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Petitions

Discrimination Generated by the Intersection of Gender and Disability

STUDY

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2013

Discrimination Generated by the Intersection of Gender and Disability

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GENDER EQUALITY

Discrimination Generated by the Intersection of Gender and Disability

STUDY

Abstract

Disabled women are at the intersection of various forms of discrimination on the grounds of gender and disability. This report provides an overview of relevant legislation and its limitations. It examines the ways this discrimination manifests itself in many domains of the private and public spheres. An intersectionality approach is seen as the most appropriate tool to analyse the complexity of this phenomenon and inform future policies and legislation, which will ensure participation and realisation of disabled women's full potential.

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LIST OF ABBREVIATIONS

CEDAW	Convention on the Elimination of all forms of Discrimination against Women
EC Treaty	Treaty on the European Community
ECHR	European Convention of Human Rights
ECtHR	European Court of Human Rights
EESC	European Economic and Social Committee
EIGE	European Institute for Gender Equality
EU	European Union
EU Treaty	Treaty on the European Union
CRPD	Conventions on the Rights of Persons with Disabilities
FRA	Fundamental Rights Agency
MDG	Millennium Development Goals
TFEU	Treaty on the functioning of the European Union
UN	United Nations
WHO	World Health Organisation

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EXECUTIVE SUMMARY

Background and Issues

Discrimination on the basis of gender and disability is a fact officially recognised by the 2006 UN Convention on the Rights of Persons with Disabilities (Article 6 CRPD) to which the European Union acceded in 2010. The Convention calls for state measures which will safeguard women's full enjoyment of all their rights and freedoms, such as equal rights in accessing services, education, employment, health care and a personal life free of torture, exploitation and violence.

However, *multiple discrimination* and i*ntersectional discrimination* on grounds of gender and disability persist, while research with emphasis on intersectionality remains overly under-developed. Intersectional discrimination and intersectionality as an approach to policy evaluation are examined in Section 2.

Disability comes in different shapes and forms. Some disabilities are physical (static or progressive), some congenital and some acquired, some visible and others not. Their degree also varies. Their onset is also important for the psychological damage they may cause to the afflicted person. *Impairment is* often located in biology and not in the social context. *Disabling conditions*, however, are always part of the social environment.

Over the last decades **there has been a clear shift from a medical model of disability, as impairment of individual functions, to socio-contextual approaches** emphasising the nature of social interaction with non-disabled people in a certain material environment, and the resulting limitation of opportunities for the disabled. Disability is viewed as a social construct and the emphasis lies in the social meaning imposed upon one's individual function. The importance of such approaches has been paramount and has given **rise to disability movements** all over the world, which brought these issues to the fore and triggered the debate on inclusion, freedom from discrimination and equal participation. Empowering and liberating as these approaches may be, they have been criticised as downplaying the importance of impairment, which even in a barrier-free social environment would still put disabled people at a disadvantage. So, a mixed approach with emphasis on the disabling environment but also including the role of impairments in the way disabled people experience their condition (Shakespeare 2006) is seen by some as more balanced and accurate, as access to health and social care services is vital in the life of people with disabilities and it has to always be borne in mind in policy-design.

Participation of disabled women as citizens is at the basis of the recognition of their dignity. Three actions are more specifically recommended by Article 16 CRPD in order to support persons with disabilities and their families and caregivers: 1) the provision of information, 2) education on how to avoid, recognise and report instances of exploitation, violence and abuse and 3) social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, or through provision of services. **Information, education and integration** are the three facets of participation. A comprehensive account of different forms of participation and exercise of citizenship rights is provided in Section 3.

Finally, Section 4 is dedicated to **forced sterilisation** of women with disabilities, as it constitutes a clear and extreme example of intersectional discrimination on the basis of gender and disability. Sterilisation is defined as 'a process or act that renders an individual incapable of sexual reproduction' (Mosby, 2009). Forced sterilisation occurs when a woman

is sterilised after expressly refusing the procedure, without her knowledge, or is not given an opportunity to provide consent. Women with disabilities are particularly vulnerable to forced sterilisation performed under the auspices of legitimate medical care or the consent of others in their name. This issue will be studied in Section 4.

Aims

This study aims at providing an overview of discrimination legislation and practices which disabled women are faced with and at suggesting ways in which policy and law can lift barriers and enable active and equal participation in all spheres of social and private life.
The objectives are:

- to provide an overview of policies and practices in the EU (as well as to draw on some non-EU innovative policy/legal instruments) with regard to women with disabilities. Emphasis is put on questions of intersectional discrimination in various aspects of social life (Section 2), on disabled women's participation as European citizens (Section 3) and on forced sterilisation (Section 4);
- to identify gaps between legislation and policies and reveal subtle mechanisms that perpetuate discriminatory practices, as well as best practices which could be used as a platform for designing and implementing new policies.

A multidimensional approach is adopted in order to sufficiently address intersectionality. From a policy perspective, the objective is to provide a comprehensive picture of intersectional discrimination against women with disabilities in various aspects of life and activities in society, which are of relevance to policy-makers with a view to improving the living conditions of disabled women in the EU. In addition to an extensive survey of the relevant literature, the focus of the report is on approaches and analyses from the substantial and constantly growing field of disability studies. A survey of the arguments and demands of civil society, as expressed through the websites of disabled people's organisations, and of gaps, deficits and areas requiring policy intervention is provided.

Intersectionality in policy denotes interaction of mutually constitutive inequalities producing an effect which is different from what each of their dimensions would produce separately, and also different from the addition of their separate parts together. When an intersectional approach is adopted, this should be done in combination with focusing on the effects of each dimension separately, so that the effects of single policy measures can be assessed in their entirety.

An intersectionality approach argues that forms of oppression (e.g. racism, sexism, disablism) overlap, defining unique social groups, and thus posits that the consequences of disability, race/ethnicity and gender cannot be understood sufficiently by studying these phenomena separately; their overall effects need to be examined by looking into how disability, gender and race/ethnicity structurally interrelate to establish access to resources (both material and relational) or lead to risks for the groups in question.

Findings

Although the European Union has created a solid and growing anti-discrimination framework, it has not yet paid sufficient attention to the question of intersectional discrimination and more specifically that of gender and disability. In 2010, the European Union joined the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which protects several rights of women and of disabled persons (see more

specifically 3, 6, 16 and 28). A first report by the European Commission is due in 2013. Viewed in the light of the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) and the Council of Europe initiatives, it can lead to a better understanding of intersectional discrimination and a better protection of disabled women. Thus, this protection could become much more concrete. To this day, Art 5 of Directive 2000/78 which provides for a reasonable accommodation for disabled persons at the workplace or the European Disability Strategy 2010-2020 disregard women's specific needs. On the other side, women equality legislation, such as Directive 2004/113, does not take the specific needs of disabled persons into account either.

The disabled people's movement has fought against their marginalisation of the disabled and has promoted a 'social model', which conceptualises disability as a product of social and material environment and emphasises 'disablism', i.e. the discrimination against disabled people (Oliver 2009). In the social model, the impairment (e.g. deafness) is a given, but the disability (e.g. communication limitations resulting from deafness) occurs as a result of environmental factors that are seen as 'disabling' (e.g. lack of hearing loops) (Martin 2011)**. Creating enabling environments** is hence at the core of fostering a non-discriminatory context for equal participation of all citizens in the social and political life of the community.

More specifically, findings are organised around the main conditions for the full participation of men and women in society:

Accessibility

Accessibility can be broadly defined in three ways:

a) Freedom of movement: In the context of the European Union, it is the right of all citizens to work, live, study and establish themselves in another EU Member State. If the relevant infrastructure is in place at the national level, free movement could become a reality for persons with disabilities.

b) Access to public spaces, products and services.

c) Access to information (physical, intellectual and social, see below). This dimension is particularly important as "information is power, and a healthy democracy must guarantee access to this information and power equally for all its citizens" (Hawthorne, Denge and Coombs 1997).

Employment

The concept of incapacity implies that some people are unable to work; however, a person's job prospects are not determined only by their personal attributes but also by the **institutional and economic framework of employment relations**. While the medical model of disability focuses on one's physical limitations, the social model stresses the constraints imposed on disabled people by social care provision, transport networks and employer practices, which create barriers to employment.

Negative stereotyping also affects the daily life of employees with disabilities and leads to a number of unpleasant and unfavourable situations, e.g. unfair treatment regarding pay, promotion or training (overt discrimination), inappropriate interpersonal treatment (subtle discrimination) or a whole negative climate and adversarial workplace culture.

An intersectional approach in the context of employment would look into ways in which different positions in terms of gender and disability create conditions of differential access to resources and can be translated into unequal representation of disabled women in the labour market, pay differentials, segregation in lower-paid jobs and all the composite effects of women's labour market disadvantage enhanced by the addition of the disability parameter.

Quota systems (voluntary or mandatory) are a regulatory approach for promoting employment of people with reduced opportunities to enter the labour market. They seem to provide some results only in the short-term and need to be accompanied by strategies such as training and education to support workers with disabilities. In any case, it is worth noting that no quotas dedicated to disabled women have been introduced.

Mainstream employment continues to perpetuate oppressive and marginalisation practices for disabled workers. Equal participation of disabled women in employment is seriously impeded by various stereotypes and prejudices. **Workplace accommodations** are part of the agenda supporting people with disabilities, including modified job schedules, provision of auxiliary aids, or physical changes in the workplace.

Education

The right to education is fundamental, as education is a necessary condition for participation in socio-economic and cultural activities. Access of girls with disabilities to mainstream education is crucial.

Education as an experience is to a great extent conditioned by the type of disability. Since the 1970s developed countries have introduced educational policies aiming at integrating children with disabilities into **mainstream education**. This has benefitted disabled girls in acquiring skills, experience more social interaction with non-disabled classmates and has led to an increased sense of belonging to the community.

Nevertheless, many countries have separate schools or separate classes for children with physical and intellectual disabilities (Human Rights Watch 2012). Furthermore, mainstreaming has not taken place with respect to vocational training, which serves more those who became disabled after having a considerable employment history. In addition, such youth have rarely been autonomous to **pursue a career**, though this seems to be gradually changing with increasing emphasis on self-determination and individual career goals (Moore, Konrad et al. 2011).

In a climate of austerity and reduction of public spending, girls with disabilities are going to be particularly vulnerable, as cuts may affect their benefits which enable them to have access to education, whereas rising unemployment and state supported-training programmes will be focusing on more mainstream and predominantly male occupations. Intersectionality here lies in the interaction of factors such as gender, disability, low economic status or race/ethnicity, which restrict access to education and later on to the labour market and perpetuate inequalities at the expense of disabled women.

Health care

Access to health care provisions is a priority in any democracy and one of the main aspects of social citizenship. Disabled people are **more frequent users** of healthcare services, as some forms of impairment require regular medical monitoring. Article 25 of the CRPD

demands that health services for disabled persons be gender-sensitive and provide the same quality and standard of free or affordable health care as those provided to non-disabled individuals. This translates into the necessity for health centres and primary care providers to have the appropriate equipment which would facilitate examination of people with mobility or other types of impairment (Human Rights Watch 2012).

Women with disabilities are **more vulnerable** to receive services of lower quality, particularly those with learning disabilities. Consequently, policy intervention should focus on the removal of barriers to quality, accessible and affordable services for women with disabilities and on their relationship with health professionals.

Better access of disabled women to health care requires among others removal of linguistic impediments stemming from different cultural and ethnic backgrounds (different definitions of health problems, perceptions of 'cure', reluctance to reveal mental health problems etc.). All these factors in addition to their usually low economic position and high cost of visits to specialists (when not free) intersect and produce or aggravate inequalities at the expense of disabled women.

The above principles should be applied to protect women and girls with disabilities from discrimination, to respect their human rights and to ensure suitable access to quality healthcare: health sector professionals need to receive suitable training in caring for women and girls with disabilities, including sexual and reproductive health; treatment and procedures should be administered on the basis of **informed consent** of the woman with disabilities.

Sexuality and reproduction

Reproductive rights are related to **women's autonomy** to decide whether to have children or not and under what circumstances, and include also rights to education and information, as well as freedom from coercion in exercising reproductive decisions and choices. These rights, though, are often not granted to disabled women, while practices such as forced sterilisation, or forced abortion are imposed on them. Ensuring disabled women's protection is a clear priority. Counselling must be given to women and girls with disabilities on their sexual and reproductive rights, so that they can make an informed decision.

Violence against women with disabilities

Violence against women with disabilities is difficult to deal with from a legal point of view. International and national legislation, treaties and acts forbid violence and abuses in general. They do not specifically take into account the situation of disabled women. National criminal law and case law punish crimes and, as such, all sorts of recognised and proven violence. The results of these actions may not be that prominent in a legal framework. Nevertheless, some progress has been made in terms of actions against violent perpetrators in case law. It is only when reports on trials are made that a trace of the types of abuse involved is found.

More precisely, **Article 16 of the CRPD** entitled 'Freedom from exploitation, violence and abuse' protects 'persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects'. If defined negatively, then violence should be avoided, if positively, then each Member State and the EU should adopt all kinds of appropriate measures in accordance with their respective

competences. Beyond the scope of legislative and administrative acts, social, educational and other actions are to be taken.

Women with disabilities are at a high risk of abuse, both of 'traditional' forms (physical, sexual, emotional) and particular forms related to their disability (withholding medication, denying access to mobility or communication equipment, obstructing personal care and hygiene, or blocking access to medical consultation). However, the **scarcity of information** regarding abuse of women with disabilities might be indicative of 'denial' on the part of society (Plummer and Findley 2012). Moreover, common perceptions of disabled women as helpless and passive make them more vulnerable to abuse, not least in medical and institutional settings.

Disabled women are also at higher risk of abuse in the private sphere (domestic violence), especially because perpetrators can be partners, family members, paid carers, or care agencies. Barriers to seeking help in situation of abuse include increased dependence (physical, emotional, financial) on the perpetrator, lack of information and difficulties in accessing relevant services, fear of institutionalisation, comprehension and reactions by police or other professionals (Nixon 2009).

Sterilisation

Although some progress has been made in terms of policies expanding the recognition and enjoyment of women's rights to sexual and reproductive healthcare services, the practice of forced and coerced sterilisation of women around the globe, including Europe, still poses a challenge to the realisation of disabled women's human rights.

Several countries are now tackling this issue. In line with the CRPD, for the EU to adopt a non-discrimination stand, it should consider proposing a directive on the basis of Article 19 in order to **prohibit forced sterilisation as a serious form of discrimination** in accordance with the interpretation by the CEDAW committee regarding violence except when there is a serious threat to life. In any case and regardless of whether the particular girl/woman has a disability, fully-informed consent is always required.

Recommendations

The recent interest shown by the EU institutions in intersectional discrimination gives rise to optimism. Beyond, recital 14 of Directive 2000/43 recognises that "women are often the victims of **multiple discrimination**". In this respect, the following recommendations are made:

Recommendations from a legal point of view

- All Member States which have not already done so should ratify and implement the CRPD.

- Enact EU legislation recognising the existence and prohibiting multiple and intersectional discrimination. This should be a statement of principle. For instance, it could be included in the preamble of the upcoming Directive prohibiting discrimination. It should not be defined more as it will be a policy matter. Policies addressing the disabled as a uniform category will never reduce inequalities.

- Ensure efficient and easy access to justice for all, especially disabled women (via tribunals and ombudsman).

Recommendations from a social point of view

Promoting the quality of life of women with disabilities:

- **An intersectionality approach shows that disability mainstreaming**, similarly to gender mainstreaming, might lead to less discriminatory practices. This derives from the idea that law in general does not take into account the diversity of the population. Even anti-discrimination laws have limitations. There is thus a need to include a positive element to counteract possible discriminatory outcomes.

- **However, positive actions** have been shown to be more effective in reducing inequalities than anti-discrimination legislation. Quotas could only make a difference, if they targeted disabled women explicitly, so as to address the intersectionality of discrimination in employment.

- **"Universal design" programmes should be developed through law, regulation and culture** integrating the inclusive dimension in the design of buildings, products and services from the start.

- **For the mainstreaming of disabilities and gender issues, awareness-raising of general population** is needed as an overarching priority. This is an overarching priority. Disability should be seen as common, multiform experience, related to the ageing process, which will eventually afflict most people who will live long, especially women who live longer. Given the demographic conditions, it will be on the increase in the years to come. Possible actions could be challenging stereotypes through art, science, media, visual representations, sport, advertisement, activism, and language, notably if related to contribution of eminent scholars, artists and thinkers. Awareness and presentation of the disability movement claims in terms of social citizenship and human rights is essential in changing attitudes of the public and of policy makers.

- **Disability and feminist movements should work together** to remove both structural and cultural barriers of equal participation of women with disabilities. The Internet seems to be contributing significantly to mobilisation, organisation and communication.

- **Training of relevant professionals** dealing with people with disabilities (health professionals, carers, teachers, social workers, staff in day centres etc.) need to have the social model of disability and research by disability studies scholars incorporated into their education and training curricula to be made familiar with the relevant issues related to their work.

- **The potential of public procurement** as a powerful tool to provide business with an incentive to develop accessible goods and services whilst stimulating innovation should be further developed.

- **The visibility of disabled women** in the public arena needs to be increased. Breaking stereotypes in the way disabled people are portrayed by the media and making linguistic adjustments in a non-simplifying and non-stigmatising way is an imperative. In this way a more accurate representation of the conditions and the experience of disabled women is ensured.

Specific measures

- EDUCATION: **Inclusive education in mainstream schools** is a vehicle toward achieving greater acceptance of disabled pupils in early years by their peer group, cultivate a sense of belonging, change stereotypes and give the chance to able-bodied pupils to appreciate disabled pupils' contribution, abilities and commonalities. Disability and gender need to be better mainstreamed into vocational training.

- EMPLOYMENT: **A less discriminatory labour market** will lead to greater social inclusion and alleviation of some of the negative material and psychological consequences of disability. As seen in Chapter 2, the existing comprehensive EU anti-discrimination framework does not address intersectional discrimination. Measures adopting an intersectional approach would aim at increasing employability of disabled women and thus enable them to become less dependent on their family (parents or partners) and capable of having a more autonomous lifestyle. In the meantime, it is down to welfare states to introduce benefits which would increase autonomous living. **Adaptation of the workplace** to the needs of disabled women workers will increase participation of the disabled in the labour market. Member States to provide reasonable accommodation to employers for necessary adjustments and possibly reduce their reluctance to hire disabled women.

