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# *Sexuality and disability: an assessment of practices under the Convention for the Rights of People with Disabilities*

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## **Thesis**

Submitted in fulfillment of the requirements for the degree of Master of Laws in Human Rights at the  
Central European University

By

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2012

## Abstract

This paper argues that the sexuality of people with disabilities is being highly disregarded in laws, policies and practices national and international levels.

Its first chapter introduces the reader to the topic. It stresses that people with disabilities have the same range of sexual needs and sexual desires as people with no disability. Explaining how sex and sexuality penetrated the human rights discourse, the standards established by the Convention on the Rights of People with Disabilities are described. National policies are afterwards scrutinized for deficiencies in those standards' implementation.

The second chapter discusses the range of difficulties people with disabilities encounter when expressing as sexual being. It touches upon lack of relevant information as a significant problem. It also debates over abortion laws and forced sterilization as forms of interference with the sexuality of people with disabilities.

Chapter III deals with criminal law provisions which, historically aimed at protecting from abuse, can interfere with sexual expression and with the ability to consent to sexual activities.

After making recommendations, that paper concludes that people with disabilities lack relevant information and are being subjected to forced abortion and forced sterilization. Their opinions are not being listened to. Their will and preferences are often disregarded. As all these represent violations of international law, the sexuality of people with disabilities needs to be mainstreamed within human rights discourses, addressed in national policies and highlighted in international guidelines. This will contribute to the overall elimination of abuse, limitation of freedom and discrimination of persons with disabilities.

D. G.: I don't have anything against gay people.  
What bothers me is seeing them kissing...

C. B.: So you don't mind seeing gay people.  
What you mind is seeing happy gay people.

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## Introduction

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This paper addresses the place of sexuality, as a legitimate component of the life of people with disabilities, within the human rights discourse. It is not aimed at debating over this legitimacy.

What it does is scrutinizing several laws, practices and policies relevant for the sexuality of people with disabilities. The standards taken into consideration are those established by the United Nations Convention on the Rights of People with Disabilities (CRPD).<sup>1</sup> This international instrument has 126 ratifying State Parties, including the European Union (EU), being therefore accepted as an important piece by the international human rights community. The examples chosen for the paper are taken from several continents to reveal that disregarding sexual and reproductive rights of people with disabilities is not a national or regional problem; instead, it is a global one, and the modification of the human rights discourse has to be done at a global scale. A comparative analysis of existing practices among State Parties to the CRPD is done.

While shortly addressing some controversies related to sexuality being expressed by people with disabilities and some of their possible causes, this paper chooses to focus on the perspective dictated by international law. It argues that while they are protected by international law and states are bound to respect, protect and fulfill them, sexual and reproductive rights are being highly disregarded and not sufficiently advocated for. This has severe implications on the life of individuals, whose rights and dignity are being disrespected.

“[Sexuality has been] an area of distress, and exclusion, and self-doubt for so long, that it was sometimes easier not to consider it, than to engage with everything from which so many were

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<sup>1</sup> United Nations. Treaty series. *Convention on the Rights of Persons with Disabilities*. (adopted December 13, 2006, entered into force May 3, 2008) G.A. Res. 61/106, U.N. Doc. A/61/611 Vol. 2515. Hereinafter (CRPD).

excluded.”<sup>2</sup> This paper however choose to acknowledge, as international law also does, that “[b]eing deemed a ‘person’ or sexual is not contingent on ability- contrary to popular belief.”<sup>3</sup> “Potentials for justice or injustice in how societies organize sexuality”<sup>4</sup> are highlighted within the disability rights framework. Taking advantage of the early stage of the sexual rights discourse formation, this paper will discuss several consequences of disregarding people with disabilities within such discourse, arguing for their inclusion.

When referring to people with disabilities this paper considers all those who have 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. By sexuality related aspects it understands a wide range of desires and practices which are connected to being sexual. This includes all manifestations to which society or the individual in question attribute sexual connotation. The reproductive human function is also to be considered in this framework.

Chapter 1, called Sexuality of people with disabilities: theoretical and legal considerations, introduces the reader to the topic. It searches for explanation of why people with disabilities are desexualized. While sexuality is very much present into the public discourse and is generally seen as a legitimate component of people’s life, for people with disabilities this is true to a much less extent.

This might have several causes. Firstly, people with disabilities are many times seen as not fitting within the idea of normalcy, and therefore not entitled to sexuality as a component of the normal life. Secondly, there is widespread misunderstanding, lack of knowledge and imaginary

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<sup>2</sup> Tom Shakespeare. *Disabled Sexuality: Toward Rights and Recognition*. (Sexuality and Disability, 2000), p. 160.

<sup>3</sup> Bethany Stevens. *Structural Barriers to sexual autonomy for disabled people*. (American Bar Association. Human Rights. Sex and the Law, 2011), p. 16.

<sup>4</sup> Mindy Jane Rossman and Alicia M. Miller. *Normalizing sex and its discontents: establishing sexual rights in international law*. (Harvard Journal of Law and Gender, 2011), p. 315.

associated with disabilities. This stigmatizes individuals and disconnects them from sexuality as presented and available in the public discourse. Sexuality of people with disabilities is not an easy subject to discuss and is often disregarded as it is perceived less as a need and more as a desire which can be controlled or repressed.

For whatever cause, while people with disabilities do have the same range of sexual needs and desires as everybody else, sexuality is rarely perceived as a legitimate component of their life.

The existence of such needs and desires has been acknowledged in the human rights discourse. To help the reader understand existing standards, the paper tracks back how sex and sexuality entered this discourse, through the right to health and looks at the relevant provisions of the CRPD and at relevant activities of the Committee on the Rights of People with Disabilities (hereof the CRPD Committee). A short overview of relevant national policies follows, explaining how the implementation of those provisions is done. It is argued that while some relevant standards do exist, in practice sexuality of people with disabilities is addressed to a much less extent than necessary and in a little comprehensive way.

The 2<sup>nd</sup> Chapter, as its name suggests, deals with the difficulties people with disabilities encounter when expressing their sexuality. Difficulties appear due to misconceptions and because people with disabilities are excluded in many areas, having less access to employment, and to social places, being generally in worse financial situations and having lower self-esteem.

How sexual expressions are to be dealt with is not of interest only for the individuals with disabilities, but also by those to whom they are in contact with, such as medical personnel, social workers and caregivers. This last group often controls the answers to sexual expressions.



Before explaining how these answers can be problematic, the paper addresses the most common justification for such practices, namely the “best interest” doctrine, arguing that such doctrine is practically not working and that it is no longer in concordance with international law.

Afterwards, the problematic answers are scrutinized. Information, although considered as not necessary, affects people with disabilities when lacking as it alters their decision making processes. Also, as information is lacking from those around them, social and environmental barriers are being build and maintained.

The next scrutinized answer to sexual expression is abortion laws. It is argued that specific problems of women with disabilities are not being addressed in the general abortion related discourse. This is further explained by looking at abortion case law from Argentina and India.

Forced sterilization is a last response to be scrutinized. Done without the knowledge or personal consent of the person, sterilization is in violation of the CRPD. This conclusion could have been reached by the European Court of Human Rights (ECtHR) if *Gauer v. France*,<sup>5</sup> a case dealing with the sterilization of five young girls, would have not been rejected on procedural grounds.

For each of these responses comments under the CRPD are provided.

Chapter 3 deals with how criminal law addresses the sexuality of people with disabilities. By regulating sexual consent. This is done either by criminalizing specific kinds of sexual expressions or by prohibiting sexual acts where people with disabilities are involved. Laws and case law from several European countries are scrutinized. While acknowledging that such laws are meant to protect people with disabilities from sexual violence and abuse, it is argued that they can sometimes also deprive them of manifesting their will, preferences and opinions.

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<sup>5</sup> *Gauer and Others v. France* (dec.). App. No. 61521/08. (ECHR, 23 of October 2012).

The paper ends with several recommendations where mainstreaming sexuality and disability in all policies is suggested. Taking into consideration the scrutinized practices and the presented international standards it is concluded that sexual and reproductive rights of people with disabilities are being commonly violated.

# Chapter I. Sexuality of people with disabilities: theoretical and legal considerations

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## I.A. The legitimacy of sexuality as a component of life

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“[S]ex is variously thought of as an adult recreation, a saleable commodity, a set of techniques, the physical embodiment of intimacy, sacred or holy, and the usual method of reproduction”<sup>6</sup>. Sexuality has always triggered reactions within communities. In past centuries it was according to some not spoken about, not because of lack of interest but because of being perceived as dangerous or too intimate. Foucault<sup>7</sup> looks at sexuality and identifies differences among cultures. He stresses that sexual activities have not been forbidden, but repressed. While acknowledged as a part of life, sexuality remained in the realm of secrets, taboos, fears and hypocrisy.

With time attitudes changed and the subject became less and less of a taboo. Humanity even experienced a sexual revolution. The 20<sup>th</sup> century came with an obvious change in expressing and dealing with sexuality within Western societies.

“Aided by the values of a consumer culture and encouraged by the growing visibility of sex in the public realm, many now regard sexual pleasure as a legitimate component of their lives”<sup>8</sup> and of the lives of those surrounding them.

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<sup>6</sup> Raie Goodwach. *Sex Therapy: Historical Evolution, Current Practice. Part I.* (Australian and New Zealand Journal of Family Therapy, 2005), p. 155.

<sup>7</sup> In Michel Foucault. *The history of sexuality.* Volumes I-III ( Vintage books. A Division of Random House, New York, 1986).

<sup>8</sup> Goodwach, p. 157.

However, the so called “sexual revolution” has not had the same far reaching effects in what concerns people with disabilities. The causes of such phenomenon can only be speculated on.

One root of this problem could be the exaggeration of the importance of elements which differentiate individuals. There is a majority understanding of what is normal and whatever does not fit this understanding is deemed abnormal, and dehumanized. This is the ideology of normalcy, which is based on the conception that “persons of difference necessarily possess a diminished level of personhood.”<sup>9</sup> This ideology is harshly exclusive, for people in general and for people with disabilities in particular, because it assumes that difference “should not be bred for but should be bred out because it is abnormal and therefore unnatural, a noncompetitive deficit and therefore harmful.”<sup>10</sup> Some deviation from the norm, for example in terms of height, weight, race, ethnicity, social origins, sexual orientation and age, has been accepted. Disability however is often seen as an extreme deviator generating exclusion.

Another possible cause of desexualizing people with disabilities can be the misunderstanding, lack of knowledge and imagery often associated with disability. Perceived as a purely medical phenomenon, disability is in many cultures, including in Western societies, assumed to have as a cause some unrelated act or supernatural activities. “Blame appears to be one of the most common factors in explaining disability in most countries, irrespective of whether religious or medical explanations dominate. Blame is often directed towards women (ie. a child has a disability because their mother has failed) or other minority groups (ie. a man is HIV positive because he is gay).”<sup>11</sup>

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<sup>9</sup> Tom Koch. *The Ideology of Normalcy : The Ethics of Difference*. (Journal of Disability Policy Studies, 2005), p. 125.

<sup>10</sup> Ibid., p. 124.

<sup>11</sup> *Ethnicity and Disability Factbook*. (Multicultural Disability Advocacy Association, 2007).

Having a disability can also be attributed to “having sinned or offended the spirits. This might have occurred through sins committed by ancestors or by the person with the disability themselves in this or a previous life. [...] The idea that disabilities can be transmitted is [also] quite common across the world. This results mostly in actions to protect pregnant women from seeing, hearing or touching people with disability or even their technical aids.”<sup>12</sup> In some religious practices disability is seen as a lesson given to the others who, seeing the disabled individual struggling learn to be grateful for having able bodies.<sup>13</sup> Such beliefs trigger fear, shame and discrimination.

While “the application of the social model of disability”<sup>14</sup> [did contribute to] transforming societal perceptions of disability, the issue of sexuality and sexual behavior, particularly for persons with mental disabilities, has not been subject to the same level of debate and advocacy.”<sup>15</sup> This might also be because while “sexuality is often the source of our deepest oppression; [and] [...] of our deepest pain, [i]t’s easier for us to talk about [...] discrimination in employment, education and

<sup>12</sup> *Ethnicity and Disability Factbook*. (Multicultural Disability Advocacy Association, 2007).

<sup>13</sup> See for example the interpretation of an Islamic clerk: “When the sound believer sees disabled people, he recognizes the blessing that Allah has bestowed upon him, so he gives thanks for His blessing, and he asks Him for good health. He knows best and is most wise, and we know nothing except that which You have taught us, and He is the All-Knowing, Most Wise” (Shaykh ,Abd al-Rahmaan al-Barraak. *Why Allah creates mentally disabled people*, available at <http://islamqa.info/en/ref/7951>).

<sup>14</sup> The social model of disability is to be distinguished by the medical model of disability. The latter understands disability as “an essentially medical phenomenon. In particular, an individual’s disability has typically been viewed as a personal, medical problem that requires an individualized, medical solution” (as explained in Bradley A. Areheart. *Disability Trouble*. (Yale Law and Policy Review, 2011), p. 348). This model identifies the problem in disability itself. It considers that disability, regardless of its type, creates a state of dependence which follows the individual in all fields of life. The lack of possible rehabilitation closes the gates to change. This model was acknowledged for a very long time not only by theoreticians, but also by those involved in all kinds of social movements, from those related to art to those related to human rights, including the disability rights movement itself. It had many positive consequences by increasing the access of disabled people to all spheres of life. However, it also triggered among them a general low self-esteem and underachievement. The social model of disability was shaped as a challenge and solution to the former approach. Instead of firstly looking at disability as a medical phenomenon it starts by acknowledging the right of disabled people to belong, live and be valued in a community. The focus shifts from describing vulnerabilities and faults to describing strengths. These strengths meet physical and social barriers when exteriorized and the problem is constituted by these barriers. In the past two decades this later model gained more and more influence and now the CRPD embraces it.

<sup>15</sup> Suzanne Doyle. *The notion of consent to sexual activity by persons with mental disabilities*. (Liverpool Law Review, 2010), p. 3.

housing than to talk about our exclusion from sexuality and reproduction;”<sup>16</sup> nor because “sexuality was perceived as a desire, not a real need.”<sup>17</sup>

Whatever the cause of the exclusion of people with disabilities is, it is clear that disability constitutes a ground for a powerful “contamination of identity”<sup>18</sup> and a source of dehumanization. Mitchell and Snyder explain:

“[People with disabilities’] conditions are understood to be embedded in the very fabric of their physical and moral personhood. This socially defined experience of organismic contamination situates the disabled person as one who harbors more than just a physical/cognitive [...] difference: disability infuses every aspect of his or her social being. This equation of [...] disability with social identity creates a tautological link between biology and self (imagined or real) that cannot be unmoored- the physical world provides the material evidence of an inner life (corrupt or virtuous) that is secured by the mark of visible difference. [...] Resistance to cure or successful rehabilitation determines disability’s unnatural status in medical and social discourse: people with disabilities are said to be fated or unsalvageable and, thus, somehow stubbornly inhuman.”<sup>19</sup>

Dehumanization triggers, among others, not acknowledging sexuality and rights to sexual expression. This does not happen only because of disability. It can also be caused unilaterally or in combination by, for example, gender-based discrimination<sup>20</sup> and sexual orientation related

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<sup>16</sup> Anne Finger. *Forbidden Fruit*. (New Internationalist, 1992).

<sup>17</sup> Marta Schaaf. *Negotiating sexuality in the Convention on the Rights of Persons with Disabilities*. (SUR International Journal on Human Rights, 2011), p. 115.

<sup>18</sup> Robert Murphy. *Encounters: The Body Silent in America*. (University of California Press, Berkeley, 1995), p. 145.

<sup>19</sup> David T. Mitchell and Sharon L. Snyder. *The Body and Physical Difference. Discourses of Disability*. (The University of Michigan Press, Ann Arbor, 2000), pp. 3-4.

<sup>20</sup> Asserting women’s sexuality was and is an important part of their movement of emancipation. Revealing sexual desire as not only a male attribute, the sexual revolution pioneered discussions about contraception and generally about sexual and reproductive rights. Women stopped being containers of babies and technically gained the freedom to decide how to use their bodies, to what to devote their time. Economic independence revealed itself as more accessible due to an increased possibility to integrate onto the labor market. This is not to say that by asserting sexuality all social problems are solved. The still low rates of women employment are revealing for the fact that not regulating fertility stands next to patriarchal mentalities and socially created attitudes when triggering gender biases. However, asserting sexuality means asserting the humanity of a being and therefore it remains an important human characteristic which needs to be addressed when creating societal and political structures.

discrimination.<sup>21</sup> While acknowledging that comprehensive policies cannot be developed without taking it into consideration, intersectional discrimination<sup>22</sup> will however not be specifically addressed in this paper.

