Assistance yet, even if they began to recognize its utility. Countries as France, Spain, Italy and Sweden are the ones adopting the negative incorporate approach. This model does not recognize sexual assistance through a specific legislation, and it associates sexual assistance with prostitution, which unlike the positive model is characterized by criminal law provision and social stigma. In France, Spain and Italy, Non-Governmental Organizations (NGO)s and several associations are however offering and supporting sexual assistance’s services, even if their actions are outside or against the legal framework (Reale, 2021; Mannino, Giunta, La Fiura, 2017).

In France, even though in 2011 a member of the Parliament Jean-Francois Chossy presented a legislative proposal concerning Sexual Assistance (Chossy, 2015), and the topic is still an ongoing debate at the regulatory level (Limoncin, Galli, Ciocca, Gravina, Carosa, Mollaioli et al., 2014). In 1964, the country adopted an abolitionist approach to prostitution where the purchase of sexual performances is considered offensive. Regarding sexual assistance, the debate started during the 2000s with an interview published on the newspaper “Le Monde”.

Successively, the issue reached the Parliamentary discussion but without success, due to the strong opposition of the neo-abolitionist politicians. In 2012, a similar position has been carried out by the “Comité Consultatif National d’Ethique pour les Sciences de la Vie et de la Santé (CCNE)”, that considers that is impossible to equate sexual assistance with any other

type of professionals since it does not respect the principle of non-commercial use of the human body, even acknowledging that the recognition of a professional and remunerated sexual assistant should require an adjustment to the legislation since it prohibits prostitution. The French institutional debate stopped after Comité's opinion and since then, a new law has been adopted regarding prostitution that incriminates clients. However, the "Association Pour la Promotion de l'Accompagnement Sexuel" (APPAS), has been a very active association on promoting training courses and on helping sexual assistants to create emotional bonds with potential service users. APPAS affirms that since prostitution is legal in the country and the organization is not receiving any benefits from helping assistants and users, the association cannot be persecuted, and it can pursue its purposes (Reale, 2021).

In 1998 Sweden was the first country in Europe to regulate prostitution and to criminalize the purchase of sexual services. In the country, sexuality is considered a very personal and private aspect of the individual's life, thus Sexual Assistance constitutes a form of "trade" of sexual services and consequently, it has been considered illegitimate (Reale, 2021; Bahner, 2012).

Furthermore, as in the country sexual service is a crime against the State and not against the individual, people who take part in the act of prostitution, either the users or the prostitutes are called in trial as witnesses and not as plaintiffs (Gangoli, 2006). Regarding Sweden's approach to Sexual assistance for PWD, it remains unaddressed both in Swedish institutional politics and in the public debate, due to the influence from the social disapproval and the legal discipline towards prostitution. Nevertheless, between 2009 and 2011 the Swedish Federation of Youth with Mobility Impairments proposed a project about disability, sexuality and sexual assistance. This project provides a mentorship program for the clients, a methods' handbook and committees on challenging any prejudices and judgmental attitudes. However, in 2011 and 2013 the Swedish National Board of Health and Welfare affirms that personal assistants should not provide the achievement of the sexual needs of another individual since in the country the purchase of sexual services is illegal, especially as these operators are considered public figures (Reale, 2021).

The Spanish legal system tolerates and respects prostitution only if it is a personal decision and consequently if it is carried out by a person over 18 years old with legal capacities of autonomy and will. However, some people might see sex work as an exploitation practice in terms of coercion and induction, especially when the individual is considered particularly

vulnerable (Reale, 2021). At a national level the Spanish regulation of prostitution could be described as moderately abolitionist, but recently a more severe approach towards it has been adopted by some municipalities, which resembles more to the prohibitionist one (Gonzales & Becerra, 2018). Concerning sexual assistance, it was firstly debated in Barcelona through some specific projects regarding sexuality and disability. It is interesting to point out that sexual assistance, unlike prostitution, is a widespread debate and addressed by several local initiatives and organisations, despite not having yet reached the Spanish politics. Indeed, even if sexual assistance is not institutionally recognized, multitudes of different approaches are emerging all around the country, proposing both factual and theoretical solution to the issue. In the “Erotic connection model”, in which it included the “Sex Asistent” and the “Tandem Team” model, sexual assistance is a free service based on two main principles, such as connection and intimacy. Instead, other organizations such as “Asistenciasexual.org” embrace a more independent belief, supporting a different type of sexual assistance named “auto-erotic model”, which is based on the personal assistance approach and considers that service as a way to reach the right of accessing one’s own body (Reale, 2021; De Asis, 2017). These variety of approaches and organizations are what mostly distinguish Spain from other countries such as France or Italy.