- POVERTY: **The link between poverty, disability and gender must be taken into account in any anti-poverty measures**. Poverty is inextricably linked with disability, either as a cause or an outcome of it. Some disabilities are caused or exacerbated by malnutrition, poor living conditions, lack of access to health care services and alternatively, when impairment exists, the disabling social conditions and barriers to education or employment for women with disability result in poverty. It is imperative in the presence of current recession in some Member States that austerity measures do not exacerbate inequalities at the intersection of gender and disability and that disabled women and their families do not suffer new forms of social exclusion and discrimination.

- HEALTH: **Health inequalities resulting at the intersection of gender and disability need to be acknowledged and included as a priority** into the research agenda of governments, as this dimension has been neglected. Doctors' and nurses' education would benefit from adopting a holistic view and taking into consideration the human rights of disabled patients as being equal to those of non-disabled ones (e.g. screening, preventive care and so on). Direct communication with disabled patients, visits at the patients' premises, as well as use of sensitive language, are important policy matters.

- VIOLENCE: Violence **needs to be recognised as a serious problem** for disabled people in general and for women in particular. Worldwide action to address the problem is necessary and is conditioned upon the generation of robust evidence for the prevalence or risk of violence through rigorous and relevant studies.

- FORCED STERILISATION: The Commission should consider proposing a directive on the basis of Article 19, prohibiting sterilisation as a serious form of discrimination or as threat to human rights and women's dignity, except where there is a serious threat to life. In any case and regardless of whether the girl/woman in question has a disability, fully-informed consent is required.

- Member States should ensure access to justice, psychological and financial reparation, including access to specific support mechanisms aiming at vulnerable categories of people, such as disabled women (for example through a regional or national bureau or centre for disabled women and their tutors). This could be linked to the implementation of the victims package.

- Member States have to ensure special training of all professionals involved in these cases.

- Member States should make sure that all law and practice should be in line with the CRPD and account for the disabled person's consent to medical procedures and take into account parental responsibilities and powers and their restrictions in certain circumstances. In all cases, the following questions should always be answered:

    - Is the sterilisation performed for other than therapeutic purposes?
    - Was it preceded by due inquiry and adequate consideration?
    - Is there a conflict between the interests of the disabled persons and her carers?

- In the framework of its obligations from the CRPD, the Commission should proceed to a complete and exhaustive comparison of the Member States' legal provisions and their implementation in practice in relation to forced sterilisation.

Need for more research

Research is not only necessary as a means of **evidence-based policy making** but also as a way to **raise awareness** and is therefore of paramount importance. Funding for targeted research to provide more accurate qualitative and quantitative data is imperative and urgent for efficient policy design which will address intersectionality. The EU can be instrumental in funding such studies, as disabled women have not been prioritised in the national context, while the current economic climate in many Member states has affected funding for research of this type.

1. SETTING THE SCENE

KEY FINDINGS

- Discrimination on the basis of gender and disability is a fact officially recognised by the 2006 UN Convention on the Rights of Persons with Disabilities (Article 6 CRPD) to which the European Union acceded in 2010.
- However, multiple discrimination and intersectional discrimination on the grounds of gender and disability persist, while research with emphasis on intersectionality remains overly under-developed.
- Over the last decades there has been a clear shift from a medical model of disability, as impairment of individual functions, to socio-contextual approaches emphasising the nature of social interaction with non-disabled people in a certain material environment, and the resulting limitation of opportunities for the disabled. However, a mixed approach with emphasis on the disabling environment but also including the role of impairments in the way disabled people experience their condition is seen as more balanced and accurate.
- Participation of disabled women as citizens is at the basis of the recognition of their dignity; nevertheless, it is often impeded in various domains of social life. Violence, including domestic violence, as well as the practice of forced sterilisation, are prevalent in different contexts and seriously hinder, among other manifestations of intersectional discrimination against women with disabilities, the enjoyment of full social citizenship.
- This study aims at providing an overview of discrimination legislation and practices which disabled women are faced with and at suggesting ways in which policy and law can lift barriers and enable active and equal participation in all spheres of social and private life.

1.1. Introduction

According to the first ever *World Report on Disability* provided by the WHO and the World Bank based on 2004 disability prevalence estimates, there were around 785 (15.6%) to 975 (19.4%) million persons 15 years and older living with disability. Of these, around 110 to 190 million (2.2-3.8%) experienced significant difficulties in functioning. If children are included, over a billion people are estimated to be living with disability today around the world (WHO 2011, p.29).

People with disabilities on average have poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities. Explanations for these trends include the lack of services available to people with disabilities, as well as the many obstacles and constraints they face in their everyday lives.

Discrimination on the basis of gender and disability is a fact, officially recognised by the 2006 UN Convention on the Rights of Persons with Disabilities (Article 6 CRPD). The

Convention calls for state measures which will safeguard women's full enjoyment of all their rights and freedoms, such as equal rights to services, education, employment, health care and a personal life, free of torture, exploitation and violence.

Despite some legislative landmarks, however, inequalities persist. Disabled women experience discrimination on the grounds of gender, disability, class, sexuality or age. They are far from being visible in terms of participation and unable to enjoy their rights. Consequently, they constitute a very vulnerable group, increasingly at risk in the current economic climate. Therefore, there is a need for policies to ensure that CRPD is not empty of meaning but is being implemented and constitutes a vehicle toward more visibility and inclusion.

This study aims at providing an overview of discrimination legislation and practices which disabled women are faced with, within the EU but also in some non-EU countries. Its focus will be on the identification of impediments and possible ways in which policy and law can lift them to enable active and equal participation in all spheres of social and private life.

1.2. The concepts

This section aims at defining the key concepts and issues involved in this analysis as well as their complexity, and at presenting the various approaches in a concise way, which will serve as a background for understanding the issues and the current debates on discrimination of disabled women.

- **Disability**: A disabled person is most commonly defined as someone with a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities. (UK Disability Discrimination Act 2005). The term is used to refer to individual functioning, including physical, sensory, cognitive and intellectual impairments, mental illness, and various types of chronic disease. Nevertheless, disability is conceptualised as being a multidimensional experience for the person involved. There may be effects on organs or body parts, or effects on a person's participation in areas of life. Correspondingly, three dimensions of disability are recognised: body structure and function/impairment (medical model), activity (and activity restrictions) and participation (and participation restrictions). The classification also recognizes the role of physical and social environmental factors in affecting disability outcomes (social model). The social construction and representation of disabled people shapes the policy and practice responses they receive, both discursive and practical, as well as their own responses (Thiara, Hague and Mullender 2011).

- **Gender** differs from sex which is based on biology and is seen as a socially constructed set of behaviours, norms, symbols, interpretations, institutions and identities.

- **Discrimination** has been the topic of controversial debates and has many facets and definitions. The European Court of Justice defines it as 'different treatment of similar situations or similar treatment of different situations'. Discrimination can be direct or indirect[1]. Though explicit discrimination has been reduced in contemporary democratic societies, more subtle forms of discrimination are omnipresent and affect

[1] ECJ, *Dassonville* case, 8-74, 11 July 1974.

specific social groups, such as the disabled. Studies have shown that discrimination has significant health impact, including depression, anxiety, psychological distress etc.; perceived discrimination has also been shown to lead to physical problems, such as hypertension, breast cancer, high blood pressure, or obesity (Pascoe and Richman 2009).

- **Multiple discrimination** occurs when a person is discriminated on the basis of several grounds operating separately, for instance, by being treated less favourably on the grounds of ethnic origin in one situation and because of gender in another (EU FRA, 2012). In most cases, under existing legislation a victim of multiple discrimination will have more difficulty to have the reality of her experience recognised. It is worth noting that multiple discrimination does not refer to situations where two grounds coincide or that one ground adds to the discrimination on another; this constitutes compound discrimination. Feminist scholars have criticised the multiple discrimination approach because, firstly, it treats all the axes as having equal importance and can be remedied with anti-discrimination legislation. This is clearly not the case, as inequalities differ in terms of visibility, choice, autonomy of individuals and the institutions in which they are situated. Secondly, they seem to matter the same. Thirdly, the multiple discrimination model favours a small anti-discrimination frame which does not allow for other measures and finally, because it totally omits class. This is not acceptable in the context of increasing socio-economic inequalities (Kantola and Nousiainen 2009).

- **Intersectional discrimination** occurs when somebody is discriminated against on several grounds at the same time and in such a way that these are inseparable; for instance forced sterilisation of Roma women is a case of intersectional discrimination on the basis of gender, ethnicity and poverty.

- **Intersectionality** (or **Intersectionalism**) was first introduced by Crenshaw (1989) in her attempt to describe the interaction of race and gender in shaping women's experiences of employment. Intersectionality refers to 'the relationships among multiple dimensions and modalities of social relationships and subject formations' (Knudsen, 2006). Various biological, social and cultural categories such as gender, race, class, disability, age interact on multiple and often simultaneous levels, contributing to systematic inequality.

1.3. The issues

This study calls for an analysis of two grounds of discrimination: gender and disability. The work on definitions shows the scope of the study:

1.3.1. A multi-faceted reality

The notion of discrimination is multi-faceted. In most cases, under existing legislation, victims of intersectional discrimination frequently have difficulty to have the reality of their experience recognised by the legal system.

1.3.2. The issues related to disability

Disability comes in different shapes and forms. Some disabilities are physical (static or progressive), some congenital and some acquired, some visible and others not. Their

degree also varies. Their onset is also important for the psychological damage they may cause to the afflicted person. The later in life disability starts, the less its psychological damage is important (Fine and Asch, 1988). *Impairments* are often located in biology and not in the social context. *Disabling conditions*, however, are always part of the social environment.

Disability is often viewed as a victimising experience itself and a biological injustice, whereas its social aspect caused by social injustice and discrimination is ignored. Consequently, changes are all attributed to the individual, while the institutional, physical and attitudinal context remains unchallenged (Fine and Asch, 1988).

Over the last decades **there has been a clear shift from a medical model of disability as impairment of individual functions to socio-contextual approaches** emphasising the nature of social interaction with non-disabled people in a certain material environment, and the resulting limitation of opportunities for the disabled. Disability is viewed as a social construct and the emphasis lies in the social meaning imposed upon one's individual function. According to this viewpoint, the social and attitudinal barriers resulting from society's failure to take into account the needs of disabled people are the truly disabling conditions (Thiara, Hague and Mullender 2011).

Disablement can be seen as a social process 'stemming from a mismatch between personal physical abilities and the demands of one's environment' (Warner and Brown, 2011, p.1246). Children with disabilities are particularly prone to stigmatisation which gives rise to feelings of low self-esteem and isolation, and as a result they show skill deficits that diminish their outcomes. Moreover, over time they understand institutional structures as designed in ways to emphasise their social rejection (Moore et al. 2011).

The importance of the above approaches has been paramount and has given **rise to disability movements** all over the world, which brought these issues to the fore and triggered the debate on inclusion, discrimination and equal participation. Empowering and liberating as these approaches may be, they have been criticised as downplaying the importance of impairment, which even in a barrier-free social environment would still put disabled people at a disadvantage. So, a mixed approach with emphasis on the disabling environment but also including the role of impairments in the way disabled people experience their condition (Shakespeare 2006) is seen by some as more balanced and accurate, as access to health and social care services is vital in the life of people with disabilities and it has to always be borne in mind in policy-design.

However, *multiple discrimination* (McCall, 2001) and i*ntersectional discrimination* (European training and Research Center for Human Rights and Democracy, 2012) on grounds of gender and disability[2] with emphasis on intersectionality remain overly under-researched[3].

[2] European Commission, Unit G4 (2007) Tackling multiple discrimination: practices, policies and laws. Study on The Situation of Women with Disabilities in the framework of the European Year of Equal Opportunities for All and in view of the UNCPRD (VC/2007/317)/ 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union.

[3] Research then was more focused on gender and race/ethnic minorities (McCall, 2005; Browne and Misra, 2003; Banda and Chinkin, 2004; Coleman, 1998; Okin, 1997; Sassen, 1997; Shachar, 2000) or on gender and poverty/social classes. It has been the subject of a UN report which sets the issues(Bradley, Healy, Forson, and Kaul, 2007) but remains too broad with regard to gender and disability. Nations Unies (2001) Background briefing on intersectionality. Groupe de travail sur les femmes et les droits humains, 45e session des Nations Unies.

1.3.3. Disabled women and violence

Violence against women with disabilities is difficult to deal with from a legal point of view. International and national legislation, treaties and acts forbid violence and abuses in general. They do not specifically take into account the situation of disabled women. National criminal law and case law punish crimes and, as such, all sorts of recognised and proven violence. The results of these actions may not be that prominent in a legal framework. What can be seen, though, is the progress made in terms of actions against violent perpetrators in case law. It is only when reports or trials are made that a trace of the types of abuse involved is found.

More precisely, Article 16 of the CRPD entitled 'Freedom from exploitation, violence and abuse' protects 'persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects'. If defined negatively, then violence should be avoided, if positively, then each Member State (and the EU that has adhered to the Convention) should adopt all kinds of appropriate measures. Beyond the scope of legislative and administrative acts, social, educational and other actions are to be taken.

Disabled women and domestic violence

'Domestic violence is the physical, sexual, psychological or financial violence that takes place within an intimate or family-type relationship and forms a pattern of coercive and controlling behaviour' (Thiara, Hague and Mullender 2011, p.760). Disabled women are at higher risk of bad treatment or abuse. They face more significant barriers to seeking help and, due to inadequate support, may face longer abuse, as well as different types of abuse than non-disabled women.

A UK study has shown that perpetrators of abuse against disabled women are multiple, including partners, family members, paid carers, or care agencies. Impairment–specific abuse by partners or carers can consist of depriving them from mobility or other aids, while neglect can involve being denied access to medicines, sanitary materials etc. Financial control and power exertion were also reported. The intersection of disability, gender and race makes domestic violence more pronounced for minority ethnic women. The same study demonstrated 'a stark lack of dedicated service and policy development for disabled women who experience domestic violence within relevant agencies, strategic partnerships and inter-agency forums'. Lack of funding and resources and prevailing attitudes were considered the biggest barriers to improvement (Thiara, Hague and Mullender 2011, p.768).

Sterilisation

Sterilisation is defined as 'a process or act that renders an individual incapable of sexual reproduction' (Mosby, 2009). *Forced sterilisation* occurs when a person is sterilised after expressly refusing the procedure, without her knowledge, or is not given an opportunity to provide consent and constitutes an extreme form of violence. *Coerced sterilisation* occurs when financial or other incentives, misinformation, or intimidation tactics are used to compel an individual to undergo the procedure. Women with disabilities are particularly

vulnerable to forced sterilisation performed under the auspices of legitimate medical care or the consent of others in their name[4]. This point will be studied in Section 4.

1.3.4. Participation of disabled women

Participation of disabled women as citizens is at the basis of the recognition of their dignity. Three actions are more specifically recommended by Article 16 CRPD in order to support persons with disabilities and their families and caregivers: 1) the provision of information, 2) education on how to avoid, recognise and report instances of exploitation, violence and abuse and 3) social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, or through provision of services. Information, education and integration are the three facets of participation. A comprehensive account of different forms of participation and exercise of citizenship rights is provided in Section 3.

1.4. International and EU law state of the art

1.4.1. International law

In International law**,** the most relevant text is the aforementioned UN Convention on the Rights of Persons with Disabilities (CRPD). It must be viewed together with the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) as they promote action in order to support persons with disabilities and their families and caregivers.

1.4.2. EU Law

EU law has a constantly growing branch of equality law. It started in the 1950s and has developed considerably with the addition of a new article 13 in the Amsterdam Treaty in 1997 now known as Article 19 TFEU. The focus on fighting discrimination has been constant. Many Directives, Communications, actions, strategies and programmes have been adopted both in the field of gender discrimination as well as in that of disability[5]. It must be underlined that despite some reservations[6], the CRPD has been an integral part of EU law since 2011[7]. However, in the current framework, intersectional discrimination is absent.

[4] Sterilisation of Women and Girls with Disabilities, A Briefing Paper, October 2011, http://www.hrw.org/news/2011/11/10/sterilisation-women-and-girls-disabilities (accessed on 5/2/13).

[5] Among others, Amsterdam Treaty (Article 13 TEC), Lisbon Treaty (Article 19 TFEU, Charter of Fundamental Rights (Article 21 – non-discrimination, Article 26 – social integration). See further, next chapter.
Disability Strategy 1996, Disability Action Plan 2003, EU Disability Strategy 2010-2020, Article 13 (now Art 19 TFEU), Directive 2000/78/EC on employment and occupation, Proposal for a directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, including the discrimination-free access to goods and services (COM(2008)426) and the corresponding resolution of the European Parliament P6_TA(2009)0211, http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P6-TA-2009-0211&language=EN&ring=A6-2009-0149.

[6] Article 27 CRPD, armed forces.

[7] Article 44 CRPD, Article 218 TFEU. See ECJ, *IATA v Department for Transport*, 2006, ECJ, *Kadi and Al Barakaat*, 2008 and ECJ, *International Foundation v Council of the EU*, 2008.

1.5. Aims and methods

1.5.1. Aims of this study

The aims of the study are:

- To provide an overview of policies and practices in the EU, as well as in non-EU countries which have introduced innovative policy and/or legal instruments to ensure implementation of the CRPD regarding women with disabilities. On the legislative level, cases which are path-breaking and can mark new developments will be highlighted. Emphasis is put on questions of intersectional discrimination in various aspects of social life (Section 2), on disabled women's participation as European citizens (Section 3) and on forced sterilisation (Section 4);
- To identify gaps between legislation and policies and reveal subtle mechanisms that perpetuate discriminatory practices, as well as best practices which could be used as a platform for designing and implementing new policies.

A multidimensional approach to the topic is adopted in order to sufficiently address intersectionality. From a policy perspective, the aim is to provide a comprehensive picture of intersectional discrimination against women with disabilities in various aspects of life and activities in society, which are of relevance to law and policy. In addition to extensive survey of the relevant literature, the focus of the report is on approaches and analyses from the substantial and constantly growing field of disability studies. A survey of the arguments and demands of civil society, as expressed through the websites of disabled people's organisations and of gaps, deficits and areas requiring policy intervention will be provided.