The fact that people with disabilities experience the same range of sexual needs and sexual desires as everybody else has often been underlined in specialized articles.<sup>23</sup> What remains obvious is that there are individuals who do have sexual interests but who „because of their disability, find it much harder than others – often impossible without assistance – to satisfy their sexual interests.”<sup>24</sup> From here, questions regarding whether societal intervention is needed arise.

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<sup>21</sup> Sexuality acknowledgment has also been central to the creation and evolution of the LGBTQ movement. This movement's "challenge to straight male masculinity [can be considered to] offer a unique and revolutionary contribution to the emancipation of the whole of humanity from all forms of oppression and subjugation" (Peter Tatchell. *Gay Liberation is Central to Human Emancipation*. (Labour Briefing, 1989)) . This is because it questions "the cult of heterosexual masculinity" deconstructing gender identities and the order of a world based on gender-separated roles.

<sup>22</sup> There are several doctrinal approaches to a situation in which a person has certain characteristics which can constitute separately or together, at the same time or at different times, grounds for discrimination. The single ground approach, namely multiple discrimination is used „to describe the phenomenon in which one person is discriminated against on several different grounds at different times. The term [...] should not be used in connection with situations in which different grounds operate simultaneously and not separately” . Another approach is the so called compound discrimination, which describes a situation in where „a person suffers discrimination on the basis of two or more grounds at the same time and where one ground adds to discrimination on another ground- in other words one ground gets compounded by one or more other discrimination grounds” . Another approach is referred to as the intersectionality approach and has received more attention in the USA and Canada. Intersectional discrimination, „in its narrower sense, should be taken to refer to a situation in which there is a specific type of discrimination, in which several grounds of discrimination interact concurrently. For instance, minority women may be subject to particular types of prejudices and stereotypes. They may face specific types of racial discrimination, not experienced by minority men. Crucial to this kind of intersectional discrimination is thus the specificity of discrimination: a disabled woman may face specific types of discrimination not experienced by disabled men or by women in general” . This is not an exhaustive list of possible approaches. The concepts themselves are many times subjected to debates. I prefer using the term intersectional as I believe it addresses best the necessity of considering the multiplicity and individuality of people with disabilities when developing policies promoting their sexuality. This is because a woman with disabilities will face sterilization with the pain of seeing her body disregarded and judged because of disability, and with the pain of having her body abused because of gender.

<sup>23</sup> See for example Shirli Werner. *Individuals with intellectual disabilities: a review of the literature on decision-making since the Convention on the Rights of People with Disabilities (CRPD)*. (Public Health Reviews, 2012), p. 16.

<sup>24</sup> Ezio Di Nucci. *Sexual Rights and Disability*. (Journal of Medical Ethics, 2011), p. 2.

## I.B. The human rights discourse

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### I.B.1. General considerations

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In order to see whether societal interventions is needed or not, the general existence of sexual and reproductive rights needs to be established. “Sex and sexuality [are seen within social movements] as an essential element of ‘the human’ who might claim rights, as well as an element of human personhood that concerns society at large.”<sup>25</sup>

Sex and sexuality were historically initially addressed from a medical, mostly pathological perspective. The focus was on health related issues, such as maternal health, gynecological care, contraceptives, methods of safe sex. This played a substantial role in ensuring basic health needs which at the end contributed to making the sex and sexuality related discourse more available to the public, and also de-demonizing sexual issues. On the other side, this discourse was focused on a biological, physical conception somehow ignoring the interdependency of sexuality and aspects of personality.

Maybe as a result, sex and sexuality entered the human rights discourse the same way: through health. The right to health<sup>26</sup> has been recognized in the Universal Declaration of Human Rights, in the International Covenant on Economic, Social and Cultural Rights, in the European Convention of Human Rights (ECHR), in the EU Charter of Fundamental Rights and in many other international human rights instruments. While connections to physical and mental health

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<sup>25</sup> Rossman and Miller, p. 315.

<sup>26</sup> Health is considered to be “our most basic and essential asset” (*Right to Health. Fact-sheet no. 31.* (Office of the United Nations High Commissioner for Human Rights and World Health Organization, 2011), p.1). When one has to deal with health problems, all aspects of life can be affected. Individuals might not be able to attend their daily work, studying or family related duties, or if they do that can cause discomfort. They might not be able to enjoy social and cultural events. They might not be able to express thoughts and desires, and they are often prevented from exercising their constructed roles within different social cells, such as family, group of friends or community. Ill health is not only about not being able to execute physical acts, but also about different psychological and social aspects.



can always be triggered, they are many times exaggerated and cannot clearly respond to all identified irregularities related to the sexuality of people with disabilities.

“Many advocates of sexual rights seek cover under ‘health’ to avoid the politics of sex and sexuality, this cover, however, [might be] impossible to sustain, especially in light of the public [...] as well as private [...] aspects of sexual rights that advocates have advanced.”<sup>27</sup>

Either way, sexual and reproductive rights, in different forms and under different denominations are promoted international and national levels, constituting “the sum of a range of civil, political, social, cultural and economic rights [and including] the right to health; to sexual and reproductive health; to family planning; to decide how many children one wishes to have and at what intervals; to marry and form a family; to life, liberty, integrity and safety[...]; to freedom from sexual attacks and exploitation; to freedom from torture and other cruel, inhuman or degrading treatment or punishment[...]; to privacy; to intimacy.”<sup>28</sup>

In the following pages I will shortly describe how the sexual needs and sexual desires of people with disabilities have been acknowledged and promoted within some legal and policy frameworks at both international and national levels, arguing that this happened in a little comprehensive way and to a much lesser extent than necessary.

## I.B.2. The United Nations (UN) system

### I.B.2.a. General considerations

As already explained, sexual and reproductive rights have entered the human rights discourse through health. The definition provided for health within the UN system states that health is “a

<sup>27</sup> Rossman and Miller, p. 334.

<sup>28</sup> Ana Pelaez Narvaez. *Sexual and reproductive rights* in Luis Cayo Perez Bueno. *Guide to gender mainstreaming in public disability policies*. (CERMI, 2012), p. 237.

state of complete physical, mental and social well-being and not merely the absence of disease or infirmity,”<sup>29</sup> revealing the abundance of aspects a right to health relates to.

Within this broad concept, sexual and reproductive health are probably the most obviously related to sex and sexuality. Reproductive health commonly refers to the “ability of men and women to have a satisfying and safe sex life [in which] they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice.”<sup>30</sup> Sexual health is defined by the World Health Organization as the “integration of the somatic, emotional, mental and social aspects of sexual being, in ways that are positively enriching and that enhance personality, communication and love.”

The aspects covered by these concepts are numerous and there is a need to underline that related rights belong to people with disabilities also. One of the bodies which did so is the United Nations Economic and Social Council, which asserted that “persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood.”<sup>31</sup>

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<sup>29</sup> In the Constitution of the World Health Organization adopted by the International Health Conference held in New York from 19 June to 22 July 1946 and entered into force on 7 April 1948.

<sup>30</sup> Rossman and Miller, p. 332.

<sup>31</sup> Committee on Economic, Social and Cultural Rights. *General Comment 5. Persons with Disabilities*. U. N. Doc. E/C. 12/1994/13.

*I.B.2.b. The Convention for the Rights of People with Disabilities (CRPD)*

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The most important and relevant instrument within the UN system is the CRPD. I will shortly enumerate several of its relevant provisions explaining their relevance to sexuality.<sup>32</sup>

Article 12 of CRPD deals with equal recognition before the law. It states that people with disabilities enjoy legal capacity on an equal basis with others in all aspects of life, and that support is to be provided when it may be required. It underlines that their will and preferences need to be respected, meaning that sexual and reproductive related decisions are to be made by people with disabilities, who have to be provided with relevant information and given the opportunity to express their will. Such conclusion flows easily once it is accepted that “decision-making is a central element of self-determination, empowerment, and social inclusion for people with disabilities.”<sup>33</sup>

Decision-making can be a complicated process for some people with disabilities. Addressing this, the CRPD mentions the obligation of states to create supported decision-making mechanisms, which have to replace existing surrogate/substitute decision making models “by which decisions are made on behalf of adults who are judged to lack decision-making capacity.”<sup>34</sup> Translated in sexual and reproductive rights related situations, this means that never the states, or guardians, or family members can decide on their own that a person with disabilities has to undergo abortion, has to be sterilized, or has to be given contraception. Nobody can decide, independently from the person with disabilities, to remove children who live with their parents just because the parent has a disability.

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<sup>32</sup> For a discussion about how sexuality related rights were adopted in the CRPD and how they are much less explicit and affirmative than those included in the initial draft see Marta Schaaf. *Negotiating sexuality in the Convention on the Rights of Persons with Disabilities*. (SUR International Journal on Human Rights, 2011).

<sup>33</sup> Werner, p. 2.

<sup>34</sup> Ibid., p. 3.

Article 16 of the CRPD provides for the freedom of people with disabilities from exploitation, violence and abuse. While acknowledging the necessity of such provision, it has to be underlined, in the light of sexual and reproductive rights, that “freedom from” should never trump “freedom to.” The Convention has to be interpreted as a whole, assuring that rights are not being disregarded in the name of protection.

Article 23 provides for respect for home and the family, indicating that states shall take effective and appropriate measures to eliminate discrimination against people with disabilities in all matters relating to marriage, parenthood and relationships. Paragraph 1(a) provides for the right to marry and paragraph 1(c) provides for the right to retain fertility. This last provision is extremely relevant in the context of coerced and forced sterilization. It is also indicated that children should never be separated from parents against their will, and in no case on the basis of a disability of either the child or one or both of the parents.

Another relevant provision is article 25 regarding the right to health. Its paragraph (a) indicates states shall provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health. Paragraph (d) states that health professionals are required to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent, underlining the necessity to give priority to the will and preferences of the person with disabilities.

The CRPD is a fairly new instrument. The text was adopted by the UN General Assembly on 13 December 2006, and opened for signature on 30 March 2007. It came into force on 3 May 2008, following, as required, ratification by the 20th party. As State Parties start developing their

policies in order to comply with it, it is important to advocate for assuring the implementation of all provisions, including of those related to the sexuality of people with disabilities.

The CRPD Committee has made some steps in underlining the necessity of taking such aspects into consideration. It has pointed out that general measures are required, such as strategies for mainstreaming gender and disability issues into legislation and programmes focusing on women, including those that deal with sexual and reproductive rights.<sup>35</sup>

Tackling the issue of information on sexual and reproductive health, it has stated that programmes meant at disseminating such information are necessary.<sup>36</sup> Such programs have to be provided in an accessible format,<sup>37</sup> and especially to girls and women with disabilities.<sup>38</sup> Legislation needs to be adopted and measures taken in order to protect people with disabilities against discrimination and ensure that people with disabilities have the same access to quality health services, including in the area of sexual and reproductive health.<sup>39</sup> The Committee also pointed out that sex education has to be taught to children and adolescents with intellectual disabilities.<sup>40</sup>

Forced sterilization and abortion constitute a distinct sexuality-related topic that needed to be specifically addressed. The CRPD Committee underlined that laws and policies which permit compulsory sterilization and forced abortion on women with disabilities are not in compliance

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<sup>35</sup> Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of Argentina*. U.N. Doc. CRPD/C/ARG/CO/1(2012), para. 13.

<sup>36</sup> Committee on the Rights of People with Disabilities. *List of issues to be taken up in connection with the consideration of the initial report of Tunisia*. U.N. Doc. CRPD/C/TUN/Q/1 (2010), para. 21.

<sup>37</sup> *Ibid.*, para. 21 and in Committee on the Right of People with Disabilities. *List of issues to be taken up in connection with the consideration of the initial report of Paraguay*. U.N. Doc. CRPD/C/PRY/Q/1 (2012), para. 24.

<sup>38</sup> Committee on the Right of People with Disabilities. *List of issues to be taken up in connection with the consideration of the initial report of Paraguay*. U.N. Doc. CRPD/C/PRY/Q/1 (2012), para. 24.

<sup>39</sup> Committee on the Rights of People with Disabilities. *Guidelines on treaty-specific document to be submitted by states parties*. U.N. Doc. CRPD/C/2/3 (2009), p. 14.

<sup>40</sup> Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of China*. U.N. Doc. CRPD/C/CHN/CO/1 (2012), para. 66.

with article 23 of the Convention.<sup>41</sup> It pointed out also that States Parties should report on measures taken to protect all persons with disabilities from forced sterilization, and girls and women from forced abortions.<sup>42</sup>

The right to home and family is also very much related to the sexuality of people with disabilities, the reproductive function of sexual intercourse being given an important role within society. In relation to this the CRPD Committee underlined that State Parties should report on measures taken to ensure that persons with disabilities may exercise the right to marry and to found a family on the basis of full and free consent, on measures taken so that they have access to family planning, assistive reproduction and adoption or fostering programmes and on measures taken to ensure that parents with disabilities, who so require, are provided with the adequate support in their child-bearing responsibilities, ensuring the parent-child relationship.<sup>43</sup>

One other issue which was specifically addressed and which is relevant to sexuality and disability is violence against, and exploitation or abuse of, persons with disabilities. The CRPD Committee requires studies to be carried out in order for certain data to be provided, data which has to include indications on the number of complaints that have been received and relevant decisions adopted by the Ombudsman's Office and other authorities, and be disaggregated by age and gender.<sup>44</sup> It also requires indications on whether there are any programmes or policies

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<sup>41</sup> Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of China*. U.N. Doc. CRPD/C/CHN/CO/1 (2012), para. 34, Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of Hungary*. U.N. Doc. CRPD/C/HUN/CO/1 (2012), para.38, Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of Peru*. U.N. Doc. CRPD/C/PER/CO/1 (2012), para. 35.

<sup>42</sup> Committee on the Rights of People with Disabilities. *Guidelines on treaty-specific document to be submitted by states parties*. U.N. Doc. CRPD/C/2/3 (2009), p. 11 and p. 13.

<sup>43</sup> Committee on the Rights of People with Disabilities. *Guidelines on treaty-specific document to be submitted by states parties*. U.N. Doc. CRPD/C/2/3 (2009), p. 14 and in Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of Argentina*. U.N. Doc. CRPD/C/ARG/CO/1(2012), para. 36.

<sup>44</sup> Committee on the Right of People with Disabilities. *List of issues to be taken up in connection with the consideration of the initial report of Paraguay*. U.N. Doc. CRPD/C/PRY/Q/1 (2012), para. 16.

that ensure the protection of persons with disabilities against sexual violence, trafficking and sexual exploitation.<sup>45</sup> Such programmes and policies have to ensure that services and information are accessible to victims, that complaint mechanisms are set up and mandatory training for the police force on handling violence against people with disabilities is conducted.<sup>46</sup> Protection services also have to be age-, gender- and disability-sensitive and accessible.<sup>47</sup>

As explained, the CRPD Committee has understood to touch upon many sexuality-related aspects and has encouraged states to improve many practices, giving certain guidelines on what is to be done. What I argue however is that the Committee's approach has not been entirely comprehensive as it did not address all sexuality relevant issues in all the state reports it has analyzed. While it pointed out the necessity to improve practices, where there were not enough details about practices, policies and laws it did not ask for it, nor did it make recommendations for more research to be conducted or more measures to be taken.<sup>48</sup>

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<sup>45</sup> Ibid., para. 17.

<sup>46</sup> Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of China*. U.N. Doc. CRPD/C/CHN/CO/1 (2012), para. 66 and para. 91.

<sup>47</sup> Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of Hungary*. U.N. Doc. CRPD/C/HUN/CO/1 (2012), para. 32.

<sup>48</sup> If we take the example of Tunisia, we can see that in the State Party Report (Committee on the Rights of People with Disabilities. *Initial report submitted by State parties: Tunisia*. U.N. Doc. CRPD/C/TUN/1 (2010)), sexual and reproductive health aspects were hardly touched upon in para. 110, 112, and 117. The first two paragraphs referred to sexual violence related laws, which exist in all countries. The problems are usually connected to the implementation of such laws and with the special trainings law enforcement officers might need. This paragraphs however only address the existence of the law. And the last mentioned paragraph assumes the obligation the state has in relation to forced sterilization. It does not however give any details on relevant legislation and measures. In the Concluding Observations (Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of Tunisia*. U.N. Doc. CRPD/C/TUN/CO/1 (2011)), the CRPD Committee chose to stay silent on manifesting concerns on such issues. It is true than in some of meeting Tunisian representatives did touch a bit more in detail upon certain aspects (see Committee on the Rights of People with Disabilities. *Summary record of the 4<sup>th</sup> meeting. Consideration of reports submitted by State parties: Tunisia*. U.N. Doc. CRPD/C/5/SR.4, para. 8 and para. 19). However, this was far from giving sufficient details or touching upon all the issues which have been touched by the Committee in other cases.