In addition, the “European Sexual Assistance Platform”, a network of several European organizations committed on working in the field of disabled sexuality and advocating for Sexual Assistance in Europe, was founded in Europe (Reale, 2021).

### **3.2.1 Sexual Assistance in Italy**

The Italian legal system has never had a peaceful relationship with sexuality. According to Lo Giudice (Ulivieri, 2015), Italy is a country where the first sexual education of a teenager is more likely to be provided by peers or TV programs instead of being provided by social institutions such as family or school. However, with the sentence 561 of 1986 the Constitutional Court upheld that the right to benefit from one’s sexuality is an absolute subjective right, which must be included among the subjective positions, directly protected by the Constitution and classified among the inviolable rights of the individual. The difficulties that PWD address while attempting to access independently to this right (social, relational, physical difficulties) cause an increase of isolation, a loss of both autonomy and self-esteem, and so a high risk to be socially exiled and to feel emotional discomfort (Ulivieri, 2015).

For that reason the law proposal N.1442 “Disposizioni in materia di sessualità assistita per persone con disabilità” aspires to establish helping and supporting services to the fulfilment of a pleasing sexuality and an independence concerning emotional and sexual relationships. With this purpose, it has been created the figure of the sexual assistant, who should provide a healthy sexuality and psychophysical wellbeing for PWD (Ulivieri, 2015).

In 2013, the LoveGiver project has been founded in Italy. The Italian association promotes sexual assistance through the National Observatory on Sexual Assistance, which has a team composed by seven people such as Maximiliano Ulivieri, project leader in accessible tourism and author of the book “Love-Ability”, Maurizio Nada, expert in social planning and author of many publications on disabilities, Fabrizio Quattrini, psychologist, sexologist, university professor and president of the Italian Institute for scientific sexology and other colleagues (Moral et al., 2020; Quattrini, 2014).

The main goals of the Observatory are networking, supervision and research. Regarding supervision, the Observatory works on increasing the dialogue in various institutions on the topics of sexuality and disability, and on bringing together the available initiatives and information concerning disabled sexuality, to ensure that the effort made to advance knowledge on this topic is monitored. However, research is the Observatory’s main mission, to advance scientifically on the topic, which is currently ongoing (Quattrini, 2014).

LoveGiver, inspired by other pioneer European countries, seeks to raise awareness within the Italian culture, changing all the misconceptions about disabled sexuality that characterized the country with indifference, ignorance, and the association of sexual assistance with prostitution. Indeed, LoveGiver promotes a new form of sexual assistance, not only focusing on the mere sexual intercourse but also including the formation of the assistants, named “wellbeing operators”, for the affectivity, emotionality, and sexuality’s education of PWDs. The Italian sexual assistant is a specialized person, either man or woman, with a heterosexual, homosexual or bisexual sexual orientation that undergo a specific formation, assists and helps PWDs to recognize, experiment and experience eroticism and sexuality (Ulivieri, 2015).

Indeed, the Italian sexual assistance offers high standards for education about sexuality, with the aim of promoting sexual independence for PWD in terms of self-stimulation or helping them to find a partner. In fact, what distinguishes LoveGiver from other sexual assistance programs is that oral sex and sexual intercourse are not included in the Italian Sexual Assistance service (Moral et al., 2020).



### **3.2.2 The European debate: sexual assistance should be legitimized or delegitimized?**

The main reasons why sexual assistance should be legitimized are clearly explained by Nina de Vries, the Swiss first sexual assistant in Europe (Mannino, Giunta, & La Fiura, 2017).

De Vries points out the differences between sexual assistance and prostitution, even acknowledging that both provide a sexual paid service. Firstly, prostitution often involves the exploitation of gigolos and prostitutes, causing sufferance and consequently hate against the job; instead, sexual assistance is a job that has been chosen without any obligation, but rather out of free will (Casalini, 2013). Secondly, the primary goal of sexual assistance, unlike prostitution, is not selling one's own body in order to earn money but to help the clients to reach their own "sexual health" in terms of become more confident and learn how to overcome fear and anxiety in their social and physical relationships in order to achieve intimacy (Mannino, Giunta, & La Fiura, 2017).