To ensure that the recommendations in this report echo the needs of the people affected by present and future policies on the inclusion of disabled people, the authors of this report have followed interviews and conducted two interviews with key stakeholders to validate their findings[8]. The authors would like to express their gratitude to Professor P. Nikiforos Diamandouros, European Ombudsman, and Baroness Tanni Grey-Thompson for their valuable insights and collaborative approach.
Comparative legal analysis will be presented in the form of tables which include Member State legislation (UK, Scandinavia, France, Germany) but also that of states beyond EU (the US, Australia and Canada).

This study provides for an overview of the main concepts, issues and dimensions, expanding on some themes more than on others while others are left out[9]. This does not reflect any intention to classify fields of action in terms of importance. Finally, forced sterilisation has been dedicated a separate section, as it constitutes not only a violation of human rights but also an extreme form of violence against disabled women.

[8] The interview with Professor P. Nikiforos Diamandouros, European Ombudsman, was conducted by telephone on 25th April 2013. The interview with Baroness Tanni Grey-Thompson was conducted by telephone on 2nd May 2012.
[9] Other possible areas which have been left out due to space limitations are empowerment,/leadership, rehabilitation, effective access to justice and participation in culture, sport and leisure.

1.5.2. Organisation of the report

After the introduction in **Section 1, Section 2** is a survey of the literature on theories of intersectionality and its use as an analytical tool to explain discrimination at the intersection of gender and disability with particular attention to Article 16§5 CRPD through the lens of both policy and law.

Section 3 focuses on several dimensions of intersectional discrimination as expressed in relation to the participation of women with disabilities as European citizens and the notion of citizenship broadly defined to deal with the complexity of the issues involved.

Section 4 deals with the issue of forced sterilisation of women with disabilities including an overview of scientific literature and international press, a comparative description of the legal frameworks related to this practice in the Member States of the European Union. An analysis follows regarding the compatibility of these legislations and practices with the obligations arising from the CRPD, as well as a presentation of the relevant bioethical and human rights dimensions and considerations.

On the basis of the aforementioned analysis, **Section 5** identifies best practices. Recommendations are made on how to combine legal and policy tools to ensure implementation of the CRPD in all Member States that have ratified it and sanctions for non-compliance. The intention is to expose the complexity of the issues and to form a platform for policy design and legislation, which will remove some of the barriers preventing women with disabilities from enjoying their fundamental rights. Moreover, new topics and areas for further research will be flagged.

2. INTERSECTIONAL DISCRIMINATION

KEY FINDINGS

- Although the European Union has created a solid and growing anti-discrimination framework, it has not yet paid sufficient attention to the question of intersectional discrimination and more specifically that of gender and disability.
- An intersectionality approach argues that forms of oppression (e.g. racism, sexism, disablism) overlap, defining unique social groups, and thus posits that the consequences of disability, race/ethnicity and gender cannot be understood sufficiently by studying these phenomena separately; their overall effects need to be examined by looking into how disability, gender and race/ethnicity structurally interrelate and affect access to resources (both material and relational) or lead to risks for the groups in question.
- Intersectionality in policy denotes interaction of mutually constitutive inequalities producing an effect which is different from what each of their dimensions would produce separately, and also different from the addition of their separate parts together. When an intersectional approach is adopted, this should be done in combination with focusing on the effects of each dimension separately, so that the effects of single policy measures can be assessed in their entirety.

2.1. International law

"Designing law to tackle discrimination was always a complex matter, even when it was ostensibly simply a question of black and white, or male and female" (Solanke, 2009). Nowadays, the idea of a multiple or intersectional discrimination invites the legislators and treaties' drafters to rethink the concept of discrimination. This is not always an easy task.

The intersection of gender and disability is not directly dealt with by international law and the time of Conventions directly addressing this intersection and the specific needs of disabled women has not come yet. For the time being, the study has to focus on texts on disability and texts on gender equality to identify intersections between the two subjects.

Beyond Article 25 of the Universal Declaration of Human Rights which grants to each person "the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control" and its prohibitions of discriminations[10], beyond the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, and thanks to the World Programme of Action Concerning Disabled People (1982), the Convention on the Rights of the Child (1989), and the Standard Rules on the Equalisation of Opportunities for People with Disabilities (1993), disability has become a human rights issue. More than

[10] Article 7 and 23.

40 nations have adopted disability discrimination legislations since the 1990s[11]. The concept of human rights for persons with disabilities is now accepted internationally.

2.1.1. Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)

The Convention on the Elimination of All Forms of Discrimination against Women promotes action in order to support persons with disabilities and their families and caregivers through:

1) The provision of information (Article 10, 14, 16)
2) Education on how to avoid, recognise and report instances of exploitation, violence and abuse 'Article 5, 10 and 16; and
3) Social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services (Article 11 and 13).

2.1.2. UN Convention on the Rights of Persons with Disabilities (CRPD)

The UN Convention on the Rights of Persons with Disabilities (CRPD) is devoted to disabilities, but some of its articles highlight the link to be made between disability and gender:

1) Article 3 focuses specifically on non-discrimination (§2) and equality between men and women[12].

2) Article 6 recognizes that women and girls with disabilities are subjects to multiple discrimination, and that State parties shall take all appropriate measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms and to ensure the full development, advancement and empowerment of women with disabilities.[13]

3) Article 16 is about Freedom from exploitation, violence and abuse[14] and focuses specially on the obligation for "States Parties to put in place effective legislation and

[11] See WHO, World Bank, 2011, http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf, p. 33.
[12] §7, point g as well as point q of the preamble.
[13] Article 6 - Women with disabilities: 1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.
[14] 1. States Parties shall 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.
2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted"[15].

4) Finally, Article 28 on *Adequate standard of living and social* protection identifies special need for women and girls when it ensures "access by persons with disabilities [...] to social protection programmes and poverty reduction programmes".

The goals of these texts are similar to those of the United Nations: founded on the principle of equality for all and dignity and worth of every human being, they give primary importance to the promotion of social justice. Persons with disabilities are, *de facto*, entitled to all the fundamental human rights upheld by human rights instruments.

States (or international organisations) ratifying the CRPD have a range of general obligations. Among other things, they undertake to:

- adopt legislation and other appropriate administrative measures where needed;
- modify or repeal laws, customs, or practices that discriminate directly or indirectly;
- include disability in all relevant policies and programmes;
- refrain from any act or practice inconsistent with the CRPD; and
- take all appropriate measures to eliminate discrimination against persons with disabilities by any person, organization, or private enterprise.

States must consult with people with disabilities and their representative organisations when developing laws, policies, and programmes to implement the CRPD. The Convention also requires public and private bodies to provide for "reasonable accommodation" for people with disabilities. The CRPD is accompanied by an Optional Protocol that, when ratified, provides for a complaints procedure and an inquiry procedure, which can be lodged with the committee monitoring the treaty.

2.1.3. Other international texts on UN level

One can also mention the United Nations Standard Rules for the Equalization of Opportunities of Persons with Disabilities, the World Health Organization (WHO) Mental Health Declaration for Europe, or the Millennium Development Goals (MDG).[16] In 2011, the first ever World Report on Disability, jointly produced by the World Health Organization and the World Bank, has reviewed evidence about the global situation of persons with

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.
5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

[15] Article 16 §5.

[16] Agreed on by the international community in 2000 and endorsed by 189 countries, it focuses on the issue of gender and disability as it noted in the 2010 MDG report that there is a need to ensure that "women and girls with disabilities are not subject to multiple or aggravated forms of discrimination, or excluded from participation in the implementation of the MDG". Implementing the internationally agreed goals and commitments in regard to gender equality and empowerment of women. New York, United Nations, Economic and Social Council, 2010 (E/2010/L.8, OP 9).

disabilities, and offered directions for policy and practice to address exclusion[17]. This report does not make specific reference to the question of handicap and gender, but it mentions an 'acute difficulty' for women[18].

2.1.4. The Council of Europe Conventions

The Council of Europe adopted a new Convention on the 23 May 2012: the Council of Europe's Convention on Violence against Women, which also takes into account disability[19]. It has been signed so far by 13 of the 47 Members States of the Council of Europe. Beyond, if the ECtHR does not protect individuals against intersectional discrimination yet, both gender and disability are grounds of the anti-discrimination article of the European Convention on Human Rights (ECHR). Both have been extensively protected by the Court[20].

The Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society 2006-2015 might gain importance regarding the implementation of a European Accessibility Act to be proposed by the Commission in 2013.

2.2. EU law state of the art

2.2.1. Literature Overview

The legal doctrine has only recently started to wonder about the notion of multiple or intersectional discrimination in the EU (Schiek, Chege, 2008; Solanke, 2009). It relies on sociological studies and previous works in the United States (Jones and Shorter Gooden, 2003). There is a vast amount of work on anti-discrimination legislation, both on EU and on national levels, and an equally high volume on policies. On the legislative front, all dimensions of discrimination have been broadly covered through the development of international conventions and gender has been at the forefront in the fight against discrimination[21] as the vast relevant literature shows(De Francisco and Palczewski, 2007)(Hooks, Bell, 1984).

In the legal field, European law has been the object of reports and a comparative study on 'Institutionalizing Intersectionality' (Krizsan, Skjeie and Squires, 2012), which is important for identifying differences of national trends toward intersectional discrimination but leaves out women and disabilities. The Report entitled *Multiple Discrimination in EU Law, Opportunities for Legal Responses to Intersectional Gender Discrimination?* drafted by the European network of legal experts in the field of gender equality (Burri and Schiek, 2009),

[17] http://www.who.int/disabilities/world_report/2011/en/index.html.
[18] "Also while disability correlates with disadvantage, not all people with disabilities are equally disadvantaged. Women with disabilities experience the combined disadvantages associated with gender as well as disability, and may be less likely to marry than non-disabled women (*48*, *49*)". Word report on disability, WHO, World Bank, 2011, http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf, p. 7. Also p. 235 : "For a person with a disability, particularly a disabled woman, it is usually even more difficult, given the frequent lack of collateral".
[19] Amongst other grounds of discrimination, see Article 4-3 of Council of Europe Convention on preventing and combating violence against women and domestic violence, see http://www.conventions.coe.int/Treaty/EN/Treaties/Html/210.htm (seen on 26/4/2013).
[20] See for a recent example: case ECtHR, *Dordevic v Croatia*, 24 July 2012, where the Court decided that Croatia had failed to protect the first applicant from inhuman and degrading treatment**.** The Court acknowledged that different individual incidents can, when perpetrated over a longer period of time meet the minimum level of severity necessary to amount inhuman and degrading treatment (Article 3 ECHR); to protect the mother's right to privacy and family life (Article 8 ECHR); to provide effective remedies for the applicants when being confronted with a hate crime motivated by hostility based on the victim's disability (Article 13 ECHR). See also further Chapter 4.
[21] United Nations, Convention on the Elimination of All Forms of Discrimination Against Women (1979).

as well as its sequel *European Union non-discrimination law: comparative perspectives on multidimensional equality law* (Schiek and Chege, 2009) have laid the foundation. Intersections between gender and disability are briefly examined below.

As for international law, EU law is slowly opening to the new idea of multiple discrimination. The European Union (EU) has had a constantly growing branch of equality law. It started in the 1950s and has developed considerably with the addition of a new article 13 TEC in the Amsterdam Treaty in 1997, now 19 TFEU. Since then, the focus on discrimination has been constant. Article 21 and 26 of the EU's Charter of Fundamental Rights prohibits discrimination on the ground of disability and recognises the right of disabled people to integration. Many directives, communications, actions, strategies and programmes have been adopted both in the field of gender discrimination as well as in that of disability[22]. Here again, discrimination based on the intersection of disability and gender can be identified by a gender-sensitive look at disability on the one hand, and where disability has different effects on men and women on the other hand.

2.2.2. Disability legislation

Legislation on disability is booming in the EU. Multiple initiatives have been counted. On 23 December 2010, the EU ratified the above-mentioned CRPD, becoming the first intergovernmental organization to join a United Nations human rights treaty and making it an integral part of EU law since 2011[23] despite some reservations[24]. It has not concluded the optional Protocol, but such a commitment is recommended by the European Economic and Social Committee (EESC) in order to ensure full enjoyment of the CRPD by Europeans with disabilities[25]. The first report on the implementation of the CRPD has to be put forward by the Commission in 2013[26].

The CRPD is an agreement, which, after ratification, binds each Member State as well as the European Union as far as the competences of the Union are concerned. Consequently, there should be no discrepancies between the existing EU law and the CRPD[27]. There are thus areas of mutual interest for the EU and international law such as accessibility, legal capacity, access to justice, independent living adequate standard of living, voting rights, monitoring mechanisms and empowering of persons with disabilities.
More interesting is the fact that CRPD includes obligations that require legislative and policy changes at EU and Member State levels[28]. This requires a further study on each Member

[22] Amsterdam Treaty (Article 13 TEC), Lisbon Treaty (Article 10 TFEU, CFR), Charter of fundamental rights (Article 21 – non-discrimination, Article 26 – social integration). Disability Strategy 1996, Disability Action Plan 2003, EU Disability Strategy 2010-2020, Article 13 (now Art 19 TFEU), Directive 2000/78/EC on employment and occupation. Proposal for a directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, including the discrimination-free access to goods and services (COM(2008)426) and the corresponding resolution of the European Parliament P6_TA(2009)0211, http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P6-TA-2009-0211&language=EN&ring=A6-2009-0149.
[23] Article 44 CRPD, Article 218 TFEU. See ECJ, *IATA v Department for Transport*, 2006, ECJ, *Kadi and Al Barakaat*, 2008 and ECJ, *International Foundation v Council of the EU*, 2008.
[24] Article 27 CRPD, armed forces.
[25] Point 1.1 of Opinion of the European Economic and Social Committee on 'The Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC' (own-initiative opinion) (2013/C 44/05).
[26] Disability High Level Group (2008), Beyond EU competence Co-operation of 'added value', 1st report.
[27] Disability High Level Group (2008), Beyond EU competence Co-operation of 'added value', 1st report.
[28] Point 1.3 of Opinion of the European Economic and Social Committee on 'The Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC' (own-initiative opinion) (2013/C 44/05).

State's state of law and regarding disability. In the light of our study, it is an opportunity to tackle discrimination on grounds of disability and gender.

Plans are made to set up an independent framework to promote, protect and monitor the implementation of the CRPD, meaning for the Commission to make an ambitious legislative proposal for a European Accessibility Act with the broadest possible scope, which includes requirements for public and private service providers and manufacturers to provide full accessibility for persons with disabilities, as well as with a clear and extensive definition of accessibility.

Art 5 of Directive 2000/78 provides for a reasonable accommodation for disabled persons. "This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer. This burden shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned".

2.2.3. Case law on disability

Reasonable accommodation has started to be implemented in the case law. In a *HK Danmark* case[29], the Court applied the CRPD as well as Directive 2000/78 and protected the rights of a disabled employee who had been dismissed because of the length of his absences caused by his disability. The Court identified an obligation to provide accommodation, for instance a part-time work and focused on the length of the period of notice.

In this case, the Court chose to give a broad interpretation of the definition of disability. It judged that the concept of 'disability' must be interpreted as including a condition caused by an illness medically diagnosed as curable or incurable, if that illness "entails a limitation which results in particular from physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers, and the limitation is a long-term one".

In the line of the Chacon Navas case[30], the Court observes that, contrary to the arguments of the employers in the two cases, the concept of 'disability' does not necessarily imply complete exclusion from work or professional life. In addition, it adds that a finding that there is a disability does not depend on the nature of the accommodation measures to be taken by the employer, such as the use of special equipment[31]. One can see that disability is more and more framed by the Court.

[29] Judgment in joined cases C-335/11, C-337/11 - HK Danmark, acting on behalf of Jette Ring v Dansk Almennyttigt Boligselskab DAB and HK Danmark acting on behalf of di Lone Skouboe Werge v Pro Display.
[30] Case C-13/05 Sonia Chacón Navas v Eurest Colectividades SA.
[31] Judgment in Joined Cases C-335/11 and C-337/11, Ring and Skouboe Werge.

2.2.4. Disability Strategy 2010-2020

The most important tool at EU level at this stage is the European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe[32]. This text identifies eight priority areas: Accessibility, Participation and Equality are all devoted to a common targeted approach of the disabled. Then, the Commission focuses on five fields in which these general principles can find specific applications: Employment, Education and Training, Social protection, Health, and External action of the EU. In this text, no special action aims at women, they are only tackled together with men and children[33]. The EESC drafted an opinion on its own initiative[34] on 26 April 2012. It calls on a thorough and participatory review of the implementation of the Disability strategy[35], a dedicated budget and an independent framework. The ombudsman also seems to be sensitive to disability issues[36].

2.2.5. Progress in disability legislation disregards women

Beyond this, several initiatives show the will to tackle disability[37]. One can thus identify a movement and a reflexion towards framing disability. Concretely, the changes to be brought to the EU legal order[38] are numerous. They include "areas of exclusive competence such as the compatibility of State aid with the common market and the Common Custom Tariff. Areas of shared competence include actions to combat discrimination on the ground of disability, free movement of goods, persons, services and capital, agriculture, transport by rail, road, sea and air, taxation, the internal market, equal pay for work of equal value of male and female workers, trans-European network policy and statistics"[39] or a new proposal for a Directive for web accessibility[40].

Unfortunately, they do not necessarily take into account multiple discriminations or the special situation of women. For instance, in the EESC report, it is noted that the CRPD includes provisions on equality and non-discrimination and specifically on mainstreaming of women's and children's needs into disability policies. However, this is hidden in a whole

[32] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions – European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe

[33] See for instance, p. 5 and 8 of European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe COM (2010) 636

[34] Opinion of the European Economic and Social Committee on 'The Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC' (own-initiative opinion) (2013/C 44/05)

[35] See further, point 1.4 of Opinion of the European Economic and Social Committee on 'The Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC' (own-initiative opinion) (2013/C 44/05).

[36] Interview with the European Ombudsman, 25/04/2013.

[37] the Digital Agenda of legislation on the accessibility of public websites and websites delivering basic services to the public or an adaptation of several EU regulations such as the Structural Fund regulations, the Connecting Europe Facility and TEN-T regulations and in Horizon 2020, the Rights and Citizenship programme, and the programmes in the area of development cooperation and humanitarian assistance are considered. The European Pact for Mental Health and Well-being is a missed opportunity to tackle women's situation. It focuses on children and old-age as well as the workplace, but it did not focus on gender differences.