## I.C. National policies

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Policies and practices related to sexual and reproductive rights of people with disabilities are extremely varied. There are countries which do include<sup>49</sup> sexuality-related aspects as a target in their disability policies, such as Australia,<sup>50</sup> Bolivia,<sup>51</sup> Denmark<sup>52</sup> and Sweden,<sup>53</sup> and countries which do not, such as Bulgaria,<sup>54</sup> Czech Republic,<sup>55</sup> Ecuador<sup>56</sup> and Fiji Islands.<sup>57</sup> The Council of Europe Disability Action Plan 2006-2015 does not specifically address such aspects as key targets either.<sup>58</sup>

The fact that such aspects are included in policies does not mean that all relevant problems are dealt with in a comprehensive way. There is actually no country which can be found to be in full compliance with the standards established by the CRPD.

Let's take the case of Australia. Sexuality related aspects are abundantly addressed in literature and through good policies and practices.<sup>59</sup> However, forced sterilization is still permitted in

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<sup>49</sup> By including such aspects I do not refer to clauses mentioning protection of abuse, which are not of specific interest to this paper; they exist in all countries and problems appear during their implementation; moreover, It is considered that such aspects are touched upon only when they are established as a key target and not when there is a vague mentioning about it.

<sup>50</sup> See the Australian *National Disability Policy*, p. 14 and 64.

<sup>51</sup> See the Bolivian *National Plan for Equality and Equal Opportunities of People with Disabilities*, p. 35.

<sup>52</sup> See *Danish Disability Policy. Equal opportunities through dialogue*. (The Danish Disability Council, 2002), p. 44.

<sup>53</sup> In its State Party Report to the CRPD Committee (Committee on the Rights of People with Disabilities. *Initial report submitted by State parties: Sweden*. U.N. Doc. CRPD/C/SWE/1 (2012)), para. 218), Sweden stated: "One target area for national public health policy in Sweden is that everyone should be entitled to a secure and safe sexuality and good reproductive health. As some injuries and disabilities can affect sexuality and a person's sex life, bodies such as the National Institute of Public Health perform work to increase knowledge within health and medical service and within various forms of care regarding which support different persons with disabilities may require. This is to ensure that those who work within health and medical service can provide good care and communicate knowledge regarding questions relating to sexuality and reproductive health."

<sup>54</sup> See the Bulgarian *National Strategy for Equal Opportunities for Disabled People. 2008-2015*.

<sup>55</sup> See the Czech *National Plan for the Creation of Equal Opportunities for Persons with Disabilities. 2010-2014*.

<sup>56</sup> See Ecuador: *Synthesis of the Second National Plan for People with Disabilities*.

<sup>57</sup> See the Fiji Islands *Disability Action Plan*.

<sup>58</sup> See *Recommendation Rec(2006)5 on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015*. (Council of Europe, 2006).

<sup>59</sup> For example, they address sexuality in their policies in many ways. In the State Report to the CRPD Committee (Committee on the Rights of People with Disabilities. *Initial report submitted by State parties: Australia*.



certain circumstances, although, as explained above, it is in blatant violation of the Convention. Even where there is a longer practice of acknowledging sexual and reproductive rights for people with disabilities, not all aspects are being covered. This is because of all the history of disability and sexuality and because comprehensive guidelines on this issue do not exist. Detailed guidelines need to be established by relevant international actors, such as the World Health Organization or the CRPD Committee.

Good policies are a sign that awareness does exist, even if it is partial. Tackling these sensitive issues has begun. However, the difference between the importance awarded to sexuality-related aspects in different countries is very big. Let's take the example of the EU, which has ratified, as an entity, the CRPD. Its compliance with related obligations is to be reviewed within the activity of the Member States, which are assumed not to be very different in relation to their awareness of human rights issues, at least having as a comparator the large scale of diversity existing globally. These states' disability policies vary significantly. In Romania there is hardly any access to sexual education for people with disabilities. In countries like Sweden, the Netherlands and Denmark there is an established practice of providing such information. Moreover, in the Netherlands and in Denmark services offered by trained sex workers and sexual surrogates for people with disabilities are subsidized by the state.<sup>60</sup> Some of the practices can only be left at the

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U.N. Doc. CRPD/C/AUS/1 (2012), para. 152) it is explained: "There are specific measures in a number of jurisdictions to ensure that persons with disabilities have access to health services in the area of sexual and reproductive health. In the ACT, persons with disabilities have equal access to reproductive and family planning education through Sexual Health and Family Planning ACT, which also conducts disability-specific courses on these topics. The Family Planning Association of Tasmania provides a program *So Safe* which teaches safe social and sexual behaviors to persons with intellectual disabilities. The WA Department of Health funds the Sexuality Education Counseling and Consulting Service, which develops and implements health promotion programs to enhance the health and wellbeing of persons with disabilities and educate the wider community in areas of sexuality and disability."

<sup>60</sup> Margrit Shildrick. *Dangerous discourses of disability, subjectivity and sexuality*. (Palgrave Macmillan, New York, 2009), p. 61.

choice of the state, being very much related to its choice regarding welfare. However, guidelines, with progressive realization related measures need to be made clear.

Let's also take an example related to specific rights. As explained above, article 23 of the CRPD provides that states shall take effective and appropriate measures to eliminate discrimination against people with disabilities in all matters relating to marriage, parenthood and relationships. People with disabilities have therefore the right to marry on an equal basis with others who are of marriageable age, on the basis of the free and full consent of the intending spouse. They also have "the right to be part of other types of affective relationships [...] and worthy of protection from public authorities."<sup>61</sup> Practices are many times not in compliance with this. For example, in Romania, the Civil Code talks about the right to marry and form a family. However, the same code bans people with intellectual disabilities and those who are not "in full possession of their mental faculties" from marrying and forming a family.<sup>62</sup> In many other countries of the EU "other types of relationships are still very rare and tend to survive despite strong resistance from families and the community."<sup>63</sup>

In conclusion, there are countries which do specifically address sexuality related aspects in their policies and/or have relevant practice. However, many countries do not consider such aspects neither in policies, nor in practices, significant differences in the approaches of State Parties of the CRPD existing. This variety shows that a treaty like the CRPD was indeed necessary. It is not necessarily a sign that states are not willing to fulfill their obligations. But even if it is only a sign that states are not fully aware of what their obligations are, what is clear is that advocacy and comprehensive guidelines are needed.

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<sup>61</sup> Pelaez Narvaez, p. 243.

<sup>62</sup> Ibid., p. 243.

<sup>63</sup> Ibid., p. 244.

## Chapter II. Difficulties in manifesting sexuality

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### II.A. General considerations

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It is often thought that “disabled people are asexual or hyper sexual; information and education about sex will encourage ‘inappropriate’ sexual behaviour; intellectually disabled people are incapable of understanding sexuality, physically disabled people are unable to have sex; disabled people cannot/should not be parents; disabled people should be grateful for any type of sexual relationship.”<sup>64</sup>

The existence of such generalized and stereotypical statements is not surprising. Minority groups are in many cases the object of ignorant, unfounded and discriminatory assumptions. Such statements are however often revealing for related practices.

Sexual expression is difficult for many people with disabilities, and not only because of what some uninformed people might wrongly assume, but because of more factual issues. Tom Shakespeare succinctly explains how studying, working and being generally involved in a community:

contributes to having “someone to have sex with. Most people meet potential partners at college, at work, or in social spaces. Unfortunately, disabled people often don’t get to go to college, or to work, or achieve access to public spaces, because of physical and social barriers. Being sexual costs money. You need to buy clothes, to feel good about, and go places to feel good in. If you are poor, as 50% of disabled Americans are, then it is correspondingly harder to be sexual. More than money, being sexual demands self-esteem. It demands confidence, and the ability to communicate. We all know that it isn’t just the size of your dick, or the shape of your body that counts when it comes to attracting potential partners, nor even the size of your

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<sup>64</sup> *Sexuality and disability*. (Irish Family Planning Association, 2007), p. 6.

wallet; it's what's between the ears. [...] Yet disabled people, systematically devalued and excluded by modern western societies, are often not in the right place to begin that task of self-love and self-worth.”<sup>65</sup>

When turning to practicalities, the sexuality of people with disabilities also stops being a private issue of an individual deemed as not able. While sexuality is a legitimate part of everybody's life, its different aspects tend to be moved more often into the public realm in the case of people with disabilities. This is because many such individuals, due to not being considered able to live on their own or to encountering societal barriers, live for prolonged periods of time or for all their lives in spaces which lack the privacy of what is usually perceived as home. These spaces can be psychiatric hospitals, psychiatric units of general hospitals, social care institutions, community centers or even prisons. Even when living outside such spaces, different actors, such as family members or state actors often interfere with sexual expressions.

Disregarding the sexuality of people with disabilities is therefore a problem with two facets: it alters the perspective of the individual with disabilities and it alters the perspective of the others. For the individual with disabilities, the legitimacy of sexual pleasure as a component of personal life is questioned by the outside world. This creates difficulties in enjoying sexual pleasure, in finding a partner and even in personally acknowledging sexuality as a trait of one's personhood because while “oppression does not produce an automatic response, [...] it does provide the conditions with which the oppressed can begin to develop their own consciousness and identity.”<sup>66</sup> The altered perspective of the others often materializes, when encountering sexual expression of people with disabilities, in repressive answers which are generally perceived as acceptable behaviors.

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<sup>65</sup> Shakespeare, p. 161.

<sup>66</sup> Jeffrey Weeks. *Coming Out*. (Quartet Books, London, 1977), p. 33.

I underline these two facets of the problem because they expose the necessity of addressing sexuality as an important aspect of disability laws, policies and activities. Sexuality is an important part of a private sphere in which at first sight public intervention is not possible. However, the superficiality of this assumption becomes easily obvious. Sexuality is a part of a public discourse generally. In the case of people with disabilities its publicity is amplified as the public assumes more roles, more rights to intervene, feeling more responsible to protect or finding something particularly dangerous with the intimate relationships of people with disabilities.

Sexual expression among people with disabilities has been often encountered with important repressive force. There has been reported the use of special drugs<sup>67</sup> and of castration<sup>68</sup>. Misleading information has also been provided with the same aim or effect.<sup>69</sup>

The objectifying of the person with disabilities goes up to the point of considering taking contraceptive and pregnancy as practical problems, burdens on health professionals, caregivers and parents. For example, in a report to an Australian Family Court, concerning a girl age 15 years, a neurologist states: “hysterectomy or endometrial ablation have the advantage of certain contraception, and the removal of the need to care for menstruation...[as well as]...avoiding the strict compliance necessary for oral contraceptive to be effective.”<sup>70</sup>

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<sup>67</sup> For example, there is a mentioning of this practice in Anthony Walsh. *Improve and care. Responding to inappropriate masturbation in people with severe intellectual disabilities*. (Sexuality and Disability, 2010), p. 31. Information about the effects of such drugs can be found in Balazs Tarnai. *Review of Effective Interventions for Socially Inappropriate Masturbation in Persons with Cognitive Disabilities*. (Sexuality and Disability, 2006), which also mentions at page 159 the existence of a practice of involuntarily administering such drugs.

<sup>68</sup> See for example: “In an institution in the United States, 656 castrations (bilateral orchidectomies) were performed to stop the men masturbating” (in Miriam Taylor. *Sterilization, drugs which suppress sexual drive, and young men who have intellectual disability*. (Journal of Intellectual and Developmental Disability, 2000), p. 92).

<sup>69</sup> This information can come from the mass media (as explained in Katherine McLaughlin. *Why focus on developmental disability?* (GULP, 2003)), from parents, from staff etc.

<sup>70</sup> Susan M. Brady. *Sterilization of girls and women with intellectual disabilities. Past and present justifications*. (Women against violence, 2001), p. 437.

Menstruation in particular seems to be an extraordinary burden on women with disabilities. The measures taken to ease this burden, which will be applied sometimes voluntarily sometimes involuntarily, include counseling, oral contraceptives, contraceptive patch/injectable, depot-medroxyprogesterone acetate, progestin intrauterine device, endometrial ablation, tubal ligation and hysterectomy.<sup>71</sup> In the literature it is explained why all this is necessary: because menstruation demands “menstrual hygiene [and because there is the possibility of acquiring] premenstrual disorders ranging from premenstrual syndrome to premenstrual dysphoric disorder.”<sup>72</sup> Menstruation is therefore in no way more harsh on women with disabilities than on women with no disabilities. The measures taken are different, are repressive and represent the interests of carers only due to a lack of acknowledgement of the sexuality of persons with disabilities.

Before scrutinizing some relevant practices and how they violate the rights of people with disabilities, I will shortly address the most common justification for ignorant and restrictive answers to their sexuality: the “best interest” doctrine.

### II.B. The “Best Interest” doctrine

The justification for ignorant or repressive answers to the sexuality of people with disabilities is in most cases related to the “best interest” doctrine. There are two main problems with this doctrine. Firstly, it is invoked as a basis for repressive measures. Repressive measures in the name of protection are like fighting a war for peace. What causes this sudden sense of responsibility for the sexual purity of about 10% of the global population?

<sup>71</sup> As explained in detail in Ora I. Paransky and Robert K. Zurawin. *Surgical Challenges. Management of Menstrual Problems and Contraception in Adolescents with Mental Retardation: A Medical, Legal, and Ethical Review with New Suggested Guidelines*. (Journal of Pediatric and Adolescent Gynecology, 2003), pp. 225-228.

<sup>72</sup> Ibid., p. 224.

A phrase in one medical article offers the explanation: “[a] major concern [...] reported in the literature related to the menstrual problems of girls with [psycho-social disabilities] is the [...] concern for contraception in cases where there is risk of sexual abuse.”<sup>73</sup> Studies show indeed that the risk of sexual abuse is many times higher in the case of people with disabilities. However, why do they refer to fixing menstruation related problems by contraception in *cases of sexual abuse*? How does the will of an individual, contraception and sexual abuse connect?

They actually do not. The connection considered is not between the well-being of the person and the sexual abuse, but between sexual abuse and the most possible and probably consequence of it: pregnancy. Pregnancy not only reveals sexual intercourse, which might trigger some form of responsibility of others, but it also reveals the ability of a person with disability to have sexual intercourse, and raises questions about whether the person consented or not. These issues do not fit in the established framework of usually dealing with people with disabilities. Sexuality is purely not there.

The solution usually adopted is to remain at a standstill and to eliminate people with disabilities’ ability to give consent and maybe most importantly their ability to show that, with or without consent, they do engage in sexual activities. Repressive measures are therefore sometimes designed to protect the interest of the abuser. Also, they are aimed not at protecting people with disabilities, but at protecting myths and the commodity in which society prefers to linger. They include putting people with disabilities under over-inclusive forms of guardianship,<sup>74</sup> recurring to voluntary or involuntary contraception, or to be certain, definitive measures, such as sterilization, which make the ability to procreate disappear. Moreover, while “[r]eferences to

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<sup>73</sup>Ibid., p. 224.

<sup>74</sup>Over-inclusiveness refers to not applying a strict selection of those which will be included. Their specific characteristic and needs will not be analyzed, but will be from the start considered similar.

[...] a need for special protections from sexual abuse are certainly merited [...] [they are] one of the few visible discourses of disabled female sexuality. These references [usually] reinforce norms of both femininity and disability that describe women with disabilities as vulnerable, sexually passive or asexual, and dependent. [...] [Also] the sexual protection discourse is gendered; male vulnerability to sexual abuse is much less frequently invoked.”<sup>75</sup>

The second problem with the “best interest” doctrine applied in the case of people with disabilities is revealed by an international trend, which led to not including the “best interest” formula in the text of the CRPD.<sup>76</sup> This is because “[t]he best interests principle emerged from law and policy focused on children [...]. A central aspect of Article 12 [of the CRPD] is the focus on the ‘will and preferences’ of the person as the determining factor in decisions about their life and this requires moving away from a ‘best interests’ approach, which brings with it the significant risk of paternalism.”<sup>77</sup>

An example of how the best interest doctrine works is a Chinese Crimes Ordinance. As explained by the Chinese government, “to better protect mentally incapacitated persons from sexual abuse, section 128 of the Crimes Ordinance prohibits any person, without the permission of the parent or guardian, from taking mentally incapacitated persons out of the possession of the parent or guardian with the intention of making the mentally incapacitated person perform any unlawful sexual act.”<sup>78</sup> This provision not only that it does not take into consideration the will and preferences of the person with disabilities, but it does not even take into consideration its

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<sup>75</sup> Schaaf, p. 115.