Another valid observation to highlight is the client's necessities in matter of sexuality. Indeed, many individuals seeking a sexual performance require a form of intimacy, which may not even involve a sexual intercourse. Thus, the third difference between sexual assistance and prostitution is the humanitarian aspect (Casalini, 2013; Brasseur, 2014). Moreover, sexual assistants provide a more controlled and less promiscuous sexual experiences than having sex with prostitutes or gigolos, who might also expose the clients to the risk of contracting sexually transmitted diseases such as HIV (Mannino, Giunta, & La Fiura, 2017).

In addition, sexual assistance acts in cooperation with a therapist, either a psychologist or a psychotherapist, which has the role of mediating between the sexual assistant and the client and of supervising their relationship (Casalini, 2013). Another key element is the knowledge; in fact, sexual assistants before practising their profession must attend a training course, essential to better understand and support their client's needs (Diserens, 2014).

Furthermore, PWDs appreciate much more sexual assistants than prostitutes and gigolos especially because their professional and prepared approach aids them to overcome all those obstacles raised during the course of their lives around their intimacy. Obviously, the sexual assistance service must be arranged through a therapeutic process in which the boundary of the relationship between the sexual assistant and the client is established and should never be crossed and always be supervised (Casalini, 2013; Limoncin, 2014).

On the other hand, the French “Comité Consultatif National d’Ethique” (CCNE) declared that there are no differences between sexual assistance and prostitution because, as already mentioned, offering sexual performances in exchange of money is the definition of prostitution. According to this point of view, sexual assistance cannot be considered as any other professions since it includes the commercialization of one’s body, which is still an ongoing debate based on the relationship existing between body, property and employment (Mannino, Giunta, & La Fiura, 2017). Additionally, in France the act of being a procurer is considered a crime (procuring offense), referring to the fact of using an intermediary individual between the prostitute and the client. Indeed, this crime is closely associated to the human trafficking, a horrible trade which enslave significant amount of people.

Another problematic aspect of sexual assistance might be the relationship between sexual assistants and PWD. Indeed, it is important to highlight that this relationship might cause twice of the risk, the potential sexual assistant’s emotional involvement might lead to serious complications for their personal psychological balance and the PWD’s vulnerability might cause an emotional transfer towards the operator (Casalini, 2013).

Furthermore, the supporters of this mind-set believe that the individual’s sexuality is the most intimate part of his/her entity, and the body is considered the carrier of all the emotional, psychological and/or pathological history of the individual. Thus, the body must be protected and not offered as a “cure” for another individual, since it may cause serious consequences to both individuals (Mannino, Giunta, & La Fiura, 2017). Claudine Legardinier, a specialist of the prostitution issue and a member of the association “Mouvement du nid”, which focuses on fighting prostitution, affirms that it exists a substantial risk in making sexuality a form of trade and this risk increases if the activities of the procurers are legitimized (Casalini, 2013).

## Conclusion

The more a society democratises itself, the less the individuals within are willing to tolerate inequalities. The society has been focused on eliminating inequalities mainly due to social conditions, such as earnings or accessibility, but nowadays all types of inequalities became central. Furthermore, even if all the individuals are today considered equal in terms of rights, they remain unequal in terms of living conditions. Therefore, to point out these inequalities it is necessary to seek in each society, which are the more impeding ones, according to the individuals. Sexuality plays an important role within the society. Consequently, individuals consider particularly frustrating the inequalities concerning sexuality, especially because of its social impact in terms of social unrecognition and widespread misconceptions such as the idea of PWD's inability (Campagna, 2015).