[38] By EU legal order, lawyers refer to the originality of the EU norms and to the fact that, by establishing the Union, the Member States have limited their legislative sovereignty and in so doing have created a self-sufficient body of law that is binding on them, their citizens and their courts. See for instance http://eur-lex.europa.eu/en/editorial/abc_c05_r1.htm.

[39] Opinion of the European Economic and Social Committee on 'The Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC' (own-initiative opinion) (2013/C 44/05)

[39] See further, point 1.4 of Opinion of the European Economic and Social Committee on 'The Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC' (own-initiative opinion) (2013/C 44/05).

paragraph focusing also on "accessibility, liberty of movement and nationality, access to justice, freedom from violence, independent living and life in the community, right to family life, personal mobility, education, employment, health, social protection, international cooperation, civil protection, amongst others, as well as the participation of persons with disabilities through their representative organisations in decision-making processes"[41].

Finally, the legislative package on victims' rights is a general improvement on citizens' and people's rights, but it does not specifically focus on disabled women[42]. This adds to the EU addressing increasingly specific groups of victims. For instance, it has started to establish protection and support for victims of human trafficking and child victims of sexual exploitation[43]. Furthermore, it funds projects including some combating violence against women[44], but again not specifically actions for disabled women. Legislation or other measures in favour of disabled women are yet to receive the attention they deserve.

2.2.6. Women's rights

Even if the Convention on the Rights of the Child and the Convention on the Elimination of Discrimination against Women (CEDAW) has not been open for ratification to the EU, it remains that discrimination against women has been the first topic to be pushed forward by the European institutions during the 70s in relation to anti-discrimination policies. Since then, equality between men and women has been recognised as a fundamental principle that is enshrined in the EU Charter of Fundamental Rights and Article 3 TEU. The Fundamental Rights Agency (FRA) and the European Institute for Gender Equality (EIGE) display numerous programs on their websites[45].

More specifically, the general Directive 2000/78 ensures equality on diverse grounds including disability and sex in the field of labour and employment. Directive 2004/113 expanded the scope of sex discrimination outside labour and employment to the area of goods and services but only for gender equality. It guarantees equal treatment in relation to social security (but not to the broader welfare system). It is interesting to note that this last Directive focuses on special risks concerning women such as pregnancy and maternity, but also in terms of insurance of these risks (point 19 of preamble) but it does not take disability into account. The case law is also very developed and dozens of cases appear each year in front of the European Court of Justice[46]. One cannot count anymore the number of studies devoted to gender equality. These acts and programs tend not to take into account disability.

2.2.7. Policy developments regarding multiple discrimination

The objectives of policies addressing discrimination on the grounds of disability and gender are horizontal, which means that they are able to be included in all other actions of the

[40] 2012/0340(COD) - 03/12/2012 Legislative proposal.
[41] According to the EESC, ibid.
[42] Communication presenting the Commission's current and future action in relation to victims, 2011, COM (2011) 274, http://ec.europa.eu/justice/policies/criminal/victims/docs/com_2011_274_en.pdf; Directive 2004/80 relating to compensation to crime victims and Directive 2012/29 on minimum standards on the rights, support and protection of victims of crime ; Proposed Regulation on mutual recognition of protection measures in civil matters, http://ec.europa.eu/justice/policies/criminal/victims/docs/com_2011_276_en.pdf.
[43] See the stockholm programme — an open and secure Europe serving and protecting citizens, (2010/C 115/01).
[44] See for instance the Daphne programme, http://ec.europa.eu/justice/criminal/programme/daphne-programme/index_en.htm.
[45] http://fra.europa.eu/en/theme/gender
[46] For instance, recently, Opinion in case C-5/12 - Marc Betriu Montull v Instituto Nacional de la Seguridad Social (INSS). Or the already very famous Test-achat case.

EU[47]. Crossing the two subjects is an emerging idea. The EU Parliament has been sensitive to the situation of disabled woman for a long time[48]. The trend is becoming visible and some EU projects have focused on multiple discrimination. EU anti-discrimination law recognises these issues. Recital 14 of Directive 2000/43, for instance, states that "In implementing the principle of equal treatment irrespective of racial or ethnic origin, the Community should, in accordance with Article 3(2) of the EC Treaty, aim to eliminate inequalities, and to promote equality between men and women, especially since women are often the victims of multiple discrimination"[49].
In 2007, the European Commission published a report on "Tackling multiple discrimination: Practices, policies, laws"[50], with the aim of determining 'workable solutions to combat the existence of Multiple Discrimination'. The report highlights the difficulties in applying the concept of multiple discrimination to policies and law. Legal practice does, according to the report, not sufficiently take into account experiences of multiple discrimination by individuals. The Commission report also reveals a general lack of relevant research and data in this field.

A study was published by the Commission in 2007 on "The Situation of Women with Disabilities in the framework of the European Year of Equal Opportunities for All and in view of the CPRD[51]. More recently, in 2011, the European Disability Forum presented a 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union and in 2012, USAID put forward the report "Women with Disabilities in Europe and the Eurasia Region".

Another comparative study is also expected from Policy Department C: Citizens' Rights and Constitutional Affairs of the European Parliament in 2013 on Member States Policies for Children with Disabilities which should include a gender perspective.

This brief overview shows that EU law is not reflecting a policy development, yet, regarding multiple discrimination but an interest in this field is growing.

2.3. Member States' Law

The diversity of the laws on multiple discrimination of the Member States has been studied by A. Krizsan, H. Skjeie and J. Squires (2012). This table provides for the most important findings.

[47] See for instance, point 4.12 of Opinion of the European Economic and Social Committee on 'The Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC' (own-initiative opinion) (2013/C 44/05).
[48] See Resolution on the social situation of handicapped women and women who look after the handicapped, *OJ C 158, 26.6.1989, p. 383.*
[49] See for instance the EU Parliament resolution of European Parliament resolution of 25 October 2011 on mobility and inclusion of people with disabilities and the European Disability Strategy 2010-2020 (2010/2272(INI)) to the Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, COM/2008/0426 final, which calls for "full integration of people with disabilities in society but takes the view that more should be done".
[50] http://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=51&type=2&furtherPubs=no.
[51] VC/2007/317.

Figure 1: Table of key findings on the diversity of Member States' Law

Country	Protection against intersectional discrimination
Scandinavia	Even though Nordic countries are famous for their fight against discrimination, they have been heavily criticized for their one-dimensional focus of targeting discrimination.
UK	The law is evolving from a system focused on race and gender towards a more clearly-defined multiple equality framework. However, multiple discrimination currently has no remedy under UK law.
France and Germany	Both countries have tried to promote gender equality. Anti-discrimination regimes have been put in place. They integrate multiple strands under a common Equality policy, but intersectional discriminations are not well understood. Significant barriers remain.
Italy, Spain and Portugal	Although a multiple inequalities agenda is beginning to blossom under the impetus of the EU anti-discrimination policy, this does not mean that truly integrated approaches have been implemented so far.
Eastern Europe	Shift from the absence of equality policies towards an emerging recognition of equality.

Source: A. Krizsan, H. Skjeie and J. Squires (2012)

2.4. Intersectionality as a concept and an approach to policy

Disabled women's claims have not been expressed by either the disability or the feminist movements. Yet, they have common themes such as their emphasis on the public/private division, their view that "the personal" is "political", and the experience of multifarious oppression.

2.4.1. The theory of intersectionality

The disadvantage of women with disabilities lies at the interface of various social divisions, mainly gender and disability but also poverty, race, class or sexuality. All these factors in conjunction with the fact that disabled women are not a uniform category since every disability is unique, call for the need of a conceptual tool that can address them all. Intersectionality lends itself to such types of analysis.

Intersectionality can be **structural**, when it refers to inequalities which people experience as a result of their position in society, for example the unequal position of disabled women in the labour market. When intersectionality is used to indicate how intersections of inequalities refer to political strategies, the term **political intersectionality** is used (Crenshaw 1989). An example of political intersectionality is the way feminism can marginalise disabled women, when their claims are omitted from the feminist political agenda.

Intersectionality in policy denotes interaction of mutually constitutive inequalities producing an effect which is different from what each of their dimensions would produce separately, and also different from the addition of their separate parts together. When an intersectional approach is adopted, this should be done in combination with focusing on the effects of

each dimension separately, so that the effects of single policy measures can be assessed in their entirety.
There are many dimensions differentiating inequalities between social categories and these inequalities are not independent; they are influenced by political, historical, social and cultural intersections (Verloo 2006), which shape individual and collective experiences (Thiara, Hague and Mullender 2011). An intersectionality approach argues that forms of oppression (e.g. racism, sexism, disablism) overlap, defining unique social groups, and thus posits that the consequences of disability, race/ethnicity and gender cannot be understood sufficiently by studying these phenomena separately; their overall effects need to be examined by looking into how disability, gender and race/ethnicity structurally interrelate to establish access to resources (both material and relational) or lead to risks for the groups in question.

Dealing with multiple inequalities which cannot be separated and are interacting simultaneously, namely with intersectional discrimination, can be a challenging task, especially if 'equality mainstreaming' is attempted. According to Verloo (2006), this cannot simply be an extrapolation of gender mainstreaming but would require new and more comprehensive analytical methods. The fact that gender mainstreaming exists could be used to develop a comprehensive mainstreaming, such as race and ethnicity mainstreaming, sexuality mainstreaming or in our case disability mainstreaming.

Some parameters to consider in intersectional analysis are that social divisions are about macro-axes of social power but have also organisational, experiential and representational forms. They involve real people and affective relationships. Social divisions also exist in the ways people experience their daily life and in their attitudes, ideologies and communities (Yuval-Davis 2006). They are not all about power but also cultural, about dominant discourses and ideas regarding representations of the body, or theories about 'normality'. All these contribute to the way disabled women experience their disability.

2.4.2. Intersectionality as a tool for policy-makers

Given that disabled women are at the intersections of gender, disability and many other inequalities, the **criteria for the evaluation of the quality of a given policy** suggested by Lombardo and Rolandsen-Agustín (2011) seem to constitute a useful tool for policy-makers. These are:

- *Is the policy **explicit** about inequalities and does it create **visibility*** of certain inequalities in the sense that naming a problem makes it visible;

- *Does the policy foster **social inclusion** of people who are being discriminated against on the basis of different grounds;*

- *Is the policy **gendered**, i.e. is gender equality one of the aims of the policy and is there an explicit reference to how men and women are each concerned by the policy; or* is the policy ***de-gendered**, i.e. differences between men and women are not tackled by the policy;*

- *Does the policy reflect the method of **intersectionality**, i.e. are the different inequalities experienced by disabled women and the way in which they influence their living conditions thoroughly examined? And is it possible to make predictions as to the degree the policy will address their concerns?*

- *Is the policy built on **structural understanding of inequality** and does the deep understanding of the structure of inequalities lead to a **transformative approach** through the method of intersectionality with the aim to transform the structure through the policy;*

- ***Does the policy avoid stigmatisation** of specific groups while challenging the privileges of others; and finally,*

- *Does the policy-making process include **consultation with civil society** aiming at the representation of all groups in the consultation phase?*

2.5. Conclusion

⇒ *More emphasis on each dimension for valid conclusions*

The EU policy has been characterised by implicit references to intersectional discrimination without particular attention to each dimension. No stigmatisation of groups takes place but also no articulation of the structural inequalities and effects of policies favouring certain groups at the expense of others. Therefore each equality category should also be considered as a lens through which policies are viewed. New elaborate methodological tools are required to analyse intersectionality. An intersectional perspective constitutes a departure from binary or unitary thinking toward a more global human rights perspective, which allows for international comparisons with emphasis on links and interaction (Emmett and Alant 2007). When studying discriminatory policy effects on disabled women in a specific social context, any non-intersectional approach not taking into account the intersections of disability, gender and poverty would lead to invalid conclusions.

3. PARTICIPATION

KEY FINDINGS

- Participation in social and political life depends on access to fundamental social structures such as employment, education, health care and free enjoyment of basic human rights, such as the right to sexuality and reproduction and freedom from institutional and domestic violence.
- An intersectional approach in the context of employment would look into ways in which different positions in terms of gender and disability create conditions of differential access to resources and can be translated into unequal representation of disabled women in the labour market, pay differentials, segregation in lower-paid jobs, and all the composite effects of women's labour market disadvantage enhanced by the addition of the disability parameter. Negative stereotyping affects the daily life of disabled employees, while quota systems, training programmes, and workplace accommodations are relevant dimensions of a non-discriminatory employment agenda.
- Education as an experience is to a great extent conditioned by the type of disability. Since the 1970s developed countries have introduced educational policies aiming at integrating children with disabilities into mainstream education. Still, mainstreaming has not taken place with respect to vocational training, while austerity and cuts in public spending are expected to affect particularly girls with disabilities. Intersectionality in education lies in the interaction of factors such as gender, disability, low economic status or race/ethnicity, which restrict access to education and later on to the labour market and perpetuate inequalities at the expense of disabled women.
- Disabled people are more frequent users of healthcare services, as some forms of impairment require regular medical monitoring. Women with disabilities are more vulnerable to receive services of lower quality, particularly those with learning disabilities. Consequently, policy intervention should focus on the removal of barriers to quality, accessible and affordable services for women with disabilities and on their relationship with health professionals.
- Reproductive rights are often not granted to disabled women, while practices such as forced sterilisation, or forced abortion are imposed on them. Ensuring disabled women's protection is a clear priority. Counselling must be given to women and girls with disabilities on their sexual and reproductive rights, so that they can make an informed decision.
- Women with disabilities are at a high risk of violence, both of 'traditional' forms (physical, sexual, emotional) and particular forms related to their disability (withholding medication, denying access to mobility or communication equipment, obstructing personal care and hygiene, or blocking access to medical consultation). Barriers to seeking help in situation of abuse include increased dependence (physical, emotional, financial) on the perpetrator, lack of information and difficulties in accessing relevant services, fear of institutionalisation, comprehension and reactions by police or other professionals

3.1. Between social citizenship and disabled women's rights recognition

3.1.1. The theory of Social Citizenship

Social citizenship as developed initially by Marshall (1992) is distinguished from political and civil citizenship and is defined as 'the whole range from the right to a modicum of economic welfare and security to the right to share to the full heritage and to live the life of a civilised being according to the standards prevailing in the society' (Marshall, 1992, p. 8). This definition has been given two interpretations, a passive and an active one. The passive one lies in granting social rights – unemployment, access to health care, protection against social risks (old age, sickness, etc.) to all citizens. The point is to achieve substantial social equality beyond a formal legal equality[52]. Social rights give a feeling of security, of belonging and a will to participate to the political community. This is where the active aspect of social citizenship lies, namely in participation to economic and social life. According to Marshall, it is **facilitated by education and employment.**

It has then been said that this theory did not take into account other social protection systems outside the UK in the 1950s and, more importantly for the purpose of this project, it did not account for minorities' rights. But this theory can be applied on different levels and include smaller social groups (Marzo, 2009).

Other approaches suggest that the study of social rights and social citizenship should combine the power resources approach with feminist approaches (Orloff, 1993). Among power resources (capacities that actors have to further their interests) some are seen as basic, in the sense that they provide capacities to punish or reward other actors and that they enable the generation of other power resources; the three main types are means of violence, economic resources and labour power. Legislated social rights are taken to be rights enabling citizens to make claims to publicly provided (outside market mechanisms) goods and services (Korpi, 1994).

3.1.2. Challenging the notion of social citizenship to include women with disabilities

In the 1990s feminist work questioned the notion of a single model of citizenship. It focused specifically on social citizenship, which it regarded as problematic because it was based on a working individual. Consequently 'significant aspects of income maintenance payments by the state, pensions, and related welfare are provided as a result of waged employment. Those who do not make provision via employment can fall back on only very meagre levels of support' (Walby, 1994, p.386). Such cases might be women with disabilities outside the labour market. Citizenship cannot be understood without a dynamic theory of gender relations. Walby proposes an **alternative approach to citizenship**, in which the differential access of inhabitants of a given territory to civil, political and social citizenship is a key feature (Davaki, 2001):

Countries are differentiated with regard to whether different groups (white men, white women, minority ethnic groups) gained citizenship at the same time or not. Besides, the structuring of the private and public spheres is crucial for the citizenship status of women:

[52] These theories being very much in link with the equality theories.

'Citizenship…has historically been bound with participation in the public sphere. European women have historically been structured out of the public by the restrictions on their paid employment…and their confinement to domestic duties…**It has only been by leaving the private sphere of the home that women have been able to gain some aspects of citizenship'** (Walby 1994, p.385).

3.1.3. Access to the policy process as an indicator for citizenship

The feminist critique of citizenship addresses the issue of broadening the political space (e.g. to include bureaucracies, or social movements) in order to achieve gender balance. It is important to consider institutional structures and the cross-national and historical variations in how relevant these structures are. The extent to which women can influence the policy process through connections with political parties, trade unions and through the feminist movement is considered equally significant (O'Connor, 1993).

This approach can be transposed to disabled women as a similar analysis of disabled women's rights can be made. Their degree of participation to **political citizenship** (right to vote and be elected), **civil citizenship** (inter alia, right to access justice) and **social citizenship** (right to adhere to trade unions, associations, or right to benefits) will be evaluated through civil society channels.

3.1.4. Focus

Accordingly, this chapter on participation is of particular interest as it will combine the policy aspect which involves a study of the relevance of intersectional discrimination as an obstacle to full enjoyment and exercise of social citizenship rights with the two other aspects of citizenship, namely civil citizenship and political citizenship.

A brief overview of societal attitudes towards the **right to vote of women with disabilities** and the degree to which policies reflect, but also shape, attitudes will also be included.

From a legal point of view, questions of political representation will be touched upon (some secondary data as an indication of exclusion of women with disabilities) and reference will be made to legislation with an explicit framework on **participation** of disabled women in EU Member States and beyond in order to draw conclusions as to best enforcement.

3.2. The legal context of participation

3.2.1. EU level

The definition of disabled people given by the European Economic and Social Committee - "Persons with disabilities include those who have long- term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective **participation** in society on an equal basis with others[53]"- shows that participation is at the heart of the fight against disability.

[53] Definition given by the Fundamental Rights Agency, http://fra.europa.eu/en/theme/people-disabilities [11/04/13] and Point 2.1 of Opinion of the European Economic and Social Committee on 'The Implementation and

The EU identifies two tools to promote participation: **funding and capacity building**[54]. But again, no law or policy focuses on disabled women participation. The EU and the Member States have made some attempts to tackle some specific needs of disabled women in very limited cases through general Disability policies and acts or through acts against gender discrimination.