<sup>76</sup> by this I mean that the formula does not appear in relation to people with disabilities in general. The formula does appear in art. 7 (2), but in relation to the child. Using the “best interest” doctrine in relation to children’s rights is not an object of this paper.

<sup>77</sup> *Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence & Equality*. (Center for Disability Law and Policy, NUI Gallaway, 2011), p. 6.

<sup>78</sup> Committee on the Rights of People with Disabilities. *Initial report submitted by State parties: Hong Kong, China*. U.N. Doc. CRPD/C/CHN-HKG/1 (2011), para 5.16.



possibility to express an opinion. The prohibition is for a possible perpetrator, and the decision maker is the parent or guardian, who could, technically, consent to the sexual abuse of the person with disabilities.

Facing these relatively theoretical critics, the laws which have as an effect prohibiting certain people with disabilities from entering into intimate relationships are also in breach of relevant international law.

Article 12 of the CRPD states that people with disabilities do have the right to exercise their will, with support where required, on an equal basis with others in all aspects of life, including in relation to their sexual behavior. Article 23 mentions people with disabilities' right to marry, to have access to reproductive and family planning education, to retain their fertility and to have their family life respected. All these rights are illusory if the person is prohibited from engaging into intimate relationships.<sup>79</sup>

This was also asserted in the Council of Europe's standards, which explicitly stipulate that "people with disabilities have the right to recognition everywhere as persons before the law."<sup>80</sup> In its *Shtukatur*<sup>81</sup> judgment, the European Court of Human Rights (ECHR) recognized that the will of a person placed under guardianship had to be taken into consideration when a restriction on a right as fundamental as the right to liberty is concerned. "In so doing, the Court recognized that a person whose legal capacity has been formally restricted may retain capacity to make

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<sup>79</sup> Article 16 of the CRPD requires states "to take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects." As illustrated above, extreme repressive measures cannot exist justified by protection. Moreover, the CRPD has to be read as a whole and one provision cannot be read as a mandate to restrict other rights outlined in the treaty.

<sup>80</sup> *Recommendation Rec(2006)5 on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015*. (Council of Europe, 2006), para. 3.12.1.

<sup>81</sup> *Shtukatur v. Russia*. App. No. 44009/05. (ECHR, 27<sup>th</sup> of March 2008).

medical and other decisions rather than having such decisions made by third parties.”<sup>82</sup> The issue of consent to sexual activities does not raise more problems than any other areas of life in which the person is stripped of the ability of taking decisions under over-inclusive guardianship systems.

Guardianship as a legal tool has started to be attacked by many disability advocates, especially the plenary one. If accepted, guardianship can only influence specific areas of life. Before finding a person not able to give consent to sexual activities, an assessment of the person’s capacity to decide matters specifically concerning reproduction and sexuality should be necessary.<sup>83</sup> I suggest this as a transitory measure. I do believe that trying to regulate and restrict, by law, the ability of engaging in sexual activities is in itself a contradiction. It is like allowing children in a big entertainment park, but, to protect them from drowning, telling them that they can never jump in the pool. Some of them will be scared of water, some will not be interested in water, some will be satisfied by just touching the water. But there will always be someone who will jump. The solution is not to forbid swimming, but to teach everybody how to swim.

Even more than the desire to swim, sexuality cannot be disregarded or deleted. Even if legally declared not able to engage in sexual intercourse, people will still do it if so they wish. Therefore what external actors can do is to educate the person in sexuality matters and provide support. As Gina di Giulio explains, “it is [anyways] more likely the case that inappropriate expressions of

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<sup>82</sup> *In the European Court of Human Rights. Joelle Gauer and Others against France. Written comments.* (Center for Reproductive Rights, European Disability Forum, International Center for the Legal Protection of Human Rights (Interights), International Disability Alliance and Mental Disability Advocacy Center, 2011), p. 7.

<sup>83</sup> The American Academy of Pediatrics suggested that such assessment should be mandatory in cases where sterilizing minors with developmental disabilities is discussed (see Gina di Giulio. *Sexuality and people living with physical or developmental disabilities: a review of key issues.* (The Canadian Journal of Human Sexuality, 2003), p. 59). While I believe sterilizing children for no clear medical reason is highly problematic, this solution could be main-streamed as a transitory response to a more needs- based guardianship system. By a needs- based guardianship system I mean a system in which the person is stripped by the ability to make decisions on its own in very specific fields. In such systems, guardians can contribute to making decisions only in the events where it has been clearly established that the person has a need for support.

sexuality are not a reflection of a lack of capacity for responsible sexual behavior but rather inappropriate behavior is the result of [...] people being placed in environments where appropriate expressions of sexuality is impossible.”<sup>84</sup>

I will further scrutinize some relevant practices, giving a few examples of how aspects related to the sexuality of people with disabilities become a problem for involved actors. It becomes a problem because they manifest themselves and the fact that sexuality is often disregarded influences the response to it.

## II.C. Lack of information

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One very important problem relating to manifesting sexuality is lack of information. The lack of information and of training is wide spread not only among people with disabilities,<sup>85</sup> caregivers, parents<sup>86</sup> and social assistants, but also among health professions.<sup>87</sup>

### II.C.1. Lack of information among people with disabilities

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When information is lacking from the person with disabilities or is insufficient, the whole process of sexual decision making is altered. “In order to exercise informed decisions, individuals must have the relevant information, [...] reflect on their values, desires and goals so

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<sup>84</sup> di Giulio, p. 59.

<sup>85</sup> See for examples the studies referred to di Giulio, p. 59; also Glynis H. Murphy and Ali O’Callaghan. *Capacity of adults with intellectual disabilities to consent to sexual relationships*. (Psychological Medicine, 2004).

<sup>86</sup> See for example the studies referred to in di Giulio, p. 59, where it is underlined: “Parental anxiety over sexual exploitation often results in overprotection, thus depriving children with developmental disabilities of their sexual rights and freedom. To alleviate fears and anxiety, parents may suppress their children’s sexuality, and thus fail to equip them with the knowledge to deal appropriately with the sexual experience they encounter.” See also the studies referred to in Miriam Taylor. *Sterilization, drugs which suppress sexual drive, and young men who have intellectual disability*. (Journal of Intellectual and Developmental Disability, 2000), p. 93, para. 3-4.

<sup>87</sup> See for example the relevant studies referred to in di Giulio, p. 59, para. 5. At page 64 she cites a study which underlines: “Professionals should feel comfortable raising the issue with the patient to permit discussion of the topic. In addition, professionals should possess enough information about sexuality and the specific disability or illness to impart limited information. Moreover, they should possess enough information to know their limits or to know what they do not know. In that case they would move up to the next level of the model, that is referring the patient to a more knowledgeable professional for specific suggestions or intensive therapy.”

as to affirm or disaffirm them, make intentional judgments and decisions based on them, and communicate that selection to others.”<sup>88</sup> Not having all this information can have important consequences.

In one study it was found that one of the eight main reasons why disabled people are more vulnerable to sexual exploitation and abuse than non-disabled is the lack of education about appropriate versus inappropriate sexual behavior.<sup>89</sup> Another study reached the same conclusion: “[a]dults with intellectual disabilities were significantly less knowledgeable about almost all aspects of sex and appeared significantly more vulnerable to abuse, having difficulty at times distinguishing abusive from consenting relationships.”<sup>90</sup> “The age at which people with disabilities receive information about sexuality is correlated with attaining sexual milestones, such as engaging in sexual intercourse and finding a sexual partner.”<sup>91</sup> “It is [also] important to recognize that deviant sexual behavior by intellectually disabled clients may be a reflection of [...] lack of information and education about sexual relationships and body parts.”<sup>92</sup>

Leonore Tiefer briefly explains how for the expression of different forms of sexual expression education and support is needed: “Imagine how you would feel if playing gin rummy, and playing it well, was considered a major component of happiness and a major sign of maturity, but no one told you how to play, you never saw anybody else play, and everything you ever read

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<sup>88</sup> Gurit Lotan and Carolyn Ellis. *Adults with intellectual and developmental disabilities and participation in decision making: ethical considerations for professional-client practice*. (Journal of Intellectual and Developmental Disability, 2010), p. 115.

<sup>89</sup> di Giulio, p. 60.

<sup>90</sup> Glynis H. Murphy and Ali O’Callaghan. *Capacity of adults with intellectual disabilities to consent to sexual relationships*. (Psychological Medicine, 2004), p. 1347.

<sup>91</sup> di Giulio, p. 60.

<sup>92</sup> Miriam Taylor. *Sterilization, drugs which suppress sexual drive, and young men who have intellectual disability*. (Journal of Intellectual and Developmental Disability, 2000), p. 94.

implied that normal and healthy people just somehow ‘know’ how to play and really enjoy playing the very first time they try!.”<sup>93</sup>

### II.C.2. Lack of information among other relevant actors

The lack of information about sexuality and disability among others also has objectifying consequences on people with disabilities because from family members and caregivers to medical professionals, the lack of knowledge is associated with the willingness to accept practices which trump the human rights of people with disabilities. These practices constitute social and environmental barriers which cannot be overcome by people with disabilities even if they themselves have received appropriate information.

A study revealed that there are groups who, having “an understanding of their sexual rights, [...] identify a number of social and cultural barriers that they fe[el] prevent[s] them from achieving sexual autonomy.”<sup>94</sup> It underlined that, next to sex education training, the “promotion of positive attitudes towards appropriate sexual expression is critical to the realization of sexual autonomy for people” with disabilities.

Information can only be effective if it proves relevant in practice, which it will if it is known also by those involved in creating practices. Social and environmental barriers can firstly suppress the process of drawing up a sexual identity. When this identity “subversively” manifests, as it will in most cases, the person will either face appalling responses such as sterilization, castration etc. or it will face a wall of ignorance, which will generate confusion.

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<sup>93</sup> Leonore Tiefer. *Sex is Not a Natural Act*. (Westview Press, Boulder, 1995), p. 12.

<sup>94</sup> D. S. Evans, B. E. McGuire, E. Healy and S. N. Carley. *Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives*. (Journal of Intellectual Disability Research, 2009), p. 905.

Information therefore has to be distributed among all relevant actors and this has to be done in a coordinated way. “When compared with the attitudes of family carers towards the sexuality of people with [...] disabilities, the attitudes of staff carers [might] more closely match those promoted by ideological developments. However, differences in attitudes between carer groups may lead to inconsistent approaches to the management of sexuality. As a consequence, [...] there is continued need to provide staff and family carers with opportunities for dialogue and an ongoing need for training in the area of sexuality.”<sup>95</sup>

Besides accomplishing the role of helping to build up a sexual identity and deal with it, information obtained by other actors about the sexuality of people with disabilities can also have a protective role. Information can have its protective role because “people who have been sexually assaulted often seek medical help but may not disclose the assault.”<sup>96</sup> By acknowledging that people with disabilities are sexual beings, medical personnel can contribute to detecting victims of abuse and helping them. It is very important however that autonomy and protection are combined and that neither prevails.

### II.C.3. Comments under the CRPD

Not ensuring access to information contravenes obligations states assumed under the CRPD, first of all because according to article 21 of the CRPD information and ideas should be imparted on an equal basis with others, and secondly because lack of knowledge is often used as an argument to sustain that people with disabilities cannot make decisions. “Individually tailored sex education programs could improve supported decision-making by regarding sexuality, pregnancy

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<sup>95</sup> Evans et. al., p. 913

<sup>96</sup> Jan Welch and Fiona Mason. *Rape and sexual assault*. (British Medical Journal, 2007), p. 1154.

and parenting, thus improving autonomous decision-making abilities,”<sup>97</sup> and contributing to respecting the right of people with disabilities to be equal with others before the law, as provided by article 12. The CRPD Committee also recommended that sex education be taught to children and adolescents with intellectual disabilities.<sup>98</sup>

## II.D. Abortion laws and women with disabilities

### II.D.1. General considerations

The legal status of abortion is an important indicator of the extent to which women are enjoying their reproductive, but also sexual rights. The fight for the liberalization of abortion laws has at its basis multiple factors. It is underlined that “[l]egal restrictions on abortion often cause high levels of illegal and unsafe abortion, and there is a proven link between unsafe abortion and maternal mortality.”<sup>99</sup>

A part of this liberalization movement, both as participants in the movement and subjects of rights, are all women, including women with disabilities. Women with disabilities however have to deal with a specific set of problems in relation to abortion. Their ability to access abortion is in many cases more liberalized than for women with no disabilities. The main problem they face is related to consent as abortion can be performed without their knowledge, without requesting their consent to it, or even against their will.

There are countries in which restrictive abortion laws make such procedure legal only in a few situations, usually to save the life of the pregnant woman, when the pregnancy is the result of

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<sup>97</sup> Werner, p. 16.

<sup>98</sup> Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of China*. U.N. Doc. CRPD/C/CHN/CO/1 (2012), para. 66.

<sup>99</sup> *Safe and legal abortion is a woman's human right*. (Center for Reproductive Rights, 2011).

rape or incest, and when the pregnant woman is “of unsound mental condition.”<sup>100</sup> In other countries the law allows for abortion in cases of rape of mentally disabled women only.<sup>101</sup> Such distinction, as explained above, might be made as a way to protect a group which is considered extremely vulnerable, or not able to take a pregnancy to an end or to cope with childcare.

In many countries health related decisions are taken by legal guardians, and abortion is considered a health issue. These legal guardians can be family members or state employees who, in some cases have never met the person. A state institution, or the state itself can also be a legal guardian.<sup>102</sup> The decision can also be taken by courts.<sup>103</sup> The fact that these persons, entities or bodies can decide if one gets to continue or not with the pregnancy is not addressed in the abortion related discourse.

#### II.D.2. Conflict between the general abortion discourse and the disability specific abortion discourse: case study on a legal decision

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The general “liberalize abortion” discourse, when not aware of the specificities of the disability related abortion discourse, can ignore them and even take advantage of this ignorance. I will explain this by looking at a recent liberalizing step of the Argentinean abortion law. Before March 2012, a victim of rape could have legal access to abort the fetus resulting from such act only if was considered to be mentally incapacitated, or using the words of the Penal Code,

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<sup>100</sup> This last situation is, for example, specifically addressed in Bhutan (see Reed Boland and Laura Katzive. *Developments in Laws on Induced Abortion:1998-2007*. (International Family Planning Perspectives, 2008), p. 114), Ethiopia (see Boland and Katzive, p. 116).

<sup>101</sup> In Ecuador (see Boland and Katzive, p. 113), in Argentina before March 2012 (see the Argentinean Penal Code, article 86, para. 2), in Swaziland (see Boland and Katzive, p. 116)).

<sup>102</sup> In *Bauer v. Second Judicial Dist. Court of State ex rel. County of Washoe*, 2012 Westlaw 5456090 (November 6, 2012) (U.S. District Court of Nevada) the Court deals with whom can choose to terminate the pregnancy of a woman with disabilities: her parents or the local social services?; this is an example of situations in which the person with disabilities is stripped of ability to consent or not to consent to abortion; its opinion is irrelevant.

<sup>103</sup> See the example of Lithuania in *Written submission to the Human Rights Committee with respect to Lithuania*. (Global Initiative on Psychiatry, Lithuanian Forum for the Disabled and the Mental Disability Advocacy Center, 2012), pp. 3-4.



“idiotic” or “demented.”<sup>104</sup> In *F. A. L. s/ Medida Autosatisfactiva*,<sup>105</sup> the Supreme Court decided that all rape victims should have legal access to abortion, which has been reported as a huge success for women’s rights,<sup>106</sup> being a step towards fully legalizing abortion.

What has not been reported is that in interpreting the law, the Court also addressed women with disabilities. The contested abortion law was stating that abortion is only permitted in *cases of rape or indecent assault against an idiotic or demented woman*,<sup>107</sup> which had previously been interpreted as allowing abortion only if the victim of rape had a mental disability. The Court explained that this legal interpretation establishes “an unreasonable differential treatment with respect to other victims of an analogous crime who may be in an equal situation.”<sup>108</sup>

Opponents stated that the legal provision existed only as an effective normative protection for women with disabilities, a “risk group” which was suffering from structural legal weakness, being already vulnerable to abuse. The Court replied that such differentiation “would not respond to the valid objective of protecting the rights of victims of sexual violence (whose vulnerability is made worse by having a mental disability), but rather prejudice them as subjects with full rights.”<sup>109</sup> It refers to people with disabilities, who can also be victims of sexual violence, as subjects with full rights, this being a progressive and visionary statement, going against guardianship systems around the world which strip people with disabilities of their capacity of subject of rights.

<sup>104</sup> Argentinean Penal Code, article 86, para. 2.

<sup>105</sup> *F. A. L. s/ Self-executive measure*, F. 259. XLVI, (March 13, 2012) (Argentina, Supreme Court of Justice).