The World Health Organization (OMS, 2002) defined sexuality one of the main aspects of the life of any human being. According to the WHO, sexuality is a source of pleasure, health and wellbeing and it concerns the satisfaction of essential needs such as contact, intimacy, emotional expression, affection and love. In addition, sexuality generates positive attitudes to people toward themselves and others. In this term, sexuality is interpreted as gender and role's identity, sexual orienting, eroticism, sexual pleasure, intimacy and reproduction. In the XVth World Congress of Sexology held in Hong Kong in 1999, the Universal Declaration of Sexual Rights declared that sexuality arises from the relationship between the individual and the social environment, and it is essential at a personal, interpersonal and social level. Sexual rights are universal human rights, based on dignity, freedom, and equality and since a person's health is a fundamental human right, sexual health must be considered in this way as well. Healthy sexuality is the result of a society that recognizes, respects, and practises sexual rights such as sexual freedom, sexual autonomy, sexual privacy, sexual pleasure, sexual emotional expression, the right to establish a sexual relationship freely and the right to sexual health care.

However, PWDs might have severe difficulties to fulfil these necessities independently. This inability might create severe social disadvantages, which have an impact on the way to solve the issue that depends on the physical, psychological, and social consequences that determine an individual's life. Sexual assistance might help both PWDs and whoever is in an emotional

and sexual marginalization, to overcome and mitigate the disadvantage and impossibility to experience physical relationships and visual, motor and sensory experiences (Ulivieri, 2015).

As already mentioned by Carla Maria Reale (2021), no country in Europe has adopted a specific legislation regarding sexual assistance, even in those who have established that service, and others did not even recognize and support the establishing of the service since they assimilated it with sex work. As previously mentioned, the perspectives taken on sexual assistance in the European countries can be divided into two main groups, the group who supports the positive model and the other supporting the negative model. Regarding the positive model's sympathizers, sexual assistance is well established and supported, and it is associated with prostitution, which is legalized. On the other hand, the supporters of the negative model do not recognize both prostitution and sexual assistance and they consider them as an exploitation practice of the human body, underlining the risks that this practise might raise, such as the risk for the disabled individual to be emotionally attached with the sexual assistant.

Since both perspectives are valid, this thesis does not intend to explain which service and method should be chosen to help the neediest people in the matter of sexuality. On the contrary, it mainly intends to introduce the sexuality of PWDs with a social approach, in order to show their difficulties, the services that they are discussing nowadays, and that their sexuality is not only a personal issue but also it should concern the commitment of the society. This perspective is well explained by the "enabling *community*" of Ulivieri (2015). Ulivieri calls "enabling community" those societies, which adopt specific measures to help the neediest people to mitigate their disadvantage in terms of sexuality. Indeed, even the literature suggests that there are no disadvantages when an individual can satisfy the same activity of other individuals even if it is performed by different ways. However, society's measures are not sufficient to provide equality in terms of sexuality, in fact it is also necessary to activate a cultural change to provide a different, more open and less stereotyped common perspective on beauty and physicality in order to increase the opportunities to achieve emotional and sexual relationships and overcome the limit of being "different"(Ulivieri, 2015).

Regardless if a society chooses to support sexual assistance or not, the conclusion of this thesis is well summarized by the belief of the philosopher Hans Jonas, who declared that

allowing whoever does not have the ability to choose to do so; it is a matter of civilisation  
*(Ulivieri, 2015)*.

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## Acknowledgements

First, I am sincerely grateful to my University, Università Della Valle D'Aosta, for affording me an unimaginable opportunity to complete my bachelor's degree in Psychology, as it has been an important professional and personal growing path to me.

Secondly, I would like to thank my Supervisor, Professor Maria Grazia Monaci, especially for her meaningful assistance, steady presence and patience, who I greatly admire for the enthusiasm she has for her field and her work.

I would also like to thank my colleague and dear friend Asia, an extraordinary and genuine person, who has always been the only person I could rely on during my stay in Aosta. She always supported me and shared with me moments of joy especially during the hardest moments of my University years; I was blessed to have you.

In addition, I would like to thank my family and my relatives as they always encouraged me and supported to pursue my goals, never with obsession for success, but with genuine desire to see me realize my greatest passion. Their support has been extremely helpful to me in order to convince even the most exhausted and resigned version of myself to still believe in my abilities.

I would like to truly thank my closest friends Marghe, Pietra and Rudy and all the people I met in Belgium, not only for their meaningful support and help received during the preparation of my thesis and the course of my studies, but also for showing me what true friendship is.

My special thanks goes to my partner Freddy, who never left me alone, always encouraged me to keep going and believed in myself and in my capabilities. Thank you Freddy to believe in my dreams as if they were yours.

To end, I would like to thank myself for holding out and never give up.