Since there is no explicit legal framework tackling participation of disabled women or in other words intersectional discrimination on grounds of gender and disability, this section on legal aspects is short.

As has been shown above, the gender dimension could have been sometimes integrated in a disability act. Similarly, the disability dimension could have been sometimes integrated in an act on gender equality. But mostly, it is not the case and legislations do not allow targeting multiple discriminations.

On EU level, there is no relevant example in its legislation and policies. The European Disability Strategy[55] dedicates a whole chapter to participation ensuring that people with disabilities enjoy all benefits of EU citizenship. For its realisation, all barriers to equal participation in public life and leisure activities should be removed and the provision of quality community-based services be promoted. Besides, the chapters devoted to **employment, education and training, social protection and health are also considered being relevant to participation** as their goals are to promote the opening of these fields to the disabled. In this text, though, no legislative framework targets specifically disabled women's participation.

The exploratory opinion of the European Economic and Social Committee devoted to *Young persons with disabilities: employment, inclusion and participation in society*[56] could constitute an interesting example of how to tackle and specify multiple discrimination on grounds of gender and disability. It focuses specifically on the needs of young people, thus considering their situation in schools, universities, or their entrance to the labour market, etc. It could be a good example of how to approach the situation of disabled women in relation to participation by taking into account their specific needs. For instance, special attention could be devoted to their participation in different fields such as the labour market, politics or healthcare[57].

3.2.2. Member States level

In France, there is no relevant legislation. Participation of persons with disabilities is promoted by an Act of 2005 about disability and citizenship. Again, in this text, there is no specific target on women. This Act of 2005 is very symptomatic: it only focuses on women where Article L. 3322-2 of the Public Health Code[58] is completed by a paragraph providing

monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC' (own-initiative opinion) (2013/C 44/05).

[54] See the opinion of the European Economic and Social Committee on 'The Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC' (own-initiative opinion) (2013/C 44/05).

[55] European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe COM (2010) 636.

[56] 2012/C 181/02.

[57] See on this topic, p. 4 of annex of report on inequalities and multiple discriminations in healthcare, February 2012, http://fra.europa.eu/en/publication/2013/inequalities-discrimination-healthcare (accessed on 11/4/13)

[58] Code de la santé publique.

for the drafting of a message on all alcoholic drinks indicating to pregnant women not to drink alcohol[59].
In the UK, the earliest anti-discrimination laws in Britain flattened identity and simplified reality in order to arrive at a workable logic that could be both understood by the public and applied by the courts" (Solanke, 2011). Nowadays, the Equality Act 2010 sought to introduce the concept of multiple discrimination into legislation but failed to deliver on its objectives (Solanke, 2011).

3.3. The policy context of participation

According to the most recent data available from 59 countries in 2004, 19.2% of women over 18 years of age were disabled and experienced significant difficulty in everyday life, whilst 2.7% were experiencing very significant difficulties (WHO 2011). Disabled women and children are particularly vulnerable to discriminatory practices and face multiple discrimination (Human Rights Watch 2012).

As previously said, disability as a condition operates alongside other forms of oppression, linked to class, race, gender, sexuality, and other discrimination grounds. Attempts to conceptualise such dynamics often resort to oversimplified notions, such as 'double discrimination', which are of limited utility, as they generalise experiences. Disabled women are discriminated against and disadvantaged on the basis of disability, gender, and possibly other grounds but these oppression mechanisms operate also in complex ways and lead to diverse experiences (Beigi and Cheng 2010). It is thus important to recognise both the **discrimination mechanisms** operating against disabled women, as well as their **experiences** and **reactions** to their situation (Nixon 2009).

The social model

The disabled people's movement has fought the marginalisation of the disabled and has promoted a 'social model', which conceptualises disability as a product of social and material environment and emphasises 'disablism', i.e. the discrimination against disabled people (Oliver 2009). In the social model, the impairment (e.g. deafness) is a given, but the disability (e.g. communication limitations resulting from deafness) occurs as a result of environmental factors that are seen as 'disabling' (e.g. lack of hearing loops) (Martin 2011).

Disability scholars thus see disability not as a condition grounded on biology, but rather as 'the embodied experience of social oppression constituted via the inhospitable social, cultural, and economic structures in mainstream society' (Erevelles 2011, p.181). The social model has, however, been criticised on the grounds that by emphasising disabling aspects of the environment it has transformed disability into a public issue and has created a **divide between public exposure and the private, lived experience of impairment**. As such, it has been suggested that the model needs to be replaced by one that is more nuanced.

[59] Loi n° 2005-102 du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées, JORF n°36 du 12 février 2005 page 2353, article 5: « Toutes les unités de conditionnement des boissons alcoolisées portent, dans les conditions fixées par arrêté du ministre chargé de la santé, un message à caractère sanitaire préconisant l'absence de consommation d'alcool par les femmes enceintes. »

The relational social model and the post-social model

The 'relational social model', for instance, retains social inequality, but prioritises lived experiences of disabled people in their interactions at personal and institutional levels (Nixon 2009). Likewise, the 'post-social model' builds upon the social model but stresses the sensitivity of **personal life experience**, which will be differentiated according to the different kinds of impairments and disabling conditions (Shakespeare 2006).

The ethic of care, often addressed with scepticism by feminists, is relevant in disability discussions from the point of view of the recipient of care and relevant issues of autonomy that lie therein. As autonomy is taken to include freedom from coercion and the capacity for making independent decisions based on a concept of a 'normal body', disability and autonomy have traditionally been seen as opposites in Western ethical theory. Feminist theory has proposed a definition of autonomy as 'a social competency that is not learned in isolation but through relationships with others' (Erevelles 2011, p.178). This re-conceptualisation of autonomy can be useful for **redefining disabled people as autonomous agents**, particularly in cases where disability is not severe.

Diversity

Diversity is another notion prevalent in the politics of the EU and is seen as a discourse for perceiving and interpreting human society, diffused through institutional practices and political frameworks. Diversity can be seen as deriving from concepts such as multiculturalism and interculturalism, which organise the living together in contemporary Europe. Having expanded beyond emphasis on culture, however, it has opened up possibilities for articulation of identities and needs of different kinds and creates a discursive space where minority identities and practices are accommodated (Lentin and Titley 2008).

It is perhaps commonplace to state that historically attitudes towards people with disabilities have been negative and have resulted in marginalisation and oppression (Chenoweth 1996). Additionally, degrees of prejudice vary according to the type of impairment involved. It is important for policy-makers to consider what it means to speak of diversity today and what the relationship is between the **discourses of diversity and social cohesion or integration**.

3.3.1. Accessibility: a cross-cutting factor of participation

Full participation in the social and political life of a community depends on the access citizens are given to fundamental social structures such as education, healthcare, political participation, employment, entertainment, communication and civic engagement. The barriers to full citizenship can be both legal and practical. The European legal framework provides for the equality of all citizens and has enshrined non-discrimination in its treaties. However practices and structures of exclusion take many forms and disabled people are still largely excluded *de facto* from socio-political activities in everyday life.

Creating enabling environments is hence at the core of fostering a non-discriminatory context for equal participation of all citizens in the social and political life of the community. Accessibility can be broadly defined in three ways:

a) Freedom of movement: In the context of the European Union, it is the right of all citizens to work, live, study and establish themselves in another EU Member State.

The implications of this concept for disabled citizens are addressed in a report by the European Disability Forum of December 2011 and are at the core of the European Accessibility Act, (due to be published in summer 2013). If infrastructures are put in place at the national level, free movement could become a reality for persons with disabilities.

b) Access to public spaces, products and services.

c) Access to information (physical, intellectual and social, see below). This dimension is particularly important as "information is power, and a healthy democracy must guarantee access to this information and power equally for all its citizens" (Hawthorne, Denge and Coombs 1997).

Access to public spaces, products and services as well as to information are at the core of enabling environments, as defined by a landmark report on disability published by the World Health Organisation (WHO) and the World Bank (WB) in 2011, as well as by reports written by civil society organisations such as the European Disability Forum. To this end, policies should incorporate **as broad a definition of accessibility as possible** to account for the variety in disabilities and specific needs, including the growing number of older people with impairments. They should also promote access on the three levels as defined by Paul T. Jaeger (2012):

a) Physical access: defined as the ability to reach something, whether material or immaterial. There is a policy bias towards this form of access, which is the most basic and familiar of all three. This dimension has been most integrated in policies, although there remains work to be done on integrating less common and/or visible forms of disabilities in accessibility policies.

Participation depends in the first place from physical access to public buildings, roads and other infrastructures. However, the lack of physical access is frequently cited as the **first hurdle to participation** of women with disabilities (Loprest and Maag 2001, Gonzales et al 2006, Leonardi et al 2009) while its solution is considered beneficial for the participation in civic, political and social life (WHO 2011, 170). This level of accessibility is quite well understood and mainstreamed. Detailed recommendations to increase physical access for persons with disabilities are also presented in the same report. (2011)

'Universal design'

Experts take the view that the EU could make a difference with a **systematic regulation of accessibility**. Regulation can be achieved through European standardisation bodies such as CEN and Cenelec, which "make an important contribution to establish *de facto* harmonised European standards for products which, once complied with, give full access to the internal market" (Waddington 2009, 576). Waddington concludes in her article that Community law has, to a limited extent, the power to **establish "mandatory Community-wide disability requirements"** (597) and impose restrictions on the free-movement of goods and services that do not respond to regulations on equal accessibility. European standardisation bodies therefore have a significant role to play in developing technical standards that must be applied across goods and services circulating in the EU, which in turn will put pressure on national markets to adapt to new requirements.

The key to durable success, however, lies beyond law and regulation: policies targeting accessibility of social and political structures for people with disabilities should focus their effort on **fostering a culture of inclusiveness**. This is essential in ensuring that 'universal design' is mainstreamed in all areas of societies. 'Universal design' - also known as 'design for all' or 'inclusive design' - is "a process that increases usability, safety, health and social participation, through design and operation of environments, products and systems in response to the diversity of people with disabilities" (WHO 2011). Systematic inclusion of accessibility norms in the design of new products, buildings and services have the combined advantages of advancing human rights, reaching a larger amount of consumers, and making economies of scale. It is estimated that "in new construction, full compliance with all the requirements of accessibility standards is generally feasible at 1% of total cost" (WHO 2011, 173; Ratzka 1994; Steven Winter Associates 1993; Schroeder and Steinfield 1979), whereas adapting them at a later stage is much more costly and complicated.

b) Intellectual access: defined as the ability to understand information (Jaeger 2012, 28) after physical access has been obtained (Svenonious 2000). Intellectual access to information "entails equal opportunity to understand intellectual content and pathways to that content" (Jaeger and Bowman 2005, 68). Here, disabled women may have more limited access to information due to unequal access to education and unequal deployment of educational resources but also inequalities may be dependent on the form of disability (for instance lack of digital literacy for a deaf person does not have the same disabling effect it has on a person with motor neuron disease who is dependent on digital technology for communication).

c) Social access: The ability to communicate and use the information in social contexts (Burnett, Jaeger and Thompson 2008). It is crucial to participation as it fosters a sense of belonging for the people able to exchange information (Johnson 2010, Williamson and Roberts 2010).

The mechanisms for increasing intellectual and social access are less known. Therefore, **intellectual and social accessibility** should be an increased object of focus for policymakers. People with intellectual and mental health impairments are often faced with discrimination and excluded from electoral participation, for example (Redley 2008) while increased political participation of people with disabilities would likely result in progress towards disability-inclusive public policies. Intersectional discrimination against disabled women in this context lies at the intersection of gender (limited participation of women in the public sphere), disability (limited participation of disabled people), education, socio-economic status etc.

Accessibility through technology

The discussions around accessibility of information and computer technologies as a means to social and political participation of disabled people are an excellent illustration of the remaining gaps in current policies.

Major advances have been made over the last decades in terms of their social inclusion especially in technologically advanced societies. The **Internet** is regarded as a double-edged sword: it could generate previously impossible levels of accessibility and inclusion by giving persons with disabilities a way into the global economy, workforce and social sphere

through online education and voting, teleworking etc., whilst, in the meantime, it could increase their exclusion if it remains inaccessible (Jaeger 2012, 174-175). This may result in discrimination against disabled women on the basis of intersectionality of gender, disability, educational and socio-economic level, due to their lower representation in the labour market.

ICT-driven societies are very dynamic. Coupled with the fact that disability is itself non-static[60], expectations, needs and enabling technologies evolve quickly; it is therefore essential that accessibility measures be embedded in all policies, so that they evolve simultaneously. Jaeger outlines a precise strategy for policy-makers to ensure that information technologies are accessible to disabled persons and that companies develop "born-accessible technologies" (Jaeger 2012, 121) - i.e. **ICTs that embed accessibility features from the start**, instead of developing parallel, accessible versions at later stages. The development of such technologies would benefit non-disabled consumers and customers alike (WHO 2011; Ahtonen and Pardo 2013). As such, the public sector doesn't stand alone. Mainstreaming universal design also into ICT products is not only a human rights issue, but also makes sense from a business perspective. There is a **commercial interest** for businesses to develop solutions that can be used globally and by a larger proportion of consumers. It has been argued that there are big opportunities for the EU to cooperate with the United States in this area, especially in the domain of eAccessibility, as the US have already developed a large market for accessible products and services (see Ahtonen and Pardo 2013).

Access of all to the Internet and information and communication technologies (ICTs) has benefits throughout a person's lifetime. Organisations have looked at the benefits at different stages of a disabled person's life. UNESCO has devoted a lot of attention to the **empowerment of people with disabilities through access to ICTs** in the field of education[6162]. A more recent report published in February 2013 expands on UNESCO's previous work and outlines high-level policy recommendations for actions that address the "challenge of identifying 'disabilities' and producing policy interventions to meet the educational requirements of persons having special needs"[63]. Although these reports focus their attention on disabled people in developing countries, a number of lessons can be drawn in the European context.

Examples of tools and good practices for accessibility

Efforts at the local level could be used as pilot studies to test the efficiency of schemes that could consequently be implemented on a larger scale. Some initiatives have proven very successful. In the **UK**, the Government's Office for Disability Issues and the Local Government Association have developed a toolkit for producing better information for disabled people destined to local authorities. Pilot partnerships have been launched with councils across the country to work on the implementation of better information policies.

[60] Paul Jaeger notes that there are variations in the level of impairment of a disabled person on a day-to-day basis, and that it is the only minority one can join during life-time (Jaeger 2012, 15).
[61] Drawing on the Declarations of Principle of the World Summit of the Information Society according to which ICTs should be used at all stages of education, training and human resource development[61], a UNESCO expert meeting in 2011 emphasised the benefits of developing personalised learning for students with disabilities through e-learning platforms and ICTs as a means of social inclusion and lifelong learning and suggested practical solutions for implementation
[62] UNESCO (2011) Consultative Expert Meeting Report, "Accessible ICTs and personalised learning for students with disabilities" (17-18 November 2011)
[63] UNESCO Global Report (2013) "Opening New Avenues for Empowerment: ICTs to Access Information and Knowledge for Persons with Disabilities" (February 2013)

Another UK project aiming at providing better information for patients was initiated by the UK's National Health Service (NHS) in Lanarkshire[64]. The evidence so far is that this scheme has improved disabled people's level of understanding of the health care options offered at the hospital (Howieson and Clarke 2012, 25).

The aforementioned tools constitute positive achievements but they are for the moment only accessible to a fraction of the disabled population in Europe. **Mainstreaming policies** are needed to create an environment in which people with physical and intellectual impairments can express their full rights as citizens. Some promising policies are starting to emerge in the field of accessible technology and information, putting the concept of universal design into practice, and schemes are being developed at governmental level, such as the "Silver economy" scheme in **France**[65].

The need for equal access to infrastructure and information, in particular the Internet, is considered by many disability rights activists and scholars as "the most pressing civil rights issues that people with disabilities now face" (Jaeger 2011, 178). Much of the progression towards universal design and "born-inclusive technologies" (Jaeger 2011) depends on policymakers emphasising the importance of accessibility for all.

3.3.2. Employment

The concept of incapacity implies that some people are unable to work; however, a person's job prospects are not determined only by their personal attributes but also by the institutional and economic framework of employment relations. While the medical model of disability focuses on one's impairments, the social model stresses the constraints imposed on disabled people by social care provision, transport networks and employer practices, which create barriers to employment.

Exclusion of disabled people from the world of work was first flagged in the 1960s as contributing to their experiences of oppression due to their ensuing inability to enjoy the material and social benefits of modern society (Oliver 1990). However, data on employment rates over almost 30 years shows a **widening gap between the employment rates of disabled and non-disabled persons**; furthermore, once people with disabilities have lost their jobs, they have more difficulty to return to work (ILO 2010).

[64] Reacting to evidence that disabled people have poorer access to mainstream healthcare services than the general population (Disability Rights Commission 2006, Mencap 2007, UK Department of Health 2008, Parliamentary and Health Ombudsman 2009, Hanna et al 2011) and receive poorer standards of care when they access such services (Mencap 2007, Gibbs et al 2008, UK Department of Health 2008, Parliamentary and Health Ombudsman 2009, Emerson et al 2011, Mencap 2012), possibly because they are unaware of certain health programmes or because gaining their informed consent to perform health screenings on them may be difficult (Alborz et al 2003, 2005), nurses in NHS Lanarkshire led a project to develop a range of easily accessible information materials (booklets, DVDs). The main hurdle that they encountered were to combine this project with their other medical duties, and more importantly for the purpose of our study, some health staff did neither support nor understand the need for such a range of products.

[65] On 23 April 2013, the government of France announced the launch of a new scheme, the "Silver economy", in collaboration with industries, companies, insurances, economists, socio-medical professionals, associations etc. The scheme aims at developing a range of high technology products that are adapted to special needs. This initiative should have the combined benefit of allowing for disabled people's full participation in society, warranting them a higher degree of independence, and tapping into a consumer market with high purchasing power, thus creating over 300 000 new jobs by 2020. Some products have already started to be developed by the high-tech industry. The electrical industry Legrand has developed a Toshiba is for example developing "light path" to guide visually impaired elderly to find their way to the bathroom at night-time. Toshiba and Isidor, a start-up specialising in the development of simplified electronic interfaces, are developing a numeric pen that allows to quickly digitise handwritten text. This new policy could be an excellent opportunity to rethink universal design and foster a culture – both in public and private sectors – taking into account the varied needs of consumers (Thomas 2013).