<sup>106</sup> See for example *Argentina decriminalizes abortion in all cases of rape*. (Center for Reproductive Rights, 2012); Rebecca DiLeonardo. *Argentina Supreme Court legalizes abortion for rape victims*. (Jurist. March 14, 2012); *Argentine court decriminalizes abortion in rape cases*. (BBC, March 13, 2012); *Argentina: Abortion is legal for rape victims*. (Reproductive and Sexual Health Law: Developments and Resources, 2012).

<sup>107</sup> Argentinean Penal Code, article 86, para. 2.

<sup>108</sup> *F. A. L. s/ Self-executive measure*, F. 259. XLVI, (March 13, 2012) (Argentina, Supreme Court of Justice), para 15.

<sup>109</sup> *Ibid.*, para. 15.

However, the Court continued by explaining why the provision applies to all women, and not only to those with mental disabilities. It distinguished between rape and “an indecent assault against an idiotic or demented woman”, pointing out that “indecent assault cannot be but a carnal access or another situation [expressed towards a *person with disabilities*] that goes against the victim’s sexuality and which may produce a pregnancy,”<sup>110</sup> “every carnal access of a woman with mental deficiencies [being] already considered a form of rape.”<sup>111</sup> It associated this with the case of minors under the age of 13, whose “carnal access is already rape.”<sup>112</sup> The Court therefore stated that all “carnal access” of women with “mental deficiencies”<sup>113</sup> goes against her sexuality and is to be punished. This can be translated into saying that these women cannot consent to sex<sup>114</sup> and that sexual activities go against their sexuality which is supposed to be expressed through something else rather than sexual activities.

In conclusion, the Court promoted women’s right by disregarding the specific rights of women with disabilities. Human rights movement had no reaction, proving that they are often not equipped to understand and deal with these issues.

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<sup>110</sup> Ibid., para 18.

<sup>111</sup> Ibid., para 18.

<sup>112</sup> Ibid., para 18.

<sup>113</sup> The Court further explains why the carnal access of a woman with mental deficiencies was called indecent assault and not rape. It says that this was an “incorrect” translation of the Swiss Preliminary Draft Code of 1916, which a source of inspiration, and which distinguished between rape of people with no disabilities, which was called “rape” and rape of women with disabilities, which was called “profanation.” The term “profanation”, used in relation to sexual abuse of people with disabilities, is an interesting reference to opinions about people with disabilities. “Profane”, according to the *American Heritage College Dictionary*. Third Edition. (Houghton Mifflin Company, Boston, 1993), means to treat with irreverence or to put in an improper, unworthy or degrading use or abuse. Usually however it is used to mark with contempt or irreverence what is sacred; and it is usually used in relation to objects. It might have been chosen because people with disabilities were considered less persons and more objects, or because they were associated with something sacred. In the Romanian Penal Code the crime of “profanation” (article 319) can be committed in relation to graves, monuments, funeral urns or corpses.

<sup>114</sup> Which is specifically stated by the Court in *F. A. L. s/ Self-executive measure*, para. 30.

### II.D.3. Problematic aspects of the disability specific abortion discourse: case study on a legal decision

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I will further consider problematic issues which can appear when courts deal with situations where women with disabilities are directly involved. I will shortly discuss the Indian Supreme Court's *Suchita Srivastava & Anr. vs Chandigarh Administration*,<sup>115</sup> which involved a 19-20<sup>116</sup> year old orphan girl with a mild intellectual disability who had lived all her life in state welfare institutions. In not established circumstances she became pregnant. While she wanted to continue carrying the pregnancy, the institution where she was living preferred abortion and considering it has the right to decide it took the matter to Court, which decided in favor of the girl.

This decision is groundbreaking for several reasons. Firstly, the Court affirmed that the termination of pregnancy cannot be permitted without the consent of the woman. It also underlined that “[h]er reproductive choice should be respected in spite of other factors such as the lack of understanding of the sexual act as well as apprehensions about her capacity to carry the pregnancy to its full term and the assumption of maternal responsibilities thereafter.”<sup>117</sup>

Secondly, it affirmed that a “claim to guardianship cannot be mechanically extended in order to make decisions about the termination of her pregnancy.”<sup>118</sup> Thirdly, it underlined the need to look beyond social prejudices in order to objectively decide whether a person who is in a condition of mild mental retardation can perform parental responsibilities.<sup>119</sup> Fourthly, it stated that assistance with childcare will be given to the mother.<sup>120</sup>

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<sup>115</sup> *Suchita vs Chandigarh Administration*. 2009 Indiankanoon 1500783 (August 28, 2009) (India, Supreme Court).

<sup>116</sup> As it wasn't certain, her age was established through an ossification test.

<sup>117</sup> *Suchita vs Chandigarh Administration*, para. 10.

<sup>118</sup> *Ibid.*, para. 13.

<sup>119</sup> *Ibid.*, para. 27, 28 and 30.

<sup>120</sup> *Ibid.*, para. 31.

The decision however has also several downsides. Firstly, it distinguished between “mental retardation” and “mental illness”, concluding that consent for abortion is needed only from the “mentally retarded.” For the “mentally ill” the guardian can consent. While it was pointed out that this differentiation had collapsed in relation to affirmative action in public employment, education and for the purpose of implementing anti-discrimination measures, the Court chose to “emphasize that the same distinction cannot be disregarded so as to interfere with the personal autonomy that has been accorded to mentally retarded persons for exercising their reproductive rights.”<sup>121</sup> Moreover, the Court also distinguished between varying degrees of mental retardation, saying that “as far as possible the law should respect the decisions made by persons who are found to be in a state of mild to moderate `mental retardation,”<sup>122</sup> therefore reducing the number of possible beneficiaries of this judgment.

Secondly, while the Court emphasized the importance of checking whether the woman consents or not to abortion, it established that even if the woman expresses her will to continue with pregnancy, a “best interest” test and/or a “substituted judgment” test is to be applied subsequently. For the specific situation the Court allowed the woman to continue her pregnancy because she wanted to, but also because it was in her best interest as she was physically capable of continuing the pregnancy, the prospective child could have been born with no congenital defects, the Expert Body agreed with her and her pregnancy had already passed the statutory limit of 20 weeks.<sup>123</sup> The Court called this a holistic assessment of physical, psychological and social parameters in which will and preferences can be considered, but also disregarded.

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<sup>121</sup> Ibid., para. 16.

<sup>122</sup> Ibid., para. 21.

<sup>123</sup> Ibid., para. 22-23.

#### II.D.4. Comments under the CRPD

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Article 6 of the CRPD indicates that girls and women with disabilities have to be ensured with the full and equal enjoyment of all human rights, including to enjoy legal capacity on an equal basis with others in all aspects of life and to have their will and preferences respected, as explained in article 12. Article 23 provides for the right not to be discriminated in any matters related to parenthood or relationship, to decide freely on the number of children one wants to have and to receive appropriate assistance in carrying out child-rearing responsibilities.

The CRPD Committee pointed out that States Parties should report on measures taken to protect girls and women with disabilities from forced abortions.<sup>124</sup> It also underlined that support had to be provided in order to ensure that the women themselves are the ones who give their informed consent for a legal abortion.<sup>125</sup> Both Argentina and India have ratified the CRPD. They are therefore bounded to promote, respect and fulfill the rights enumerated above. When Argentinean courts say that women who are “idiotic” or “demented” can never consent to sexual activities they are not respecting their right to all matters related to relationship, or to possible parenthood. When Indian courts say that it does not matter what women with disabilities say they want in relation to their pregnancy they are in violation of the CRPD because they do not recognize legal capacity and do not respect will and preferences.

#### II.D.5. Concluding remarks

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The legal status of abortion is an important human rights issue for all women. Women with disabilities have specific problems due to the fact that they are many times stripped of the opportunity to express their will in relation to the termination or continuation of pregnancy. Such

<sup>124</sup> Committee on the Rights of People with Disabilities. *Guidelines on treaty-specific document to be submitted by states parties*. U.N. Doc. CRPD/C/2/3 (2009), p. 11 and p. 13.

<sup>125</sup> Committee on the Right of People with Disabilities. *Concluding observations on the initial report of Argentina*. U.N. Doc. CRPD/C/ARG/CO/1 (2012), para. 32.

issues are not sufficiently addressed by the general abortion related discourse, which does not advocate for a holistic approach addressing all the problems all women face when their bodies are being publicly discussed. This makes it possible for practices, judicial decisions and laws violating the rights of women with disabilities to exist.

## II.E. Forced Sterilization

### II.E.1. General considerations

Forced sterilization, by which is understood both the practice of undergoing the operation without the knowledge of the person, and of undergoing the operation without the consent of the person, is in violation of sexual and reproductive rights of all women.<sup>126</sup>

Forced sterilization is a current practice in many countries, constituting a human rights problem. Sometimes the law provides a legal framework for it;<sup>127</sup> but it does happen and often remains unpunished even if it is not lawful.

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<sup>126</sup> For example, Miriam Taylor explains: “it is estimated that more than 70,000 people with intellectual disability were sterilized in the United States under the *Buck v Bell* legal precedent . Smith and Polloway (1993) reported that at a large residential institution in the state of Virginia 212, sterilizations (87 men and 125 women) occurred between 1969 and 1989. [...] [R]ecent research in Queensland (Carlson, 1994; Carlson and Wilson, 1994a), found that sterilization had occurred for 15 (50%) of a sample of 30 young women with intellectual disability and high support needs. (in Taylor, p. 92).

<sup>127</sup> For a description of the legal situation and practice in relation to sterilization for young men with an intellectual disability in Australia see Taylor, p. 94 and *Forced Sterilization and Women with disabilities*. (Dawn Ontario. Disabled Women’s Network Ontario, 2006). For a description of sterilization laws in the US see Paransky and Zurawin, pp. 228-230; the United States is an interesting case, underlining the necessity of a special Convention on the rights of people with disabilities, and of special policies and disabilities. This is because in *Griswold v. Connecticut*. 381 U.S. 479 (June 7, 1965) (U.S. Supreme Court) , the Supreme Court affirmed that every person has the right to privacy, to certain forms of sexual conduct, and to make reproductive decisions. However, in some states there are laws allowing sterilization, this being very much like a statement that a person with disabilities is not just like “every person.” Moreover, in the United States there were also compulsory sterilizations programs for people with disabilities up until the mid ‘70s (see Paul Lombardo. *Eugenic Sterilization Laws*. (Eugenics Archive, 2012)), which were sustained by the Supreme Court in *Buck v. Bell*. 274 U.S. 200 (May 2, 1927) (U.S., Supreme Court). Eugenics sterilization laws also existed, among others, in Japan (see Takashi Tsuchiya. *Eugenic Sterilizations in Japan and Recent Demands for Apology: A Report*. (Newsletter of the Network on Ethics and Intellectual Disability, 1997)).

Several reasons have been given to justify these practices. They include “the prevention of expressions of sexuality, decreased chances of sexual exploitation, and reduced likelihood of acquiring sexually transmitted diseases.”<sup>128</sup> There has also been reference made to the necessity to eliminate the reproduction of children with disabilities and to protect the wellbeing of the State, community or family, as disabled women and girls and their potentially disabled offspring place a burden on resources and services.<sup>129</sup>

These justifications are discriminatory and none of these objectives is accomplished through sterilization.<sup>130</sup> Moreover, invoking a necessity to prevent sexual expression, while revealing the generality of such lines of thoughts, denies the existence of a human trait in a human being.

The most common justification for sterilization is however the “best interest” of the person, an approach which is, as explained in Chapter I, more and more criticized within the international human rights community.<sup>131</sup>

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<sup>128</sup> di Giulio, p. 59.

<sup>129</sup> *In the European Court of Human Rights. Joelle Gauer and Others against France. Written comments.* (Center for Reproductive Rights, European Disability Forum, International Center for the Legal Protection of Human Rights (Interights), International Disability Alliance and Mental Disability Advocacy Center, 2011), p. 6.

<sup>130</sup> Of course sterilization can have some impact on such matters. For example, in a lecture given by Manisha Gupte in November 2012 at the ILS College in Pune, India, she explained that many times women with psychosocial disabilities are taken as second wives in communities where polygamy is allowed. They are considered to be able to give birth to children without interfering too much in other activities. This, in certain circumstances, can constitute a form of sexual abuse (ie. If the woman does not consent to sexual intercourse etc.) Therefore, if not being able to give birth to children, the person might not find herself in the position of being sexually abused. However, this case remains as all others: the problem is not the ability of the woman to procreate and this should not be the object of a policy. The problem is the stigma and stereotypes attached to disability.

<sup>131</sup> The “best interest” doctrine can have serious downsides when used as a justifications for sterilization. As explained in Brady, p. 435, “the current boundaries for the expression of best interests are broad and most commonly include the use of decision-making principles, such as ‘quality of life’, ‘the least restrictive alternative’, ‘normalization and inclusion in community life’, ‘the expressed wishes of parents’ and ‘burden of care’.”

## II.E.2. Forced sterilization in the European context

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Within the EU forced sterilization has been specifically reported to have happened up to the late '90s.<sup>132</sup> In practice, if the guardian consents to sterilization, the operation is not considered to be forced.

The lack of very recent comprehensive reports is not a sign that such practices are inexistent; researches have just not been made. Cases are difficult to reveal when sterilization is made without the knowledge of the person and when human rights activist do not see sterilization with the consent of another party as a human rights problem. "The UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment has also highlighted the invisibility of abuses occurring in institutional settings as one of the main reasons for the lack of judicial pronouncements on this issue."<sup>133</sup> Zuzana Durajova<sup>134</sup> stated that forced sterilization does happen and explained that in her work field in the Czech Republic she heard about such cases several times. She gave the example of a woman with psychosocial disabilities who found out she had been sterilized when she went to undergo the procedure for contraceptive purposes.

The ECtHR has never substantially dealt with a case of forced sterilization of women with disabilities.<sup>135</sup> It only dealt with the forced sterilization of Roma women, where it underlined that sterilization grossly interferes with physical integrity, depriving women of their reproductive

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<sup>132</sup> See for example the case of France( see Emilie Helmstein. *En France aussi, on stérilise des handicapées* (L'Association Française contre l'Abus Psychiatrique, 2000)), Germany (in Gotz Aly, Peter Chroust, Christian Pross and Belinda Cooper. *Cleansing the Fatherland: Nazi Medicine and Racial Hygiene*. (Johns Hopkins University Press, Baltimore, 1994)), Sweden (in *Sweden admits to racial purification. Forced sterilisation of 'inferior' women unchecked for 40 years*. (The Independent, August, 25, 1997)).

<sup>133</sup> *In the European Court of Human Rights. Joelle Gauer and Others against France. Written comments*. (Center for Reproductive Rights, European Disability Forum, International Center for the Legal Protection of Human Rights (Interights), International Disability Alliance and Mental Disability Advocacy Center, 2011), pp. 8-9.

<sup>134</sup> Zuzana Durajova [Legal Monitor]. Personal Interview. Budapest, November 18, 2012.

<sup>135</sup> The issue only came up before it in *Gauer and Others v. France*. The case concerned the sterilization of five young girls with disabilities who were sterilized without their knowledge or their consent, as none of these was required by law. The case was found inadmissible as the application was made after the 6 months term had elapsed.



capacity.<sup>136</sup> It also stated that “it bears on manifold aspects of the individual’s personal integrity including his or her physical and mental well-being<sup>137</sup> and emotional, spiritual and family life.<sup>138</sup>

Most importantly, it noted that sterilization “may be carried out only with the prior informed consent of the person concerned [with the exception of] emergency situations in which medical treatment cannot be delayed and the appropriate consent cannot be obtained.”<sup>139</sup>

The Court never dealt with the issue of informed and full consent to sterilization by people with disabilities, which remains unclear. It only dealt with what it considered to be a “mentally competent adult,”<sup>140</sup> a specificity which was found to be relevant and with a person underage,<sup>141</sup> where it mentioned that the person had the right to “freely decide, together with her representative.”<sup>142</sup> But it did find that eliminating or restricting legal capacity can be in violation of the Convention in situation including being kept in an institution against one’s will,<sup>143</sup> not being heard in adoption proceedings concerning one’s children,<sup>144</sup> not having an effective remedy,<sup>145</sup> not being able to vote<sup>146</sup> or to administer and defend one’s own property.<sup>147</sup>

The Court therefore found that sterilization and guardianship can be in violation of the Convention. The Council of Europe’s standards explicitly stipulate that “people with disabilities

<sup>136</sup> *N. B. v. Slovakia*. App. No. 29518/10. (ECHR, September 12, 2012), para. 79 and *V. C. v. Slovakia*, App. No. 18968/07. (ECHR, February 8, 2012), para. 116.