However, statistical data regarding disabled women in employment are scarce. Interestingly, the international experience shows that women with disabilities are severely under-represented in the public sector.

Developments in the field of legislation such as the European anti-discrimination legislation or the 1995 Disability Discrimination Act (DDA) in the UK or the Americans with Disabilities Act (ADA), aim to prevent discrimination against disabled people. The UK DDA makes it unlawful to discriminate against people with disabilities with regard to employment and the provision of goods and services.

Negative stereotyping also affects daily life of employees with disabilities and leads to a number of unpleasant and unfavourable situations, e.g. unfair treatment regarding pay, promotion or training (overt discrimination), inappropriate interpersonal treatment (subtle discrimination) or a whole negative climate and adversarial workplace culture; all these lead to lower levels of job satisfaction among disabled employees (Anderson Snyder, Carmichael et al. 2010).

Domestic arrangements and distribution of tasks in households with people with disabilities range. A study in California of 59 households where women but not men were disabled demonstrated a fair division of labour; however, work/family balance for young disabled women is a significant challenge (Kirshbaum and Olkin 2002).

Moreover, the differentiation between those capable and those incapable of work is an oversimplification, as it rules out a wide range of conditions between, including a huge variety of impairments which affect people's working prospects in varying ways; last, but not least, it disregards other parameters such as family status and educational qualifications (Berthaud 2011). An **intersectional approach in the context of employment** would look into ways in which 'the interlinking grids of differential positionings' regarding gender and disability create in specific contexts 'hierarchies of differential access' to labour resources and overall diverse employment status (Yuval-Davis, 2006, p. 199). This can be translated into **unequal representation of disabled women** in the labour market, pay differentials, segregation in lower-paid jobs and all the composite effects of women's labour market disadvantage enhanced by the addition of the disability parameter.

Quota systems

Quota systems (voluntary or mandatory) are a regulatory approach for promoting employment of people with reduced opportunities to enter the labour market; they have been introduced as a measure to promote gender equality and also employment of people with disabilities. Italy has the highest mandatory provision of work to disabled people among the OECD countries (7%). Flat-rate quotas are becoming less common, and are increasingly varied according to size of the employer or the sector, as in Germany, Austria, or the Netherlands. A variant of the quota system is the quota-levy system, which allows employers to opt out of hiring people with disabilities by contributing to a special monetary fund (available in Hungary, Austria, Poland, Germany, the Czech Republic, Romania) (Kim 2011).

In accordance with the Equity of Germans with Disabilities Act of 2000, employers with 16 employees or more are obliged to have at least 6% severely disabled people in their workforce, or pay a compensatory levy. There are also quotas for women working in the public sector. France introduced a similar quota of 6% for disabled employees in 1987.

The effectiveness of quota systems and discrimination prohibition depends on political support, technological support, administrative capacities and organisational culture towards environments that are friendly for disabled employees. Discrimination prohibition does not seem to have had significant results, and it also suffers from problems in the interpretation of the law. Quotas systems seem to provide some results only in the short-term and need to be accompanied by strategies such as training and education to support workers with disabilities. For these reasons, many developed countries have chosen non-compulsory means combined with vocational training and rehabilitation (US, Canada, Denmark, Sweden and Finland). In many EU countries, including France, Germany and Spain, anti-discrimination legislation co-exists alongside quota systems. France introduced in 1990 legislation to protect employees against discrimination on the basis of health or disability. Britain suggests that every civil service department should have a diversity action plan, with some measurable performance. Germany allows employers to pay hiring charges for disabled workers by the degree of hiring and not a flat rate (Kim 2011).

It is worth noting that no quotas dedicated to disabled women have been introduced. Consequently, there can be cases of **disabled women may not benefit from either gender-based or disability-based quotas**, as employers may prefer able-bodied women or disabled men to fulfil their obligations. So, this can be seen as intersectional discrimination on the grounds of gender and disabilities.

Workplace accommodations

Workplace accommodations are part of the agenda supporting people with disabilities, including modified job schedules, provision of auxiliary aids, or physical changes in the workplace. Legislation, such as the DDA in the UK make such adjustments compulsory for employers, but legal requirements have been framed generally and not in relation to specific employees, while absence of financial incentives often result in employers avoiding hiring disabled personnel due to incurring costs, such as hiring and firing, or possible litigation and adjustment costs (Kim 2011, Bell and Heitmueller 2009). Research has shown that the DDA may increase costs for employment of disabled people, which might have reduced demand (Jones and Latrielle 2010) and led to lower employment numbers for the disabled in the post-DDA period. Even when financial incentives are available, employers are often ignorant or unwilling to take them up because of the conditions attached to them. Unless enforcement is in place (either through tribunals or through name and shame) legislation does not seem to have a positive impact on the employment rates of people with disabilities. **Positive action** is part of the legislative agendas in countries such as Spain, where the Act on the Social Integration of Disabled Persons of 1982 defines a number of forms of integration; however, 80% of Spanish firms do not fulfil the conditions (Lopez Gonzalez 2009).

Mainstream employment continues to perpetuate oppressive and marginalisation practices for disabled workers[66]. Programmatic and legislative mechanisms to generate employment

[66] As negative prejudice against disabled people is taken for granted, the degree to which this is related to discrimination in the labour market merits serious consideration. Based on data from the European Community Household Panel from 11 countries during the period 1995-2001, a recent study sought to disentangle the effect on wage differentials attributed to disability discrimination from the effect due to unobserved productivity differentials (linked also to disability). It identified three groups of workers: disabled persons hampered by their disabilities in their daily activity; disabled persons not hampered in their daily activities; and persons who were not disabled. The findings demonstrated that those not hampered usually earned the same wage as workers without disabilities; certain differences were observed, but they were not linked to discrimination, but rather to characteristics of jobs and the productivity of workers. However, regarding the first category, evidence of a wage differential based on discrimination was found, together with lower productivity levels (Malo and Pagan 2012).

opportunities have emphasised employability of individuals, rather than the **disabling character of workplaces** and the need to make mainstream work sites more accommodating. Alternative spaces which might help enable disabled women workers have been explored, such as union membership, which can give support and reduce feelings of precariousness; employment in the social economy, which operates more in accordance with rules emphasising accommodation; or voluntary and artistic work, as vehicles for incorporating excluded people, though in reality the share of disabled people participating is far lower than for non-disabled ones for reasons of access, income and negative attitudes. Certain grassroots organisations are committed to providing opportunities for the disabled (Hall and Wilton 2011).

Breaking stereotypes

Equal participation of disabled women in employment is seriously impeded by various stereotypes and prejudices. For instance when it comes to work performance of disabled women, as summarised by Lopez Gonzalez (2009): mobility limitations, including handling objects and machinery, poorer training and performance, problems in social relations, or higher rates of absenteeism.

Studies using in-depth and longitudinal ethnographic methods and following feminist principles have been limited, but important in breaking stereotypes. The study by Lopez Gonzalez (2009) on two generations of disabled women in **Spain** demonstrated that most of the participants obtained a paid job in their youth, then married, suggesting that they departed from the stereotype which would have anticipated denial of their work and marital ambitions. Furthermore, the participants valued work, not least for reasons of financial and emotional independence; saw themselves as part of a community and making a contribution; appreciated the importance of having responsibilities; welcomed the opportunity to break from their family into the outside world; took advantage of the chance to communicate with others and share feelings and experiences, as well as to learn, take risks and face challenges; valued social relationships, social integration and good working environment more than remuneration or promotion. This picture clearly proved opposite to stereotypes of disabled women seeking dependence or social isolation or exhibiting low motivation and productivity. On the contrary, participants affirmed high levels of productivity and motivation and low levels of absenteeism of disabled women, together with low costs of adapting the workplace for them.

Links between employment and identity are differentiated across disabled women: the younger ones tend to seek fulfilment through paid employment, while the older ones receive satisfaction for doing domestic work efficiently (Lopez Gonzalez 2009). While participation in productive work has often been championed as the main source of identity, more critical authors and activists have emphasised the need to break from this model, as it operates against those women and disabled people who either voluntarily or involuntarily do not participate in the labour market; they call for the **recognition of non-productive work**, including care work, which should be seen as contributing to social reproduction and they demand recognition of citizenship for all individuals.

Equal opportunities

Empowering disabled people with more rights might play a part in removing the stigma often attached to them and increase the chance that disability is reported (Bell and Heitmueller 2009). Self-reporting of disability in employment seems to be higher than the estimate provided by the employer. Employee-employer data from 2295 establishments in

the **UK** have shown that disability related-practices are important determinants of the relative earnings of disabled workers, with disabled workers earning more (ceteris paribus) in places where formal equal opportunities are practised (Jones and Latreille 2010). On the other hand, establishments which have made adjustments for disabled employees seem to be passing some of the cost to them.
The situation is likely to deteriorate in the current climate of austerity and special attention by policy-makers is required. Given the importance of **qualifications** in employability, discrimination against disabled women in the labour market is strongly related to education and opportunities, as well as to disability and their lower representation in forms of collective action, such as trade-unions and decision-making bodies. This means that their percentages among the unemployed will increase, while measures taken often do not include either goals of gender equality or promoting disabled women's employment.

3.3.3. Education

The right to education is fundamental, as education is a necessary condition for participation in socio-economic and cultural activities. In some countries the chance that a child with disability does not attend school are two to three times greater than those of an able-bodied child (Human Rights Watch 2012). Educational attainment is an important parameter in labour market outcomes of people with disabilities. People are either born with some impairment or acquire it later on in life. This makes a difference when educational attainment statistics are evaluated.

Research on people who experienced disability onset during childhood is notably limited. Generally speaking, people with childhood onset of disability have lower levels of formal education, and lower likelihood of completing high school. Moreover, they very often suffer **long-term stigmatisation** which can induce feelings of inadequacy, reduced aspirations, isolation, and various skills deficits. Stigmatisation, thus, has a profound impact on career development and vocational experience for such children and then youth. On the other hand, children with disabilities have fragmented education patterns, reduced hours or interruptions, or follow alternative schooling, which tends to be inferior in terms of outcomes compared to standard school. Due to limited education and vocational training these children begin their careers with limited understanding of workplace, lack of knowledge regarding opportunities and low efficacy in career success; as a result they are more in need of support of workplace accommodation (Moore, Konrad et al. 2011).

Education as an experience is to a great extent conditioned by the type of disability. A wheel-chair user's experience is totally different from that of a woman who is hard of hearing or from that of a woman with autism. Since the 1970s developed countries have introduced educational policies aiming at integrating children with disabilities into **mainstream education**. This has benefited children in developing skills, experiencing more social interaction with non-disabled classmates, developing a sense of community and belonging and achieving superior results compared to special education classes. Nevertheless, many countries have separate schools or separate classes for children with physical and intellectual disabilities (Human Rights Watch 2012). Furthermore, mainstreaming does not seem to have taken place with respect to vocational training, which serves more those who became disabled after having a considerable employment history. In addition, such youth have rarely been autonomous to **pursue a career**, though this seems to be gradually changing with increasing emphasis on self-determination and individual career goals (Moore, Konrad et al. 2011).

In a climate of austerity and reduction of public spending, girls with disabilities are going to be particularly vulnerable, as cuts may affect their benefits which enable them to have access to education, whereas rising unemployment and state supported-training programmes will be focusing on more mainstream and predominantly male occupations. Intersectionality here lies in the interaction of factors such as gender, disability, low economic status or race/ethnicity, which restrict access to education and later on to the labour market and perpetuate inequalities at the expense of disabled women.

3.3.4. Healthcare

Access to health care provision is a priority in any democracy and **one of the main aspects of social citizenship**. Disabled people are more frequent users of healthcare services, as some impairments require regular medical monitoring.

Inequalities in health are well-documented (Graham 2009; Anand 2012). Women with disabilities are more vulnerable to receive services of lower quality, particularly those with learning disabilities (Emerson and Baines 2011). Consequently, policy intervention should focus on the **removal of barriers** to quality, accessible and affordable services for women with disabilities and on their relationship with health professionals.

Better access of disabled women to health care requires among others removal of linguistic impediments stemming from **different cultural and ethnic backgrounds** (different definitions of health problems, perceptions of 'cure', reluctance to reveal mental health problems etc.). All these factors in addition to their usually low economic position and high cost of visits to specialists (when not free) intersect and produce or aggravate inequalities at the expense of disabled women.

In relation to health care, the CRPD mentions that people with disabilities are citizens with human rights, including the right to health care, the right to rehabilitation in the community and the right to have a say in their own treatment. The CRPD also takes into account different needs of men and women with disabilities and promotes that they can make their own choices, including in matters of fertility and medical procedures. Procedures have to be performed only after **authorisation** or they are regarded as cruel and inhuman, as Article 15 articulates. Article 25 demands that health services for disabled persons be gender-sensitive and provide the same quality and standard of free or affordable health care as those provided to non-disabled individuals. This translates into the necessity for health centres and primary care providers to have the appropriate equipment which would facilitate examination of people with mobility or other types of impairment (Human Rights Watch 2012). Non-accessible spaces (e.g. for provision of services or use of resources) are a significant part of the picture of abuse and violence, as they exclude women with disabilities from the mainstream health screening. Special equipment to facilitate routine gynaecological examination should be available in health centres in every area. Another factor which prevents disabled women from accessing health care can be **limited financial resources** (Barile 2002), so the intersection of disability and poverty is manifested.

The relationship of disabled people with medical and nursing professionals

The relationship of disabled people with medical professionals is worth focusing on. With the deployment of new technologies and scientific developments and in association with welfare state developments, the medical profession laying claims to expertise and authority has forged disability as a clinical concept. Moreover, the medical model of disability, now heavily criticised, has imposed a notion of medicalization of disability, professional

dominance of practitioners on the lives of people with impairments, as well as low prioritisation of clients in favour of acute medical practice. However, this model is flawed, as clinical objectivity is limited due to the fact that there is a lot of subjectivity involved in 'measuring' disability (Erevelles 2011).

Junior doctors seem to have more progressive attitudes, but they are often confronted by the more traditional agendas of their elderly colleagues. Prevention of discrimination and abuse of women with disabilities by healthcare professionals and non-discrimination in the ways in which genetics knowledge and technology is used in their individual cases will be more effective, if some type of social model is adopted. In this way people with impairments will not be discriminated against, particularly in cases of congenital or long-term conditions which should not be seen as pathological (Shakespeare, Iezzoni and Groce 2009).

Nursing as a profession has a moral, professional and, in some countries, legal responsibility to promote equality in the provision of health care and nursing services. The nursing profession has traditionally viewed disability through the medical model, as a condition deviating from the norm and resulting in dependency. As a result, it has **failed to acknowledge the uniqueness and differentiation of the needs of disabled people** and shown unwillingness to adapt nursing practice to such needs. Consequently, it has propagated discriminatory practices and negative experiences of disabled patients.

Therefore, in nursing practice, specifically, adoption of the social model would introduce new ideas in nursing curricula, as well as greater inclusion of disabled people in nursing education and training. The **social model** is expected to challenge discrimination, empower nurses to serve their obligations and reinforce their advocacy role (Scullion 2010). Being in a traditionally feminine profession, nurses have been at the receiving end of discrimination themselves and could be more sensitive to serving the care needs of disabled women and more pro-active. Doctors' education would also benefit from adopting a **holistic view** and taking into consideration the human rights of disabled patients as being equal to those of non-disabled ones (e.g. screening, preventive care and so on). Direct communication with disabled patients, visits at the patients' premises, as well as use of sensitive language, are important considerations (Shakespeare, Iezzoni and Groce 2009).

The above principles should be applied to protect women and girls with disabilities from discrimination, to respect their human rights and to ensure suitable access to quality healthcare: health sector professionals need to receive suitable training in caring for women and girls with disabilities, including sexual and reproductive health; treatment and procedures should be administered on the basis of informed consent of the woman with disabilities (European Disability Forum 2011).

It is imperative that health specialists – as the general population – are educated in the special needs of people with impairments. They must be trained to responsibly determine what health information they can recommend to their patients with disabilities, be it online or in print[67]. In the **United States**, accessibility can be tested through an online evaluation tool, WAVE, developed by Web Accessibility in Mind (AIM), an initiative from Utah University[68].

[67] Geiger, B. et al (2011) "The Healthy Web – Access to online health information for individuals with disabilities". *International Electronic Journal of Health Education* (14), 93-100.
[68] Utah University, Centre for Persons with Disabilities. Constructing a POUR website. Putting People at the Centre of the Process; 2010. http://webaim.org/articles/pour

3.3.5. Sexuality and reproduction

The right to decide on all aspects of sexual and reproductive freedom is fundamental. Society has traditionally viewed disabled women as asexual and has subjected them to repression of their sexual rights and needs. **Sexual rights** include the right to exercise sexuality without coercion of discrimination, the right to free sexual orientation, as well as the right to information on sexual matters and to access health services. However, disabled women are vulnerable to sexual exploitation, violence, unwanted pregnancies and sexually-transmitted diseases (European Disability Forum 2011).

The idea of discrimination against women with disabilities assumes a bipolar gender system and thus fails to account for the experience of disabled men and women who do not belong to these fixed gender categories. Disabled women and men who are uncomfortable with their sexuality and/or become transgender may encounter discrimination on that basis in addition to discrimination on the grounds of disability. Masculine and feminine stereotypes promoted culturally and socially are related with **social roles**, which might not be fulfilled in cases of disabled men or women (e.g. disabled men seeking occupations with less muscular power), again resulting in discrimination (Beigi and Cheng 2010). It is imperative that rights to motherhood, sexual contacts and relationships are guaranteed for different gender conditions, including gay/lesbian and transgender (European Disability Forum 2011).

Reproductive rights have to do with **women's autonomy** to decide whether to have children or not and under what circumstances, and include also rights to education and information, as well as freedom from coercion in exercising reproductive decisions and choices. These rights, though, are often not granted to disabled women, while practices such as forced sterilisation, or forced abortion are imposed on them. Ensuring disabled women's protection is a clear priority. Counselling must be given to women and girls with disabilities on their sexual and reproductive rights, so that they can make an informed decision.

In terms of the identity of being a mother, there are two broad perspectives in feminist literature: one argues that women become mothers by engaging in mothering work following the birth of their child; the second suggests that women engage in mothering work during pregnancy and therefore become mothers before birth. Both relate mother identity with the baby; however, it is possible that the mother identity is also formed by other experiences, or factors. The socio-cultural context and particularly support networks are important in the process forging the mother identity, not least for the health of women and their babies (Mayes, Llewellyn and McConnell 2011).

While the above perspectives fit the experience of white, middle-class, heterosexual women, they are not at ease with women with disabilities, who struggle to gain **social recognition** as women before their struggle to be recognised as mothers. Women with intellectual disabilities are silent either because of cognitive impairment or because they are not seen as capable of being mothers; indeed historically they have been prevented from becoming mothers through institutionalisation or sterilisation. Studies have indicated the significance attached by these women to the mother identity, as well as the importance of social networks in establishing and maintaining this identity (Mayes, Llewellyn and McConnell 2011).

3.3.6. Violence

Freedom of exercising citizenship rights and equal participation in social life in the case of disabled women is at risk, given their **increased vulnerability** to violence. Adults with disabilities indeed are at increased risks of violence compared to non-disabled adults. Most studies have focused on people with mental illness, while research is dominated by high-income countries, mainly the US and the UK (Hughes, Bellis et al. 2012).

Human Rights Watch (2012) mentions estimates that women with disability are up to **10 times more likely to be abused** either physically or sexually by a family member or caregiver that women without disabilities. Violence among women with disabilities takes many shapes and forms, which can be individual or systemic (Barile 2002). The experience of violence in disabled women is mediated by intersections of oppressions that occur around age, sexuality, ethnicity, race and class (Nixon 2009). Portrayal of women with disabilities as helpless, or evil and deserving punishment contributes to discrimination. Very often, people with disabilities are, for instance, seen as genderless. The media play a significant part through the use of imagery and text that reinforce stereotypes.

Women with disabilities are at a high risk of abuse, both of 'traditional' forms (physical, sexual, emotional) and particular forms related to their disability. However, the **scarcity of information** regarding abuse of women with disabilities might be indicative of 'denial' on the part of society (Plummer and Findley 2012). Even in certain societies where it is now generally accepted that violence is indeed experienced by women with disabilities, this has not been accompanied by better services (Barile 2002).

The dynamics of abuse of disabled women presents considerable complexity. Disabled women can suffer multiple forms of abuse and neglect related to their disability, which include withholding medication, denying access to mobility or communication equipment, obstructing personal care and hygiene, or blocking access to medical consultation.

Plummer and Findley (2012) and Nixon (2009) have summarised a number of studies demonstrating that women with disabilities:

- seem to be subject to increased risk of abuse due to lack of accessibility, mobility, and increased social isolation;
- are exposed to multiple potential abusers (partners, family members, health care providers, personal assistants and so on), partly because of higher frequency of interaction and different settings of such interaction with some of these abusers;
- are exposed to continuing abuse, particularly from care assistants, partly due to the continuing nature of their relationship with them.

The above becomes more intense the more isolated a disabled woman becomes, leading to increased risk of abuse. Additionally, such trends are exacerbated with age, though the abuse of older women still needs more research (Nixon 2009). So, the intersection of gender, disability, dependency on carers leads to discrimination and confinement of disabled women in the private sphere and seriously impedes their active presence and participation in public life.

Moreover, common perceptions of disabled women as helpless and passive make them more vulnerable to abuse, not least in medical and institutional settings. Key characteristics

in the relationship between disabled people and carers are dependency and intimacy which are also dominant in relationships of abuse and outweigh the experience of abuse or violence, making them more palatable (Nixon 2009). Factors such as societal discrimination are often internalised and lead to **low self-esteem**, which again makes abuse more acceptable and even natural (Plummer and Findley 2012).

Barriers to seeking help in situation of abuse include increased dependence (physical, emotional, financial) on the perpetrator (husband, family member, carer), lack of information and difficulties in accessing relevant services, fear of institutionalisation, comprehension and reactions by police or other professionals (Nixon 2009). Significantly also, there are plenty of disability conditions that will prevent cognition and therefore the clear perception and reporting of abusive practices. In such cases, the use of screening methods and devices by physicians with the intention of detection of abuse is deemed necessary.

More qualitative studies need to look in-depth into the experience of abuse focusing on the intersections of various factors of violence, so as to identify patterns of abuse differentiation in line with types of disability, as well as different abusive tactics and practices (Plummer and Findley 2012). These experiences need to be addressed holistically, breaking the barrier between violence at home vs. abuse in residential or medical settings. **Domestic violence**, a specific form of violence has been documented as a notable problem. In the case of disabled women, however, it has not been high on the agenda or either the feminist or the disabled people's movement in the UK. This leaves them more exposed to abuse and less able to seek help (Nixon 2009).

Implications of abusive practices have included psychological effects, such as depression, anxiety, stress, suicidal disposition; however, physical health consequences have not been explored adequately. Future studies need to include different cases of individuals and forms of disability, as well as a range of possible forms of abuse to do justice to such a complex matter.

3.3.7. Feminist movement and disabled women

The feminist movement has not taken into account the experiences of disabled women, though it acknowledges the multiple identities of women. The relationship between the feminist and disability movements has been one of ambivalence; disabled women have had grievances with regard to the fact that while the feminist movement was dealing with issues of relevance to them, their experience of disability was not addressed. In addition, some feminists have promoted ideas that run counter to the premises of the disability movement, such as reproductive freedom or issues of care (Arenas Conejo 2011). The idea of a single women's movement was questioned by second wave feminists and women with disabilities positioned themselves on the periphery of the movement and contributed to a re-visioning of feminism (Barile 2002).

3.4. Policy conclusions for more participation

⇒ *General non-discrimination or empowerment measures could still have an impact on disabled women as well as other people (risk of indirect discrimination).*

⇒ *The legal framework is still to be imagined. The example provided by the exploratory opinion of the European Economic and Social Committee devoted to*

Young persons with disabilities is interesting. This should be developed in another study.

⇒ *Moreover, law must be completed/replaced by programs to tackle multiple discrimination.*

⇒ *Use intersectionality to study the experiences of women with disabilities.*

Policy needs to consider the experiences of disabled women, including those of abuse and violence. Disabled women's **life experiences** are differentiated with respect to age, family background, social status, class, income, language, geographical location, race, sexual orientation and such differentiations need to be taken into consideration. In addition, disabled women respond to disabling environments in diverse ways (Barile 2002). The only way of capturing all these dimensions is clearly an intersectional approach which does justice to all those factors contributing to the uniqueness of the experience of each disabled woman.

⇒ *Promote research on the experience of discrimination of women with disabilities*

Research is thus needed that will enhance understanding of the personal experience of disability by women of different class, background, race, education, family, work and overall personal circumstances. This research needs to be based on **ethnographic methods**, including participant observations, focus groups and in-depth interviews. Significantly, these studies need to adopt **feminist research methods** that will enhance empathic understanding, will empower the researched and will enable them to share experiences; at the same time a **longitudinal character** is needed so as to address changes in the circumstances of women with disabilities over time. Such studies will, among else, shed light on the relationships between disabled people and carers and the associated perception of lack of autonomy on the part of the disabled due to their dependence on their caregivers (Erevelles 2011).

⇒ *Give voice and representation*

In accordance with the right to be heard, disabled women should be given **voice and representation** in relevant committees, political entities, boards and planning groups. This will promote the necessity to break stereotypes about disabled women: regarding their attitudes to employment, their aspirations and goals, the balance of production (employment) and reproduction (care) as characteristics of their identity.

⇒ *Use the Internet as an opportunity to participate*

The Internet seems to contributing significantly to mobilisation, organisation and communication capacity. Recent analysis of the websites of a number of disabled women's organisations has revealed two dominant strategies: a) a defensive dimension, articulated within a human rights framework and promoting eradication of violence and sexual abuse, moral autonomy and the elimination of disabling barriers; b) a proactive strategy which contains flexible concepts of femininity and disability.

⇒ *Respect the right to autonomy as a precondition for social participation*

The right to autonomy has been a claim of both feminist and disability movements and at the centre of struggles for women's full citizenship, evolving later to include the human needs of interdependence and reciprocity. Gleeson's idea of 'enabling justice' provides a useful framework combining cultural recognition and social equity, which includes access to spaces and the means to participate socially. This is based on the recognition that disabled people want social inclusion and self-respect, or in other words interdependence, rather than independence (Gleeson 1999).

⇒ *Reinforce the human rights framework for women with disabilities*

International agreements on human rights, together with the emerging infrastructure of global citizenship will become a central political vehicle (Lister 2003), despite on-going problems in enforcing human rights frameworks. Despite older cleavages, in the last 20 years disabled women have become part of **transnational activism** linked to women's human rights. However, according to the International Network of Women with Disabilities very few efforts have been taken by governments to enable women and girls with disabilities enjoy their fundamental human rights on an equal basis with non-disabled women (INWD 2010). On the other hand, **flexible definitions of disability** break down the blurred barriers between able and disabled by treating all human beings are potentially disabled (aging, mortal, with occurrences of illness etc.); this strategy will enable disability groups to join forces with feminist and other groups and enhance solidarity (Arenas Conejo 2011).

⇒ *Recognise violence as a serious problem for women with disabilities*

Violence is a serious problem, not only for women, but for disabled people in general, while worldwide action to address the problem is absent, not least because robust evidence for the prevalence or risk of violence is limited and suffers from methodological weaknesses; more research of epidemiological nature is needed to examine the extent of the problem in low- and middle-income countries and to cover different forms of disability (Hughes, Bellis et al. 2012). Studies exposing the power differentials between carers and disabled persons will increase awareness of the possibilities for abuse in these relationships (Erevelles 2011).

⇒ *Increase employment and enhance protection against bad working conditions*

While cultural changes and adverse attitudes towards disability take long time to change, **quota systems** can improve the representativeness of disabled people, particularly if **combined with other measures**, such as education and training. The target of disability employment policies should switch to severely disabled people, as well as disabled women, who are seriously under-represented in the workforce (Kim 2011).

Disabled people in general and women, in particular, need to be protected against differential treatment in employment, adversary work conditions and low pay and income, which seems to be more persistent in households with disabled members after controlling for several other variables (Parodi and Pastore 2012). Employment policy should address the issue of **wage discrimination** against disabled workers. Policy measures should provide circumstances for disabled workers to increase their productivity and consequently their wages. In the case of people with more severe disabilities, anti-discrimination measures should be provided to help them earn more, as well as other measures (technical facilities, personal support etc.) to make their daily life more manageable and compensate

for the severe limitations that their impairments impose on them (Malo and Pagan 2012). More specific anti-discrimination legislation may enable women with disabilities to declare a health problem more openly; at the same time, by increasing *their* chances to be employed it may contribute to them feeling less disabled (Bell and Heitmueller 2009).

⇒ *Further promote the rights-based and inclusive approach enshrined in the CRPD*

Disability policy has often been based on charity and welfare but not on the pledge of integrating disabled people in society and grant them the status they deserve; as a result, people with disabilities experience violation of their human rights and could be seen as the largest minority suffering from such violation. This is more pronounced for women with disabilities, who also suffer gender discrimination and are marginalised, isolated, reduced to low status, neglected and stigmatised (Issac, Raja et al. 2010).

Legislation is a necessary condition towards equality but in most national cases it is based on rehabilitation and support, rather than on anti-discrimination and rights-based principles. Rehabilitation of people with disabilities is often seen as a solution but does not really create opportunities for employment or integration of the disabled in society, but rather reduces the disabled to conditions of poverty and dependence on the welfare state.

Disability policy should provide support to disabled people, including women with disabilities, so as to exercise their social citizenship rights, as well as contributing to their community; their marginalisation comes at a cost for the community on the whole. Governments and NGOs can lead by example in including disabled people. All-inclusive education is key, not least because 'children who learn together, learn also to live together' (Issac, Raja et al. 2010).

4. STERILISATION

KEY FINDINGS

- Forced sterilisation occurs when a woman is sterilised after expressly refusing the procedure, without her knowledge, or is not given an opportunity to provide consent. Women with disabilities are particularly vulnerable to forced sterilisation performed under the auspices of legitimate medical care or the consent of others in their name.
- Although some progress has been made in terms of policies expanding the recognition and enjoyment of women's rights to sexual and reproductive healthcare services, the practice of forced and coerced sterilisation of women around the globe, including Europe, still poses a challenge to the realisation of disabled women's human rights.
- It is an imperative for policies at the EU and national level to address the underlying reasons that are used to justify forced sterilisation of women with disabilities. Eugenic policies and practices can only be eradicated by law, while negative stereotypes can be eliminated by fundamental changes in policy frameworks that ensure and support inclusion and non-discrimination, as well as empower women and girls with disabilities and enable them to make informed decisions.

4.1. Introduction and definition

Sterilisation is defined as 'a process or act that renders an individual incapable of sexual reproduction' (Mosby, 2009). Forced sterilisation occurs when a person is sterilised after expressly refusing the procedure, without her knowledge, or is not given an opportunity to provide consent. Coerced sterilisation occurs when financial or other incentives, misinformation, or intimidation tactics are used to compel an individual to undergo the procedure. Women with disabilities are particularly vulnerable to forced sterilisation performed under the auspices of legitimate medical care or the consent of others in their name[69]. Forced sterilisation of women constitutes an **extreme form of discrimination and violation of disabled women's rights** on the basis of gender and disability.

This practice is not new. Tubal litigation has been performed on women in marginalised populations worldwide, without their consent, for often eugenic reasons[70]. This practice specifically emerged from eugenics in the 1930s (Frohmader, 2012). Women with disabilities are particularly vulnerable to forced sterilisation performed under the auspices of legitimate medical care or consent of others in their name. It amounts to the denial of their right to experience their sexuality, to have sexual relationships and to found and maintain families. The right to bodily integrity and the right of a woman to make her own **reproductive choices** are enshrined in a number of international human rights treaties

[69] Sterilisation of Women and Girls with Disabilities, A Briefing Paper, October 2011. http://www.hrw.org/news/2011/11/10/sterilisation-women-and-girls-disabilities (accessed on 5/2/13).
[70] Matthew Connelly, *Fatal Misconceptions*(Cambridge, MA/London., England: Belknap Press of Harvard University, 2008)

and instruments.[71] Forced sterilisation constitutes an act of violence,[72] a form of social control and a violation of the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.[73] In many countries, forced sterilisation is debated and justified by governments, professionals and family members and carers as being in the 'best interests' of women and girls with disabilities.

When it comes to women with disabilities, the debate has taken another turn. The question was raised whether this practice was either good for the individual herself or for society. In several countries, the practice of sterilisation of disabled women was not unknown. State programs were even implemented. Nowadays, these programs have mostly been withdrawn, but the practice has sometimes remained.

Several international texts and standards set the basis and rights in this field. Many organisations are active to recognise the rights enshrined in the CRPD, among which the International Federation of Gynaecology and Obstetrics (FIGO)[74], as well as the Open Society Foundations, which published in 2011 a briefing paper[75]on Sterilisation of Women and Girls with Disabilities.

The **free and informed consent** of the woman herself is a requirement in the CRPD for sterilisation. Women with disabilities must be provided with information that sterilisation is a permanent procedure and that alternatives to sterilisation exist, such as reversible forms of family planning.[76] Physicians performing sterilisation are responsible for ensuring that the patient has received proper counselling regarding the risks and benefits of the procedure and its alternatives.[77] Sterilisation for prevention of future pregnancy does not constitute a medical emergency and does not justify departure from the general principles of free and informed consent. This is the case even if a future pregnancy may endanger a woman's life or health.[78] Last, sterilisation should not be performed on a child.

After a brief literature review, the international standards should be studied before the States' legal regimes are examined.

[71] 18 See for example: UN General Assembly, Convention on the Rights of Persons with Disabilities, 24 January 2007, A/RES/61/106, [Art.23]; UN General Assembly, International Covenant on Civil and Political Rights, 16 December 1966, 2200A (XXI), [Art.7, 17]; UN General Assembly, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, 2200A (XXI), [Art.10]; UN General Assembly, Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, 34/180, [Art.16]; United Nations, The Beijing Declaration and the Platform for Action: Fourth World Conference on Women, Beijing, China, 4-15 September 1995, A/CONF.177/20/Add.1; [paras.94-96].

[72] FIGO (International Federation of Gynaecology and Obstetrics), Contraceptive Sterilisation Guidelines, Recommendation 5. Available at: http://www.figo.org/files/figo-corp/FIGO%20-%20Female%20contraceptive%20sterilisation.pdf.

[73] UN Human Rights Council, Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development: report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Manfred Nowak, 15 January 2008, A/HRC/7/3, [paras.38, 39]. See also UN Committee Against Torture (CAT Committee), General Comment No. 2: Implementation of Article 2 by States Parties, 24 January 2008, CAT/C/GC/2 [para.22];
UN General Assembly, Rome Statute of the International Criminal Court (last amended January 2002), 17 July 1998, A/CONF. 183/9 [Article 7(1) (g)].

[74] http://www.wwda.org.au/FIGOGuidelines2011.pdf

[75] Sterilisation of Women and Girls with Disabilities: A Briefing Paper (November 2011), see http://www.wwda.org.au/sterilise2011.htm.

[76] FIGO Contraceptive Sterilisation Guidelines, Principle 1.

[77] FIGO Contraceptive Sterilisation Guidelines, Principle 12.

[78] FIGO Contraceptive Sterilisation Guidelines, Principle 10, Recommendation 3.

4.2. Legal analysis of forced sterilisation

4.2.1. Literature review

The literature has not given much thought to forced sterilisation, especially there is a lack **of research at the EU level** and regarding comparative national laws of the Member States. One article (Zampas and Lamackova, 2011) provides an overview of the legal surroundings of forced sterilisation although it is not focused on disabled women. There are some articles on voluntary sterilisation[79]. Some studies have been made in given countries (Dowse, 2004) but they aim at creating a primary basis for comparison. It is more human rights associations and civil society organisations that are more eager to take action[80] – such as the Forum on Disability[81] - that have consequently helped identifying abuse and steps forward. Associations Activism has been major in Australia[82] and triggered the current debate in Slovakia. In an international context, 'Guidelines on Female Contraceptive Sterilisation'[83], the CRPD[84], or Reports of the Special Rapporteur[85] or of the Council of Europe[86] identify directing principles such as rights to reproductive autonomy; to informed decisions about contraceptive use, sex education and family-planning services; and the right to be fully informed of options in agreeing to treatment, including potential benefits, adverse effects, and alternatives. Furthermore, they request that States should ensure access to good-quality health care for women, delivered in a way that ensures informed consent, respects a woman's dignity, and is sensitive to her needs and perspectives. There is a clear need for a more thorough study not only of the phenomenon itself, but of its context and social implications.