<sup>137</sup> The fact that forced sterilization entails mental suffering was also noted in *N. B. v. Slovakia*, para. 80.

<sup>138</sup> *V. C. v. Slovakia*, para. 106.

<sup>139</sup> *Ibid.*, para. 108.

<sup>140</sup> *Ibid.*, para. 105 and 107.

<sup>141</sup> In *N. B. v. Slovakia*.

<sup>142</sup> *Ibid.*, para. 78.

<sup>143</sup> *Stanev v. Bulgaria*. App. No. 36760/06. (ECHR, January 17, 2012).

<sup>144</sup> *X v. Croatia*. App. No. 11223/04. (ECHR, July 17, 2008), para. 53.

<sup>145</sup> *Berkova v. Slovakia*. App. No. 67149/01. (ECHR, June 24, 2009).

<sup>146</sup> *Alajos Kiss v. Hungary*. App. No. 38832/06. (ECHR, May 20, 2010).

<sup>147</sup> *Zehentner v. Austria*. App. No. 20082/02. (ECHR, July 16, 2009), para. 78.

have the right to recognition everywhere as persons before the law.”<sup>148</sup> In its *Shtukaturv*<sup>149</sup> judgment, the ECtHR recognized that the will of a person placed under guardianship had to be taken into consideration when a restriction on a right as fundamental as the right to liberty is concerned. “In so doing, the Court recognized that a person whose legal capacity has been formally restricted may retain capacity to make medical and other decisions rather than having such decisions made by third parties.”<sup>150</sup> Therefore being deprived of the ability to express will in relation to sterilization can be found to be in violation of the Convention. Only this solution would be in line with the standards established by the CRPD.

### II.E.3. Comments under the CRPD

In article 23 1(c), the CRPD states that people with disabilities have the right to retain their fertility on an equal basis with others. The CRPD Committee pointed out that laws and policies which permit sterilization of people with disabilities are not in compliance with article 23 of the Convention.<sup>151</sup> It has expressed concern about the lack of clarity in the scope of legislation “to protect persons with disabilities from being subjected to treatment without their free and informed consent.”<sup>152</sup> It underlined that support had to be provided in order to ensure that the women themselves are the ones who give their informed consent for sterilization.<sup>153</sup> Therefore

<sup>148</sup> *Reccomendation Rec(2006)5 on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015.* (Council of Europe, 2006), para. 3.12.1.

<sup>149</sup> *Shtukaturv v. Russia*. App. No. 44009/05. (ECHR, March 27, 2008).

<sup>150</sup> *In the European Court of Human Rights. Joelle Gauer and Others against France. Written comments.* (Center for Reproductive Rights, European Disability Forum, International Center for the Legal Protection of Human Rights (Interights), International Disability Alliance and Mental Disability Advocacy Center, 2011), p. 7.

<sup>151</sup> Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of China*. U.N. Doc. CRPD/C/CHN/CO/1 (2012), para. 34 and Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of Hungary*. U.N. Doc. CRPD/C/HUN/CO/1 (2012), para. 38.

<sup>152</sup> Committee on the Right of People with Disabilities. *Concluding observations on the initial report of Tunisia*. U.N. Doc. CRPD/C/TUN/CO/1 (2011), para. 28.

<sup>153</sup> Committee on the Right of People with Disabilities. *Concluding observations on the initial report of Argentina*. U.N. Doc. CRPD/C/ARG/CO/1 (2012), para. 32.

sterilization is in violation of the Convention both when it is performed without the knowledge of the person, or with the knowledge of the person but with the consent being given by a third party.

#### II.E.4. Concluding remarks

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Forced sterilization involves both the situations when the person does not know that the operation is being carried out, and when the person knows but it did not personally, and with full and informed consent agreed to it. Forced sterilization is being carried out around the world at the moment, in many places lawfully. Examples of such practices exist within countries which are members of the Council of Europe. The ECtHR case law does suggest that such practices would be in violation of the Convention. However, it did not explicitly address the problem. What remains certain is that such practices are in violation of the CRPD.

## Chapter III. Criminal law

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### III.A. General considerations

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The sexuality of people with disabilities has been distorted and disregarded by members of the community, by legal and medical professionals. One way through which all legislations touch upon sexuality is through criminal laws aimed at protecting people from sexual abuse, which are often the only recognition existent in laws and policies of the fact that people with disabilities are able to be involved, voluntarily or not, in sexual acts.

Criminal laws need to be discussed in this paper firstly because all national criminal laws deal with the sexual abuse of people with disabilities.<sup>154</sup> Secondly because this form of sexual abuse has particularities not encountered in the sexual abuse of the non-disabled. Thirdly because autonomy of sexual expression goes hand in hand with protection from sexual abuse. Sexuality can only be portrayed if both the “‘freedom to’ (engage in desired activities- and [...] the ‘freedom from’ (undesired activities)’”<sup>155</sup> are being considered.

There are several ways in which sexual expression, especially sexual intercourse is, in practice, regulated by the state. The first part of this chapter addresses the criminalization of specific kinds of sexual expression, referring to a problem which can be encountered by all people with disabilities, whose sexual expression may not conform to normalcy as a normative dictated standard.

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<sup>154</sup> For example see relevant provisions from Tunisia in Committee on the Rights of People with Disabilities. *Initial report submitted by State parties: Tunisia*. U.N. Doc. CRPD/C/TUN/1 (2010), para. 110 and 112.

<sup>155</sup> Michelle McCarthy and David Thompson. *People with Learning Disabilities: Sex. The Law and Consent*. in Mark Cowling and Paul Reynolds. *Making Sense of Sexual Consent*. (Ashgate Publishing Company, Burlington, 2004), p. 227.

The second part scrutinizes laws prohibiting sexual intercourse with people with disabilities, dealing significantly with the issue of consent. The ability to consent is being denied through different types of guardianship, which are generally established for people with intellectual or psycho-social disabilities, but not only. This section addresses the problems encountered by those who have been stripped of their ability to consent.

### III.B. Criminalizing a specific kind of sexual expression

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#### III.B.1. General considerations

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Criminalizing a specific kind of sexual expression is done, for example, through anti-sodomy laws.<sup>156</sup> While usually it is not directly described how should sexual intercourse look like in order to be lawful, this is dictated, indirectly, by prohibiting certain kinds of sexual expression. While at first glance it seems this does not have so much to do with consent, this laws are, in effect, stripping members of certain groups of their ability to consent to a sexual expression of their own choice.

The group in relation to which the inadequacy of such provisions has been many times underlined is the LGTBQ community.<sup>157</sup> Although not as obvious, similar provisions can touch upon sexual expressions of people with disabilities.

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<sup>156</sup> This can be done by describing the prohibited act or as explained in Aaron Xavier Fellmeth. *State Regulation of Sexuality in International Human Rights Law and Theory*. (William and Mary Law Review, 2008), p. 6, by prosecuting individuals “under nebulous prohibitions on ‘immorality’, ‘debauchery’, ‘obscenity’ or ‘hooliganism’.” The article also mentions that same-sex intercourse remains subject to criminal penalties in 41 of the 192 United Nations member states for women and in 81 states and 3 sub-state provinces for men, including almost all of Africa and the Middle East, and much of Asia. On August 1, 2003, Europe became totally free of laws criminalizing same-sex, adult, consensual intercourse.

<sup>157</sup> Look at the foot note above related to anti-sodomy laws and same sex relations

### III.B.2. The Romanian Criminal Code: the crime of sexual perversion

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I will explain how this is possible by taking the example of a Romanian legal provision which criminalizes so-called acts of sexual perversion.<sup>158</sup> The Romanian High Court of Cassation and Justice explained what an act of sexual perversion means:<sup>159</sup>

“ All ways in which sexual relations occur between people of same or different sex constitute a sexual act [as a constitutive element of the crime of rape]. But unlike the act of sexual perversion, a sexual act means primarily sexual penetration, whether it is done by conjunction between aggressor and victim body or using an object [...].

All other sexual practices which, physiologically, are not able to produce orgasm can not be considered sexual acts under the law and constitute acts of sexual perversion. Examples of such acts are obscene caressing, fetishism, voyeurism, exhibitionism and bestiality. [...].

By its nature, sexual perversion consists in practicing unnatural acts of sex, other than those with homosexual character, resulting in aberrant manifestations of the sexual instinct, which are not aimed at realizing sexual intercourse, but just at obtaining incomplete sexual excitement. [...].

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<sup>158</sup> Art. 201 from the Romanian Criminal Code, which states:

“Acts of sexual perversion committed in public or if producing public scandal be punished with imprisonment of one to five years.

Acts of sexual perversion with a person who has not attained the age of 15 years shall be punished with imprisonment from 3 to 10 years and interdiction of certain rights.

The same punishment applies in cases where acts of sexual perversion are committed with a person between 15-18 years, if the offense is committed by a guardian or trustee or the supervisor, caregiver, physician, teacher or educator, using its quality, or if the perpetrator abused the trust of the victim or its authority or influence over it.

If acts of sexual perversion with a person who has not attained the age of 18 years were determined by offering or giving money or other benefits from the offender, directly or indirectly, the punishment is imprisonment from 3 to 12 years and the prohibition of rights.

If the deeds stipulated in para. 2, 3 and 3<sup>1</sup> were committed for the purpose of producing pornography, the punishment is imprisonment from 5 to 15 years and interdiction of certain rights, and if coercion was used, the punishment is imprisonment from 5 to 18 years and the prohibition rights.

Acts of sexual perversion with persons unable to defend themselves or to express their will are punishable by imprisonment from 3 to 10 years and interdiction of certain rights.

If the deed stipulated in para. 1-4 results in serious bodily injury or health, the punishment is imprisonment from 5 to 18 years and interdiction of certain rights, and if they result in the death or suicide of the victim, the punishment is imprisonment from 15 to 25 years and the prohibition rights.

<sup>159</sup> Within the Romanian jurisprudence an explanation was necessary as courts started finding it difficult to distinguish between the acts which constitute sexual perversion and the sexual acts which can be taken into consideration as a constitutive element of the crime of rape.

Sexual perversion, as an abnormal manifestation related to sexual psychopathology may lead to committing especially dangerous offences against others, which calls for a differentiated and effective penal treatment, which also serve to prevent such event. [...]

Such events, with obvious pathological nature, requires not only choosing the appropriate criminal coercive measures, but put, often, the problem of capacity of the persons concerned and, of course, to establish the safety measures required to be taken.”<sup>160</sup>

This explanation is in many ways problematic.<sup>161</sup> Acts of sexual perversion are deemed to be “all sexual practices which, physiologically, are not able to produce orgasm”, all “unnatural acts of sex”, all “aberrant manifestations of the sexual instinct, which are not aimed at realizing sexual intercourse, but just at obtaining incomplete sexual excitement.”

Terms such as “unnatural” and “aberrant manifestations” make this definition potentially over-inclusive. The assessment remains to be made by individual judges in individual cases. It is only underlined that all “unnatural acts” constitute acts of sexual perversion with the exception of those of “homosexual character.”<sup>162</sup>

<sup>160</sup> *Referral in the interest of law*. 3/2005. (May 23, 2005) (Romania, High Court of Cassation and Justice).

<sup>161</sup> One problematic aspect which I will not specifically address in this paper is related to the definition of rape. Defining the constitutive element of the crime of rape as “primarily [meaning] sexual penetration, whether it is done by conjunction between aggressor and victim body or using an object.” In *Prosecutor v. Kunarac*. IT-96-23-T&IT-96-23/1-T. (ICTY, February 21, 2001), the Court addressed the issue of defining rape as it follows: “While rape has been defined in certain national jurisdictions as non-consensual intercourse, variations on the act of rape may include acts which involve the insertion of objects and/or the use of bodily orifices not considered to be intrinsically sexual. The Chamber considers that rape is a form of aggression and that the central elements of the crime of rape cannot be captured in a mechanical description of objects and body parts. . . . The Chamber defines rape as a physical invasion of a sexual nature, committed on a person under circumstances, which are coercive. Sexual violence which includes rape, is considered to be any act of a sexual nature which is committed on a person under circumstances which are coercive.” As explained in Sanja Kutnjak Ivkovic. *Justice by the International Criminal Tribunal for the Former Yugoslavia*. (Stanford Journal of International Law, 2001), p. 287 this statement permits the “reformation of the standards of rape prosecution [which] may also assist in the creation of generally accepted international standards on the adjudication of sexual offenses.” It applies not only in relation to war crimes, but also in relation to ordinary crimes. And it applies to all women, including therefore women with disabilities. People with disabilities are not discriminated against only because of their disability. Discrimination on multiple grounds is as common, here a second identified ground being gender.

<sup>162</sup> The Court probably finds it necessary to explicitly exclude homosexual acts because at the level of the Council of Europe laws criminalizing homosexual relations have not been accepted ever since ECHR’s *Dudgeon (Dudgeon*

A given example of “unnatural” sexual practices is “obscene caressing.” In sex and disability related literature it is underlined that “[t]hose with nerve injuries can have sensations, including orgasm, in other areas of the body [sometimes not around the genitals]. Women with spinal cord injury have reported orgasm from stimulation of their breasts, nipples, neck, mouth/lips, and ears.”<sup>163</sup> Can such acts ever be found by any judge in the country to be obscene caressing?

The Court also states sexual practices which “are not able to produce orgasm” or which are aimed at “obtaining incomplete sexual excitement” are acts of sexual perversion. Sieber however explains that:

“A crucial consideration for people with disabilities is not to judge their sexuality by comparison to normative sexuality but to think expansively and experimentally about what defines sexual experience for them. Sex may have no noticeable physical signs of arousal or may not conclude with an orgasm. When touching is involved, the places being touched may not be recognizable to other people as erogenous zones [...]. Sex may extend beyond the limits of endurance for penetrative sex, resembling slow dancing instead of the twist. It may seem kinky by comparison to what other people are doing.”<sup>164</sup>

The act of sexual perversion remains therefore a crime which has the potential to infringe upon the rights of people with disabilities firstly because it attributes to sometimes the only possible sexual expressions of people with some kind of disabilities the derogatory connotation of the term sexual perversion. Secondly because it opens the possibility of their prosecution and sanction if judges consider their sexual expressions to constitute an “unnatural” or “abnormal” behavior.

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*v. The United Kingdom*. App. No. 7525/76. (ECHR, October 22, 1981)) and *Norris ( Norris v. Ireland*. App. No. 10581/83. (ECHR, October 26, 1988)) cases.

<sup>163</sup> Yvonne K. Fullbright. *Disability and orgasm: your orgasmic potential*. (Disabom, 2012).

<sup>164</sup> Tobin Siebers. *Sexual Culture for Disabled people* in Robert McRuer and Anna Mollow. *Sex and Disability*. (Duke University Press, Durham, 2012), p 49.



The acts are indeed criminalized only if underwent in public or if they produce public scandal. This does not however delete the derogatory connotation of the term sexual perversion. Moreover, sexual expression of people with disabilities is highly likely to produce public scandal because of all the myths and stereotypes related to their sexuality, because of their less “natural” ways of manifesting their sexuality and because of the patriarchal need of society to protect them.

The existence of such legal provisions denotes on one hand the lack of understanding of the complexity of this issue by legal professionals. On the other hand, it reveals the lack of involvement of policy makers in such issues.

### III.C. Laws prohibiting sexual intercourse with people with disabilities

#### III.C.1. General considerations

State can regulate sexual expression also by criminalizing the act of engaging into sexual intercourse with certain groups of people which are generally those who did not reach the age of consent and, in certain conditions, people with disabilities. Historically, these provisions were elaborated for a protective purpose. Technically they do not specifically state certain people do not have the ability to consent to sexual intercourse. However, the effect is making such ability vanish.

There are variations of laws with such effect.

#### A.I. General criminal laws

General criminal laws protect against abuse, along with everybody else, also people with disabilities. I will take the example of Romania and Italy to explain in what way.

The Romanian Penal Code states that rape is a sexual act in which, among others, an individual took advantage of the impossibility of the victim to express will.<sup>165</sup> Similarly, the Italian Penal Code defines sexual violence as engaging in sexual acts by taking advantage of the “mental inferiority” of the victim.<sup>166</sup>

The positive aspect of such provisions is that in both countries the ability of expressing will and the mental inferiority are assessed on a case by case basis. Therefore, at least technically, there is no assumption made by the law in relation to the ability of people with disabilities to consent to sexual intercourse.

To understand how this works in practice I firstly went through different Italian newspapers. I found 13 articles<sup>167</sup> related to sexual abuse of people with psychosocial disabilities, dating from March 2012 to November 2012. 9 of the reported investigations had been initiated by family members, friends or the police, while 4 were initiated by the alleged victims themselves. In 3 of the 13 cases it wasn't clear what the opinion of the person with psychosocial disabilities was about the sexual act. In one of the cases, which had been initiated by the parents of a girl, the alleged victim insisted that she had consented to the sexual acts and the Court ruled in favor of the accused. This reveals possible problems: the alleged victim might not always be given the

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<sup>165</sup> Romanian Penal Code, article 197.

<sup>166</sup> Italian Penal Code, article 609 bis.

<sup>167</sup> *Violenza sessuale e maltrattamenti su una disabile da parte di una socio assistente*. (Corriere Salentino.it, November 17, 2012); *Madre porta la figlia disabile a far sesso con un 74enne*. (Today.it, October 27, 2012); *Violenza sessuale su una disabile: condannato a quattro anni*. (Il Reporter.it, November 8, 2012); *Violenza sessuale su ragazza disabile. Arrestato 90enne, riconosciuto al parco*. (Il Messaggero.it, September 25, 2012); *Irsina: violenza sessuale nei confronti di un disabile*. (Sassiland, September 12, 2012); *Canicattì, violenza sessuale nei confronti di minorenne disabile: iniziato il processo a carico di 4 giovani*. (CanicattiiWeb.com, October 31, 2012); *Violenza sessuale: abuso di ragazza disabile*. (Ansa.it, February 18, 2012); *Violenze sessuali, botte e insulti alla figliastra disabile per ben 14 anni: arrestato 48enne*. (DirettaNews.it, September 10, 2012); *Operaio abusa di disabile, arrestato*. (Il Secolo XIX, August 9, 2012); *Violenza sessuale, abuso di un disabile e un bimbo: condannato 5 anni*. (Bologna Today, July 12, 2012); *Violenza sessuale sulla nipote minorenne e disabile, denunciato 50enne*. (Il punto a Mezzogiorno, March 11, 2012); *Nessuna violenza sessuale ai danni di una giovane disabile, ma una storia d'amore tra un 63enne ed una 24enne*. (Corriere Salentino.it, October 26, 2012).

opportunity to express opinion and investigations can be carried out against the will of the alleged victim.

These same issues have been identified while looking at Romanian case law, more specifically at 8 random cases,<sup>168</sup> in 7 of which the accused was found to be guilty.

Keeping in mind that such laws offer protection against sexual violence to people with disabilities, I argue that while the law opens the possibility of prosecutions, it does not take safeguards to ensure that all aspects of this sensitive issue are given due consideration.

One relevant aspect is the person who initiates the trial. In 7 of the cases I looked at the investigation was initiated by members of the family of the alleged victim, and in only one case the initiator was the alleged victim. In 4 of the 8 cases the family members had heard about the alleged sexual abuse from the victims themselves which, however, were not the ones to initiate the investigations.

This is relevant in the light of *B. v. Romania*,<sup>169</sup> a case which dealt with the obligation of judicial organs to investigate allegations of rape coming directly from people with psychosocial disabilities. The complainant had alleged that the police ignored on several occasions her allegations of rape or attempted rape and sent her to psychiatric institutions. The ECtHR found a violation of art. 3 considering that, in one particular case, the investigation of an alleged rape was inappropriate. The Court took into consideration that there was no further interrogation of the complainant, that she was not subjected to any examination except a gynecological one that

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<sup>168</sup> *Penal Decision*. No. 141/R. (February 25, 2009) (Romania, Galati's Appeal Court); *Penal Decision*. No. 40/A. (December 2, 2009) (Romania, Galati's Appeal Court); *Penal Sentence*. No. 14. (January 21, 2010) (Romania, Tirgu Neamt's General First Instance Court); *Penal Sentence*. No. 58. (April 7, 2010) (Romania, Hirlau's General First Instance Court); *Penal Decision*. No. 484. (October 27, 1997) (Romania, Suceava's Appeals Court); *Penal Decision*. No. 9. (January 9, 2010) (Bacau's Appeals Court); *Penal Sentence*. No. 94. (Unknown, 2011) (Romania, Unknown, General First Instance Court); *Penal Decision*. No. 228/R. (May 14, 2009) (Romania, Oradea's Appeals Court).

<sup>169</sup> *B. v. Romania*. App. No. 42390/07. (ECHR, April 10, 2012).

she refused and that in their report about the complaint the police did not mention anything about the alleged facts but focused on describing the mental health state of the complainant.

This reveals potential problems of criminal investigations of sexual abuse of people with disabilities. In the analyzed Romanian case law almost all of those who reached the courts had been initially supported by other members of the community. There is no disaggregated data available showing how many sexual abuse related complaints are made in Romania by people with disabilities and how many reach the courts. Cases such as *B. v. Romania*<sup>170</sup> suggests there are problems with the credibility people with disabilities have in front of judicial organs when alleging sexual abuse. This is not a country specific problem. Reports of sexual abuse of people with disabilities are widespread,<sup>171</sup> and in many cases poor records of punishing perpetrators of sexual crimes of people with disabilities are also revealed.<sup>172</sup>

Coming back to the 8 Romanian judgements, it was observed that the victims were heard in only half of the cases. In these criminal trials very sensitive issues appear. Families are known to be overprotective to people with disabilities.<sup>173</sup> In relation to sexuality they are particularly known

<sup>170</sup> The problem is not country specific. The ECHR dealt with the prosecution of sexual crimes against people with disabilities also in *X. and Y. v. Netherlands*. App. No. 8978/80. (ECHR, March 26, 1985).

<sup>171</sup> See for example *Better health, better lives: children and young people with intellectual disabilities and their families*. (World Health Organization, 2010); Leigh Ann Davis. *People with Mental Retardation and Sexual Abuse*. (The Arc, 2009); *Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities*. (Mental Disability Rights International, 2006); *Behind Closed Doors: Human Rights Abuses in the Psychiatric Facilities, Orphanages and Rehabilitation Centers of Turkey*. (Mental Disability Rights International, 2005); *People with disabilities and Sexual Assault*. (Wisconsin Coalition against Sexual Assault, 2000).

<sup>172</sup> See for example Davis; McCarthy and Thompson; *Behind Closed Doors: Preventing Sexual Abuse against Adults with a Learning Disability*. (Voice UK, 2001); Lillian Burke, Cheryl Bedard and Susan Ludwig. *Dealing with sexual abuse of adults with a developmental disability who also have impaired communication: supportive procedures for detection, disclosure and follow-up*. (The Canadian Journal of Human Sexuality, 1998).

<sup>173</sup> A study conducted in Ireland showed that "staff careers were more inclined than family careers to openly discuss issues of sexuality with service users, and to suggest environmental, rather than service-user characteristics, as impediments to such discussions. [...] [Also,] the majority of family carers (80%) showed a preference for low levels of intimacy in service-user relationships" (in D. S. Evans, B. E. McGuire, E. Healy and S. N. Carley. *Sexuality and personal relationships for people with an intellectual disability. Part II: staff and family career perspectives*. (Journal of Intellectual Disability Research, 2009), p. 913).

to be repressive, especially in more conservative environments. They cannot be the only ones initiating investigations and giving testimonies.

The testimony of the alleged victim can be of particular relevance both for its own interest and for not infringing upon the fair trial rights of the accused. Courts have to make sure that they testimonies are not over influenced by fear of reactions of other members of the community. This is especially because family members can be very influential in the views and decisions of all people, including people with disabilities.<sup>174</sup>

Another aspect analyzed while reading the judgments was the vocabulary used to refer to people with disabilities, and also the extent to which the court considered the fact that the person was known to have a psychosocial disability. In two cases the judges found that the accused had taken advantage of the mental health state of the victims, who were considered to be “practically not able to defend themselves or express will.”<sup>175</sup> In other cases the psychosocial disability was considered, but corroborated with other factors such as age and the number of people committing the abuse.<sup>176</sup> The non-unitary practice is mainly due to the fact that judges are given the liberty to choose the factors and circumstances they consider most relevant.

In all the analyzed case law judges considered the medical diagnosis of the victim. However, all decisions were taken without any medical expert being called to testify. If undue consideration is given to medical reports and alleged victims are not given the possibility to explain their views and explore their feelings the whole purpose of the criminal trial might be endangered. It can be diminished to having a retributive purpose for the victim, or for its family. Because of all the

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<sup>174</sup> For a study underlining this see D. S. Evans, B. E. McGuire, E. Healy and S. N. Carley. *Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives*. (Journal of Intellectual Disability Research, 2009), p. 905.

<sup>175</sup> For example in *Penal Decision*. No. 141/R. (February 25, 2009) (Romania, Galati's Appeal Court).

<sup>176</sup> For example in *Penal Decision*. No. 40/A. (December 2, 2009) (Romania, Galati's Appeal Court).

history of the disability movement and all the obscurity created around their sexuality, judges cannot be left to decide and behave according to their understanding of psychosocial disabilities. Comprehensive guidelines need to be established by policy makers and legislators. Special tribunals<sup>177</sup> can be established where legal professionals are familiar to relevant issues. Alleged victims need to be given the opportunity to express their will and preferences and for this expression reasonable accommodation has to be provided. This will influence both the response of the individual with disabilities and of the public opinion to sexual encounters of people with disabilities.

The analyzed case law reveals specific problems existing in relation to trials involving people with disabilities. People with disabilities must be able, both legally and practically to complain about sexual violence, but also to oppose such complaints when it regards their own bodies. They must be heard and treated with respect in court. While making the balance between a right to sexual relationship and protection is a difficult issue, the ability of giving consent cannot be disregarded. As pointed out in a study about sexual abuse of people with intellectual disabilities in the UK, “[c]lear agreed protocols for establishing consent would be useful.”<sup>178</sup> Awareness about the particularities of sexual abuse on people with disabilities, of sexual expression of people with disabilities and of disabilities related issues must be widespread among legal

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<sup>177</sup> When establishing such special tribunals or special units one important thing to keep in mind is not to associate people with disabilities with children and consider expertise in child witness would be appropriate. Such confusion has been identified, for example, in the United Kingdom. A recent study on that practice underlines: “the assumption that the training and experience appropriate to the interviewing of children will serve for this ‘very different group’ is misplaced. Also, training which relates in particular to sexual offences may not help with a variety of different offences. Those who suffer from learning disability may present an entirely different set of problems in communication, comprehension and anxiety. This group are also, typically, victims of a wide variety of crimes. Mencap research indicates that people with learning disabilities are twice as likely as other adults to be the subjects of assault, robbery or personal theft, as well as of sexual offences” (in Sami Hamdan AL- Rawashdeh, Hasan Awad Tarawneh, and Ahmad Mousa Hayajneh. *The Treatment of Vulnerable and Intimidated Witnesses in the English Criminal Justice System*. (European Journal of Social Sciences, 2012), pp. 65-66).

<sup>178</sup> Thomas Athol Joyce. *An audit of investigations into allegations of abuse involving adults with intellectual disability*. (Journal of Intellectual Disability Research, 2003), p. 613.

professionals. These are all issues which have to be taken into consideration by policy and decision makers.

### III.C.2. Criminal laws aimed at protecting specifically people with disabilities against sexual violence

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Besides general criminal law provisions, there is legislation which addresses the issue of sexual acts specifically with people with disabilities. One example of such legislation is the Irish Criminal Law (Sexual Offences) Act 1993 on the Protection of Mentally Impaired Persons. Its Section 5 criminalizes the act through which a person “has or attempts to have sexual intercourse [...] with a person who is mentally impaired (other than a person to whom he is married or to whom he believes with reasonable cause he is married).” “Mentally impaired” is defined as “suffering from a disorder of the mind, whether through mental handicap or mental illness, which is of such a nature or degree as to render a person incapable of living an independent life or of guarding against serious exploitation.”

One other example was Section 7 of the 1956 Sexual Offences Act which criminalized sexual intercourse with “defective” people. “There has been little clarity as to who may or may not be equated to being a ‘defective’. The legal definition has been understood to be a person suffering from a state of arrested or incomplete development of mind which includes severe impairments of intelligence and social functioning within the meaning of the Mental Health Act 1959.”<sup>179</sup>

There are multiple problems with such legislations. Firstly, both of these two examples are built upon a so called diagnostic approach, which means that “a person’s capacity to make a specific decision is deemed inadequate because they have a certain level of disability.” The focus therefore is on the diagnosed disease, which is the cause of the problem. The UK Sexual

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<sup>179</sup> McCarthy and Thompson, p. 229.

Offences at 1956 has been replaced by the Sexual Offences Act 2003, the notion of “defective” being replaced by person having a “mental disorder impeding choice.” The focus on diagnosis therefore still remains.

An example of a special law which keeping the diagnosis approach, can be seen as a better practice in addressing the problem is the South African Mental Health Care Act. Its article 14 addresses limitation on intimate adult relationships by stating: “subject to conditions applicable to providing care, treatment and rehabilitation services in health establishments, the head of a health establishment may limit intimate relationships of adult mental health care users only if due to mental illness, the ability of the user to consent is diminished.” This is a good example because by providing for limitations to intimate adult relationships it implies that there is a right to such relationships for people with disabilities. It actually implies that adults are engaging in relationships. In order for them to be stopped certain conditions have to be met. Such provision could be used to, for example, ask for funds to make sure that adults have the possibility to exercise such right.

The downside of the provision remains that limitations can be imposed on a diagnosis basis.

When one focuses on the diagnosis, it is difficult to eliminate misconceptions about sexuality and disability and to respect the humanity of the person. These observations are entrenched in the now promoted social model of disability which is supposed to replace the medical model.

“IQ test and other assessments of general ability have been used [...] to determine whether an individual is covered by such legislation.”<sup>180</sup> Therefore general abilities are measured without taking into consideration the specific needs and competences a person might have in a specific area of life, such as that connected to sexuality.

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<sup>180</sup> Ibid., p. 229.



The Irish Act mentioned above is a classic example of imposing this kind of general assessment of disability. Its definition of mentally impaired includes the inability “of living an independent life or of guarding against serious exploitation”, which is difficult to assess. If one lives with the family or in a group home does this mean the person is not capable of living independently? Why does this have to mean the person cannot engage in intimate relations?

The difficulties of interpreting such provisions take us to their second problem: insecurity, danger of over-inclusiveness. It has been reported that in Ireland “many service provider organizations have received legal advice that they would be in breach of their duty of care if they permitted persons whom they support to engage in sexual activity or have an intimate relationship. There is a fear about criminal liability under the 1993 Act as persons receiving services or supports could be deemed ‘incapable of living an independent life.’”<sup>181</sup>

The Irish provision “operates on the out-dated status approach by assessing capacity on the basis of where a person lives and does not respect the person’s ‘will and preferences’. People with intellectual disability are subjected to a higher test of capacity to consent to sexual relations than their ‘non-disabled’ counterparts.”<sup>182</sup> Not only that policy makers and legislators do not assume their obligation to fulfill rights by, for example, providing relevant sexual education to people with disabilities, to families and to medical professionals. Instead, by legislation with this effect they are not restraining from interfering with the exercise of rights through criminal law, which is one of states’ most repressive tools available to the state.

A third identified problem is related to the final decision-maker in individual cases. For England and Wales the jury decides. It “may take advice from expert witnesses. This is problematic

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<sup>181</sup> *Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence & Equality*. (Center for Disability Law and Policy, NUI Galway, 2011), p. 31.

<sup>182</sup> *Ibid.*, p. 31.

because most people sitting on juries will not have much, if any, personal or professional knowledge of people with learning disabilities.”<sup>183</sup>

An alternative to the diagnosis approach, which tries to resolve some of the issues identified here, is the outcome approach. This approach can be found, for example, in New York’s sexual consent capacity standard, also known as the morality standard. According to this standard, “a person must be mentally capable of understanding the social mores of sexual behavior.”<sup>184</sup> The New York Court of Appeals explained that in order to be considered able to give sexual consent a person with disabilities must have “an understanding of coitus [which] encompasses more than a knowledge of its physiological nature. An appreciation of how it will be regarded in the framework of the societal environment and taboos to which a person will be exposed may be far more important. In that sense, the moral quality of the act is not to be ignored.”<sup>185</sup> Such approach moves away from taking into consideration only the diagnosis of the person. It also basis its decision not only on the general abilities of the person, but on the specific knowledge related to sexuality. However, such approach is obviously extremely restrictive and conservative. It also remains vague. Establishing “societal environment and taboos” in order to asses what exactly should a person be aware of is a subjective matter. Moreover, the role given to final decision-makers, which might and probably won’t have appropriate knowledge is enhanced. Their liberty of movement is also enhanced by being connected to something so difficult to define as morality. The will and preferences of the person remain not to be listened to, but to be assessed in their compatibility with society’s norms.

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<sup>183</sup> McCarthy and Thompson, p. 229.

<sup>184</sup> Martin Lyden. *Assessment of Sexual Consent Capacity*. (Sexuality and Disability, 2007), p. 5.

<sup>185</sup> *People v. Easley*. 42 N.Y.2d 50. (June 16, 1977) (U.S., New York Court of Appeals).

Between the diagnosis approach and the outcome approach there is the functionalist approach. This one is best reflected by the practice from New Jersey where “an understanding of the risks and consequences of the sexual conduct is not required.”<sup>186</sup> In order to be found able to consent to sexual activity a person must “understand the sexual nature of an act and that the person’s decision to engage in the sexual behavior [must be] voluntary.”<sup>187</sup> It is obviously a less restrictive approach. It is the approach to which general criminal laws are most similar to. They move away from an emphasis on the diagnosis. However, the medically determined condition of the person can still constitute an important element for those entitled to take the decision. The vagueness remains; the will and preferences of the person might not be considered but it is not clear to what extent.

One last aspect of laws specially addressing people with disabilities I will touch upon is the fact that they many times include prohibitions of sexual relations between patients/clients and staff members. This is the case in England and Wales,<sup>188</sup> in Germany, Netherlands and some American States.<sup>189</sup> They are meant of protecting both inpatients and outpatients. It has been underlined that sexual abuse by members of staff is “one of the most difficult forms of sexual abuse for people with learning disabilities to disclose”<sup>190</sup> and that “staff rarely need to employ force , [...] [as] [a]bsence of force is more a reflection of the power staff hold over people with learning disabilities and therefore should not be interpreted as evidence of their good character nor of the willing participation of the person.”<sup>191</sup>

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<sup>186</sup> Lyden, p. 6.

<sup>187</sup> Ibid., p. 6.

<sup>188</sup> Sexual Offence Act 2003, Sections 38-44.

<sup>189</sup> For more details see McCarthy and Thompson, p. 231.

<sup>190</sup> Ibid., p. 231.

<sup>191</sup> Ibid., p. 231.

The argumentation used to sustain these laws is obviously well-intentioned. We can see here consequences of the “best-interest” doctrine. I believe however that such legislation can induce some theoretical and practical problems. Firstly, such legislation is a part of policies to protect against sexual abuse. However, they tend to be used as a scapegoat to prove that a policy exists. However, they are not a sufficient answer. Policies need to extend more extensively. There is a lack of comprehensive studies in relation to sexual abuse in many European countries. There is also a lack of proper complaint mechanisms put at the disposal of people with disabilities. Secondly, they many times eliminate the issue of determining if the person consented or not, somehow assuming that people with disabilities cannot consent. Laws which protect people against those which have authority and might try to make use of it in order to engage in sexual relationships do exist. But if in those cases consent is being determined, such issue should be raised in relation to people with disabilities also; otherwise discrimination issues are raised.

### III.D. Comments under CRPD

In list of issues to which governments are required to ensure the CRPD Committee underlined the necessity of being provided with relevant information. For example, in relation to violence against, and exploitation or abuse of, persons with disabilities it required indications on the number of complaints that have been received and relevant decisions adopted by the Ombudsman’s Office and other authorities, which have to be disaggregated by age and gender.<sup>192</sup> It also required indications on whether there are any programmes or policies that ensure the protection of persons with disabilities against sexual violence, trafficking and sexual

<sup>192</sup> Committee on the Right of People with Disabilities.. *List of issues to be taken up in connection with the consideration of the initial report of Paraguay*. U.N. Doc. CRPD/C/PRY/Q/1 (2012), para. 16.

exploitation.<sup>193</sup> The Committee underlined that “protection services [should be] age-, gender- and disability-sensitive and accessible.”<sup>194</sup>

The CRPD Committee pointed out that “the law enforcement personnel be trained on handling violence against women and girls with disabilities.”<sup>195</sup> It also pointed out “that services and information [need to be] made accessible to victims [of exploitation, violence and abuse. [And] [i]t specifically encourages[...] to set up a complaint mechanism and conduct mandatory training for the police force on this issue.”<sup>196</sup>

### III.E. Concluding remarks

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Criminal law addresses the issue of sexuality of people with disabilities. While being aimed at offering protection, it does ignore certain specificities of sexual abuse of people with disabilities. Such ignorance has been identified in both laws which address specifically the sexual abuse of people with disabilities and in general laws which address sexuality and sexual abuse. People with disabilities are not always assumed to have the ability to give sexual consent, therefore to have sexual needs and desires; they are not always allowed or given the opportunity to express their opinion; investigations are being carried out against their will; and it does happen that they are not given enough credibility to be able to initiate an investigation. Their opinions, wills and preferences are being given less consideration than their medical diagnosis. Their diagnosis is being used to create laws, to assume abilities and to take decisions. Many laws reflect the insecurities and lack of understanding of involved professionals, being vague and giving the

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<sup>193</sup> Ibid., para. 17.

<sup>194</sup> Committee on the Rights of People with Disabilities. *Concluding observations on the initial report of Hungary*. U.N. Doc. CRPD/C/HUN/CO/1 (2012), para.32.

<sup>195</sup> Committee on the Rights of People with Disabilities.. *Concluding observations on the initial report of China*. U.N. Doc. CRPD/C/CHN/CO/1 (2012), para. 66.

<sup>196</sup> Ibid., para. 91.

opportunity to being interpreted as over- inclusive by external actors. Final decisions are being taken by people who lack comprehensive training and appropriate knowledge; their practice is non unitary. People with disabilities remain at the hand of a system which is meant to protect something it does not fully understand, being therefore itself many times abusive and inconsiderate.

## Recommendations

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### 1) *Need assessment*

- As there is a history of ignoring, denying or repressing sexuality a needs assessment is absolutely necessary. This should include:
  - ◊ Gathering disaggregated data
  - ◊ Assemble specialized committees to analyze the data and make recommendations

### 2) *Disaggregated data*

- The data has to be disaggregated taking into consideration a whole range of issues.
  - ◊ It is absolutely necessary to have disaggregated data relating to the realization of each relevant right provided by the CRPD;
  - ◊ such data has to be disaggregated by sex, age, type of disability (physical, sensory, intellectual and mental), ethnic origin, urban/rural population and other relevant categories, on an annual comparative basis.
  - ◊ To understand what other relevant categories can be let's take the example of situations of sexual abuse. The necessary data to be obtained include:
    - How many cases of sexual abuses are being reported in relation to people with disabilities; how many are for inpatients and how many are for outpatients; who are usually the perpetrators.
    - How many complaints of sexual crime against people with disabilities are made; how many of them are made by people with disabilities themselves; how many of them reach the courts

### 3) *Distribute sexuality and disability related information*

- Offer education, through adapted and accessible means, about relationships, sexuality, personal boundaries and personal safety; such education should always take into consideration factors such as age, gender and disability related characteristics
- information has to be distributed among all people with disabilities but also among other relevant actors such as medical and legal professionals, social workers, caregivers and family members

- such information has to be provided in schools and other establishment where people with disabilities can refer to
  - ◊ for example, hospitals many times deal with different ranges of disability; it has to be assured that:
    - such information is accessible to people with disabilities
    - the medical personnel has relevant training
    - Special sexual and reproductive health services exist and are available to people with disabilities

#### 4) *Offer platforms for discussions*

- Dialogue is extremely important. A place for dialogue should be offered:
  - ◊ for people with disabilities only
  - ◊ for staff, family and carers
  - ◊ For mixed groups

#### 5) *Mainstreaming sexuality and disability in disability specific strategies and also in general laws and practices*

- When doing so it is very important to:
  - ◊ take into consideration intersectional discrimination
  - ◊ be careful that stereotypes are not being reinforced. The discourse has to be carefully constructed. For example, policies cannot reinforce norms of women being sexually passive or asexual, or dependant. Also it has to be established and considered the fact that men also have sexual needs and sexual desires, that they don't need to conform to male established roles, and that they can also be subjected to sexual abuse.
  - ◊ Practices based on the best interest doctrine need to start being eliminated and consideration the will and preferences of people with disabilities need to be taken into consideration
- Special fields to be addressed:
  - ◊ Sexuality needs to be included within the deinstitutionalization process;
    - while implementing such policies it has to be acknowledged that institutions will exist for a period of time; therefore services addressing sexuality need to be introduced



- services addressing sexuality need to be developed for community living centres, for day care centres and for those living independently.
- Examples of what could be done:
  - ✓ In psychiatric facilities:
    - (i) Offer special training to medical professionals
    - (ii) Medical professionals<sup>197</sup> can make proposals to have patients of different gender sharing words; to have sexual education provided; to ensure access to contraceptive means such as pills and condoms; to allow access to sex workers
  - ✓ In community living centres:<sup>198</sup>
    - (i) Offer sexual education
    - (ii) Organize social events aimed at educating clients on how to behave when they want to approach a potential partner; for example, organize dance evenings where people who live in the community and medical professionals invite each other to dance; then they offer the clients the opportunity to do the same
    - (iii) When sexual behaviour such as masturbation is done in non-conformist ways, such as in public, do not react in a repressive way. Discussions with the clients are necessary. Also, explaining that this should be done in private and offering the opportunity to have such privacy is absolutely necessary
- ◇ In relation to guardianship laws
  - Reviewing laws addressing legal consent and guardianship.
  - Developing comprehensive models for determining sexual consent capacity. There are several examples in the literature.<sup>199</sup>
  - developing decision-making skills among people with disabilities, allowing them opportunities for decision-making, training professionals in supported decision-making, and fostering the philosophy of person-centred planning.

<sup>197</sup> Source of example : Prerna Kukreti [Psychiatrist]. Personal Interview. Pune, November 1, 2012; her proposals were denied as they were considered to be against traditional societal values.

<sup>198</sup> Source of example: Christine Erasito [Medical Professional]. Personal Interview. Pune . November 6, 2012.

<sup>199</sup> See for example Lyden, pp. 8-16.

## Conclusion

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This paper is arguing that the sexuality of people with disabilities is being highly disregarded in laws, policies and practices at national and international levels.

In its first chapter it introduces the reader to the topic. It highlights how sexuality is considered to be a legitimate component of people's life generally. But that this is true to a much less extent for people with disabilities. It describes the possible causes of this phenomenon, touching upon the ideology of normalcy, upon misunderstanding, lack of knowledge and imaginary often associated with disabilities. It also underlines the fact that sexuality is a subject which was not too often brought up in the disability discourse such as other areas where discrimination exists. This might be because it was considered a too difficult topic or because it was considered to constitute an object of mere desire, and not of need.

The most important idea that the first part presents is however that people with disabilities have the same range of sexual needs and sexual desires as people with no disability. This was stressed in articles published by medical professionals and people with disabilities. Moreover, the idea is not foreign to the human rights discourse either. Sex and sexuality penetrated this discourse through the right to health, initially ignoring the interdependency of sexuality and aspects of personality. This has changed. While relevant provisions of the CRPD are being enumerated, the reader can see that besides the biological and physical conception of sexuality, the human rights discourse now comprises aspects related to being in a relationship, to consenting to different acts, to manifest will and preferences. Relevant comments of the CRPD Committee are also being provided to underline that the importance of such aspects is being more and more recognized at the international level, and that disregard does constitute human rights violation. However, this

recognition is not consistent; even the CRPD Committee does not stress the importance of considering all relevant issues in all cases.

The problems with implementing these emerging international standards are even more visible at the national level. National policies are very diverse. Some do include sexuality of people with disabilities as key target; some don't even mention it. Even where it is included not all relevant issues are being dealt with. This is a problem because it affects all people with disabilities. It is also a legal problem. The CRPD has 154 signatories and 126 ratifying State Parties. It establishes standards according to which sexuality has to be considered in legislation, policies and practices. These standards are being overlooked, international law being therefore violated.

When people with disabilities manifest as sexual beings they encounter, as explained in the second chapter of this paper, a whole range of difficulties. First of all there are many misconceptions about their sexuality. Secondly, they have less access than people with no disabilities to an average financial and social status. This has an impact on their self-esteem and social skills which are ultimately reflected in their sexual expressions.

Societal intervention is needed because interference with the sexuality of people with disabilities exists at all levels. As many of them live in closed institutions such as psychiatric hospitals or social care institutions, they find medical personnel interfering. Even when they live independently family members or other members of the community tend to interfere.

Sexual expression is often faced with repressive answers. Because this repression exists, the problem has to be addressed through laws and policies. Interestingly, the most common justification for repressive attitudes is best interest. Everything is supposedly done in the best interest of the person with disabilities. But repression and ignorance of personal will and preferences is obviously an attitude opposed to what best interest means. This is not done to

protect people with disabilities, but to protect myths and the commodity in which society prefers to linger. When something is not understood, had been ignored for a lot of time and raises the necessity of deconstructing concepts, then society prefers to pretend it didn't see it. But as it is actually there, it will manifest. In order to keep pretending it is not there, society will react in a repressive way.

The sexuality of people with disabilities has received various repressive responses. One is denial of necessary information. This is wide spread among people with disabilities and among those with whom they interact. Because information is lacking from people with disabilities, their process of sexually related decision making is altered. They have an increased vulnerability to sexual exploitation, they are delayed or have hardship in attaining sexual milestones. As deviant is a social normative construct of which existence and limits you have to hear to understand, people with disabilities are sometimes found to develop sexually deviant behavior.

Moreover, relevant information is also lacking from others. This is often associated with the willingness to accept practices which trump the human rights of people with disabilities. When one has more accurate information about how sexuality manifests, understands the issue and is more free from normative sexuality, it will be more likely that the given response will not be repressive. If such information is lacking the person will either be repressive or surprised and ignorant. Both of these possibilities contribute to building and maintaining social and environmental barriers which are difficult to be passed even if the person with disabilities does have relevant information. Therefore such information has to be wide spread among person with disabilities and also among other relevant actors such as medical professionals, social workers, caregivers and family members.

Other repressive answers to sexual expressions of people with disabilities are forced abortion and forced sterilization. They appear as well to deny that people with disabilities are sexual beings. While supposedly needed to protect people from burdens and children from hard lives, they stand as a message that reproduction, as a common consequences of sexuality, is not a right for people with disabilities. Not a right in the sense that they don't have to know about it or that they do not need to consent to abortion or sterilization. Such attitudes are spread in human rights discourses, among legal professionals and among policy decision-makers. While liberalizing abortion, the fact that abortion is often done against the will and preferences of women with disabilities is not often addressed. Judges and policy makers are not embarrassed to state that sexual intercourse is not how people with disabilities should manifest sexually. They are not being stopped from saying that they can step in other people's shoes and take decision for them. People with disabilities find themselves trapped between desires and needs and disability specific expected behaviors. As if all their identity would be encapsulated in what was deemed to be a disability.

As not providing information, abortion and sterilization undergone without the knowledge or personal consent of the person do violate CRPD provisions. And they are problems which need to be addressed. Now. Because they are not.

One other evidence that dealing with sexuality within policies needs to be done is criminal law and its relevant provisions. Criminal law does touch upon sexuality of people with disabilities through laws aimed at protecting them from sexual abuse. Such laws sometimes criminalize a specific kind of sexual expression. This is done because such sexual expression does not fit certain boundaries. As the sexuality of people with disabilities does in some cases raise the necessity of deconstructing normative sexuality, such laws can endanger sexual expression.

Other times criminal law prohibits sexual acts where people with disabilities are involved. This is done through special laws which aim at protecting people with disabilities or through general laws protecting all from sexual abuse, problems appearing at implementation. In investigations and trials the will, preferences, opinion and knowledge of people with disabilities are often disregarded. Sometimes rape complaints made by people with disabilities are not given due attention. Sometimes it happens that during the trial the person is not given the opportunity to speak and to express an opinion. Sometimes the fact that the person with disabilities says that she is in a consenting relationship does not stop a rape investigation against the partner. Decisions are being taken by other people who might or might not understand all aspects of the situation. With no safeguard, special training or assessment they are being given the power to do this. This is because people with disabilities have less credibility in front of public officials and because of all assumptions existing in relation to their sexuality. Such ignorance reveals the necessity of special training of legal professionals and of law enforcement officers in such problems, a necessity which has been underlined within the CRPD and by the CRPD Committee.

To conclude, the sexuality of people with disabilities is being highly disregarded in legislation, policies and practices. The necessity to consider relevant aspects have reached the highest forums and have been included in international treaties. However, people still lack relevant information. They are being subjected to forced abortion and forced sterilization. Their opinions are not being listened to. Their will and preferences are often being ignored. As more and more states ratify the CRPD, the time for change has come. For change to take place the sexuality of people with disabilities needs to be mainstreamed within human rights discourses, addressed in national policies and highlighted in international guidelines. This will contribute to the overall elimination of abuse, limitation of freedom and discrimination of persons with disabilities.

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