4.2.2. International and EU law state of the art: overview

The UN conventions and bodies mentioned in chapter 2 have been the pioneers in the interdiction of forced sterilisation. This has been mirrored by the Council of Europe and it is starting to be addressed in the European Union in relation to the CRPD.

[79] http://www.engenderhealth.org/files/pubs/family-planning/factbook_chapter_4.pdf
[80] World Medical Association (2011) Global Bodies call for end to Forced Sterilisation (September 2011) The World Medical Association (WMA) in conjunction with the International Federation of Health and Human Rights Organizations (IFHHRO) issued a Press Release on 5 September 2011, calling for an end to forced sterilisation. Global Campaign to Stop Torture in Health Care (2011).
[81] The European Disability Forum (2009) Violence against Women, Forced Sterilisation of Women with Disabilities is a Reality in Europe.
[82] Women with Disabilities Australia (2011) Submission to the United Nations Special Rapporteurs regarding forced sterilisation in Australia (June 2011) and policy report from the government.
[83] International Federation of Gynaecology and Obstetrics (FIGO) Guidelines on Female Contraceptive Sterilisation (June 2011) At its Executive Board Meeting in June 2011, the International Federation of Gynaecology and Obstetrics (FIGO) released new Guidelines on 'Female Contraceptive Sterilisation'. These Guidelines recognise the long history of forced and coerced sterilisation of marginalised women, including women with disabilities, and provide detailed recommendations for when and how consent to sterilisation can be obtained.
[84] Preamble to the Convention and Article 6.
[85] Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak. Geneva: Human Rights Council. Seventh Session, 2008, Para 38. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt. Geneva, Commission on Human Rights. Sixty-first Session, 2005, § 9 & 12.
[86] Report by Thomas Hammarberg, Commissioner for Human Rights of the Council of Europe, following his visit to the Czech Republic from 17 to 19 November 2010. Strasbourg: Council of Europe; 2011. §82–88.

Figure 2 : Overview of international and EU law on sterilisation

Organisation	Reason
CRPD (ratified by EU)	Article 12 of the CRPD states the basic rights.
CEDAW	Relevant recommendations to States on forced sterilisation.
Council of Europe	The Council of Europe's Commissioner for Human Rights has repeatedly called for effective remedies.
ECtHR	Several relevant cases including the pending Gauer v France case.
EU	Growing body of law on non-discrimination on grounds of gender and disability. No clear focus on forced sterilisation.

4.2.3. Detailed analysis: International law

CRPD

International and comparative law standards demonstrate that States have a positive obligation to apply stringent and effective safeguards so as to protect persons with disabilities from forced sterilisation[87]. The main text is the CRPD[88]. It does not precisely forbid forced sterilisation. It does not explicitly focus on this question. But several of its articles can be interpreted in order to identify disabled women's rights.

a) Article 23 obliges States Parties to respect the rights of persons with disabilities to decide freely and responsibly on the number and spacing of their **children**; to provide them with access to age-appropriate information; to recognise their right to reproductive and family planning education; and to provide the means necessary to enable them to exercise these rights.

b) Article 12 focuses on **legal capacity**. Applied to forced sterilisation, it requires that persons with disabilities enjoy legal capacity on an equal basis with others. In other words, a third party cannot decide in lieu of the disabled person, especially when it comes to living arrangements, medical treatment, or family relationships. In addition in the exercise of rights and decision-making, an individual who so wishes may receive support and be provided with safeguards against the abuse of rights. A reasonable accommodation (as defined in Article 2) is to be provided.

c) According to Articles 15, 16 and 17, the CRPD enjoins States Parties to take all appropriate **measures to protect** persons with disabilities from violence, exploitation and abuse and expressly requires them to provide assistance and support to prevent such rights violations from occurring. This is to be monitored by independent authorities[89] and a proper legal framework is to ensure protection of persons with disabilities.

[87] See also in the same direction Written comments submitted on 16/08/11 jointly by Centre for Reproductive Rights, European Disability Forum, International Centre for the Legal Protection of Human Rights (Interights), International Disability Alliance, & Mental Disability Advocacy Centre, Gauer v. France.
[88] See general explanations in Section 2.
[89] Article 16 and 33-2

d) Article 22-1 protects **privacy**. Sterilisation could be considered an "unlawful interference with his or her privacy". It is added that "Persons with disabilities have the right to protection of the law against such interference or attacks". States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others[90].

e) **Dignity** and **autonomy** are protected by Article 3(a).

f) **Discriminations** or "aggravated forms of discrimination" are prohibited by Articles 5 and 6-1. They are completed by Article 17 which guarantees the right of persons with disabilities not to be discriminated.

g) **Access to justice** is ensured by Article 13 together with Article 12.

In national reports, the CRPD committee has the opportunity to define the Convention. In its first set of Concluding Observations concerning the protection of personal integrity, the CRPD Committee underlined the requirement of informed consent to medical treatment. It called for "the legislative abolition of treatment without full and informed consent and for the law to **particularly respect women's rights to found a family and the right to health** under articles 23 and 25 of the CRPD".[91] This recommendation addresses "gender inequalities reinforced by political, economic and social structures resulting in women being routinely coerced and denied information and autonomy in the health care setting,"[92] and confronts the particular risks, which women with disabilities face.

Similarly, the Special Rapporteur on Torture has noted that "under article 23(c) of CRPD States Parties have an obligation to ensure that 'persons with disabilities, including children, retain their fertility on an equal basis with others' and to ensure their right to decide freely and responsibly on the number and spacing of their children.[93]

CEDAW

Another fundamental text is the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). All 27 Member States of the EU have ratified it but it is not binding if not either directly applicable or implemented into national law. Article 16 of this text guarantees women the right to decide freely and responsibly on the number and spacing of their children.

The CEDAW Committee issued a general recommendation on Article 12 on health. It underlines the importance of **informed consent** for medical procedures. Women have a right to be fully informed about medical procedures and acceptable services are those which are delivered in a way that ensures that a woman gives her fully informed consent; respects her dignity; guarantees her confidentiality; and is sensitive to her needs and perspective.[94]

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[90] §2.
[91] CRPD Committee, *Concluding Observations: Tunisia*, Para. 29, U.N. Doc. CRPD/C/TUN/CO/1 (2011). As mentioned in Written comments submitted on 16/08/11 jointly by Centre for Reproductive Rights, European Disability Forum, International Centre for the Legal Protection of Human Rights (Interights), International Disability Alliance, & Mental Disability Advocacy Centre, Gauer v. France, p. 7.
[92] *Secretary General, Right to Health* 2008, *supra* note 54, Para. 54.
[93] *Special Rapporteur on Torture Interim Report 2008 supra* notes 36, Para. 60.
[94] Committee on the Elimination of Discrimination against Women, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, (20th Sess., 1999), *in* Compilation of General Comments and General Recommendations, Adopted by Human Rights Treaty Bodies, at 358, Para. 22, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II) (2008).

This body has also issued **recommendations** on how States should address their obligations in order to comply with their international human rights obligations. In two country reports, the CEDAW committee has specifically called on a particular State party to "review its domestic legislation pertaining to the principle of informed consent and ensure its conformity with international human rights and medical standards, and monitor public and private health centres which perform sterilization procedures." It does not address the issue of intersectionality of gender and disability but it promotes practical measures. It also recently called on a State to "adopt legislative changes on informed consent to sterilization as well as to provide justice for victims of such acts undertaken without consent."[95] It finally expressed concern at some on-going practice of non-therapeutic sterilisations of women and girls with disabilities and recommended that some Governments "enact national legislation prohibiting, except where there is a serious threat to life or health, the use of sterilisation of girls, regardless of whether they have a disability, and of adult women with disabilities in the absence of their fully informed and free consent".[96]

Council of Europe and ECtHR

The Council of Europe has drafted a **European Convention on Human Rights and Biomedicine** signed by most Member States of the European Union; it provides guidance on informed consent. Its Article 5 provides that "an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time".

Judging on the basis of the **European Convention of Human Rights**, the European Court of Human Rights (ECtHR) has pursued jurisprudence turned towards the protection of disabled women fundamental rights. Its first cases only related to disability, but they can be applied to our focus.

More specifically, in the *Glor v Switzerland* case, the ECtHR is willing to apply Article 14 of the Convention about equality to discrimination based on the ground of disability. Referring in particular to the CRPD, the Court found that there existed a European and universal consensus on the need to protect persons with disabilities from discriminatory treatment[97].

In its *Shtukaturov* judgment, the ECtHR recognized that the will of a person placed under guardianship had to be taken into consideration. The Court thus focused on legal capacity and the possibility for someone whose legal capacity has been formally restricted to retain capacity to make medical and other decisions rather than having such decisions made by third parties[98].

Turning to sterilisation, in the *V.C. v. Slovakia* case, the ECtHR found that the sterilisation of a Slovakian woman of Roma descent violated the European Convention on Human Rights. The patient did not give her informed consent, this creating a violation of Article 3,

[95] CEDAW Committee: *Concluding Observations: Hungary*, Para. 8, U.N. Doc. CEDAW/C/HUN/CO/6 (2007); CEDAW Committee, *Concluding Observations: Czech Republic*, Para. 23, U.N. Doc. CEDAW/C/CZE/CO/3 (2006).
[96] CEDAW Committee: *Concluding Observations: Australia*, CEDAW Forty-sixth session, 12 – 30 July 2010. CEDAW/C/AUS/CO/7.
[97] §53, Glor v. Switzerland, 13444/04, ECtHR (2009).
[98] §94, Shtukaturov v. Russia, 44009/05, ECtHR (2010). As mentioned in Written comments submitted on 16/08/11 jointly by Centre for Reproductive Rights, European Disability Forum, International Centre for the Legal Protection of Human Rights (Interights), International Disability Alliance, & Mental Disability Advocacy Centre, Gauer v. France, p. 7.

which guarantees that 'no one shall be subjected to torture or to inhuman or degrading treatment or punishment,' due to her experiencing prolonged suffering and the positive obligations to provide legal safeguards to protect the patient's reproductive health of Article 8 (right to respect for [everyone's] private and family life).

The most relevant case, the *Gauer and others v France* case, has not been decided yet. In this case, disabled women were unlawfully sterilised by force from 1995 to 1998 in the city of Sens. On September 11th 2000, a disability association pressed criminal charges by filing a complaint to the tribunal of Sens for "aggravated mutilation" and "obstruction of justice". The procedure was difficult and ended with the result that the Cour de Cassation considered the case inadmissible for several procedural and substantial reasons. The plaintiffs turned to the ECtHR. Several organisations have pleaded in an *amicus curiae* that forced sterilisation of disabled woman amounted to torture and ill treatment (violation of Article 3), a violation of the right to respect for private and family life where there was a failure to ensure free and informed consent to sterilisation (Article 8), a violation to the right to found a family (Article 12) and a discrimination where disabled women are treated in a different way from other women with no objective and reasonable justification (Article 14 in conjunction with the other articles), as well as potentially a denial of access to justice (violation of Article 6)[99]. The judgement is expected.

This is very interesting as one sees how a legal system which might appear fair at first sight is nevertheless unable to deal effectively with cases of severe abuse. The lack of reaction by the judges shows how difficult it can be to enforce the law. Some commentators identified in this behaviour the violation of at least four fundamental rights. This example shows the need to commission a further study devoted to the question of forced sterilisation in Europe.

The Council of Europe's Commissioner for Human Rights has also repeatedly called for effective **remedies, including compensation**, to be provided to victims of such practice and for necessary legislative reforms, including "a doctor's obligation to inform the patient in writing and orally about the nature of the sterilisation, its permanent consequences, potential risks and available alternatives, and a period of at least seven days between the provision of such information by the doctor and the expression of consent by the patient".

4.2.4. EU law

For the time being, there is **no legal provision on EU level** prohibiting forced sterilisation. Such an applicable body of law would depend on the general prohibition of discrimination (Article 19 TFEU, reinforced by the Charter of Fundamental Rights)[100]). Because the CRPD has been ratified by the EU, it is to be implemented and respected by the EU institutions and in each Member State (when they apply EU law, or where they have ratified this Convention).
In relation to the CRPD and mostly its article 23, the European Disability Forum published a paper addressing several issues related to the sexual and reproductive health of women with disabilities, among which forced sterilisation. It asks "all public powers to revise the legal framework regulating forced sterilisation, addressing the issues of "informed consent" and "legal capacity" in order to make the necessary accommodations and fulfil the spirit of,

[99] See written comments submitted on 16/08/11 jointly by Centre for Reproductive Rights, European Disability Forum, International Centre for the Legal Protection of Human Rights (Interights), International Disability Alliance, & Mental Disability Advocacy Centre, Gauer v. France.
[100] See above, Section 2.

and obligations under, the UN CRPD, which requires States to **introduce legal reforms** acknowledging that respect for the home and family and the dignity and integrity of persons with disabilities are fundamental rights which may not be violated. In the course of the provision of health services for all women with disabilities, the right to receive care also includes the right to refuse it"[101].

In a resolution related to the external dimension of the EU, the **European Parliament** stated that it is against forced sterilisation or forced abortion in general[102]. In the same sense, the EU budget explicitly prohibits the use of EU funds to a country which proceeds to it[103].

Up to now, the European Court of Justice has never been asked to issue a preliminary reference regarding the sterilisation of a disabled woman[104].

4.3. Policy analysis of forced sterilisation

Although some progress has been made in terms of policies expanding the recognition and enjoyment of women's rights to sexual and reproductive healthcare services, the practice of forced and coerced sterilisation of women around the globe, including Europe, still poses a challenge to the realisation of disabled women's human rights.

4.3.1. Impressions from EU Member States (see also annex 1)

Despite the existence of national legal frameworks and international recommendations to address the issue of coerced sterilisation of women with disability, there is still variation in the practices and policies being adopted and followed in different European countries.

Forced sterilisation constitutes the ultimate form of intersectional discrimination of women on the basis of gender and disability and a violation of human rights. It constitutes a form of **social control** of women's reproductive rights and is in sharp contrast with existing discourses and official declarations of protection of rights and promotion of equal treatment. In addition to being a discriminatory practice on the basis of gender, since it is performed only on women, it can be seen from a feminist point of view as patriarchal and male-dominated control over women's sexual and reproductive rights by men and the male-dominated medical establishment.

[101] European Disability Forum input to the general discussion of the CESCR on sexual and reproductive rights, October 2010 , see http://www2.ohchr.org/english/bodies/cescr/docs/discussion/EuropeanDisabilityForum.pdf, p. 4 and 8.

[102] See Resolution of 5 July 2012 on the forced abortion scandal in China, EUR. PARL.DOC.P7_TA(2012)0301, available at http://www.europarl.europa.eu/sides/getDoc.do?type=TA&language=EN& reference=P7-TA-2012-301 and EU development aid: coercive abortion & sterilisation White Paper World Youth Alliance Europe, Juan Ignacio Fernandez Torres & Meghan Grizzle, Sept 2012, http://www.wya.net/EU%20development%20aid-coercive%20abortion%20&%20sterilisation%20White%20Paper.pdf

[103] Title 21 of Section III (the Commission section) of the 2012 European Union Budget forbids Community assistance for coercive reproductive health practices in African, Caribbean and Pacific states. It states, 'Union assistance should not be given to any authority, organisation or programme which supports or participates in the management of an action which involves such human rights abuses as coercive abortion, involuntary sterilisation or infanticide, especially where such actions apply their priorities though psychological, social, economic or legal pressure, thus finally implementing the specific Cairo International Conference on Population and Development (ICPD) prohibition on coercion or compulsion in sexual and reproductive health matters.' It also calls on the Commission to 'present a report on the implementation of the Union's external assistance covering this programme.' Section III, Title 21, General Budget of the European Union for the financial year 2012, available athttp://eur-lex.europa.eu/budget/data/D2012/EN/SEC03.pdf.

[104] Given that a question was raised regarding abortion, one could imagine a question relating to sterilisation.

Unfortunately, there is often a lack of data on forced and coerced sterilisation and abortion practices because very often medical professionals do not keep records of the procedures (Human Rights Watch, 2011). This section will explore the different attitudes and practices enacted in European countries today, drawing attention on persistent discriminatory practices, but also touch on changing practices and guiding principles to prevent multiple discriminations.

The occurrence of coerced and forced sterilisation of women is not new in Europe. Intellectually disabled women were targeted as victims of Nazi persecution, including through forced sterilisation singled out on eugenics grounds (Roy, 2012). The practice emerged in the 1930s throughout Europe, and even after the Second World War this practice continued in some countries. Over the past decade, reports of such practices have arisen across Europe and internationally. Some countries, for example **Sweden** and **Norway**[105], where state-supported eugenics policies led to tens of thousands of women being coercively sterilised from the 1930s to the 1970s[106] (Borberg, 1996) are responding with policies with regard to past sterilisation policies and practices. After exposure of the broad practice, Sweden set up a commission to survey the extent of the practice, which offered recommendations for legal and policy reform and for compensating persons whose rights had been violated (Zampas and Lamaková, 2011). In these countries, there have been no present-day allegations of such practices.

In other countries, such as the **Czech Republic** and **Slovakia**, recent practice of forced and coerced sterilisation of Roma women brought up challenges of intersectional discriminations upon gender, race and disability (CRR, 2003; CEDAW, 2010). To address these violations, the Czech Public Defender of Rights (Ombudsman) issued a report on the practice and offered recommendations to the government on how to address the issue after numerous complaints were led by **Roma** women who were coercively sterilised (Zampas and Lamaková, 2011). The recommendations, and those following from the Czech Human Rights Council, called for the government to acknowledge the practice and express regret over it, and take legislative and other measures to help prevent the practice from reoccurring. These measures included instituting a 7-day waiting period before sterilisation is performed. The recommendations would also place legal obligations on healthcare providers to inform patients on the permanency of sterilisation and alternatives to sterilisation, provide training to health professionals on informed consent, and institute a compensation scheme for women who have fallen victim to such practices. As a result, the Czech Government adopted a resolution in 2009 expressing regret over the individual "errors" identified in relation to illegal sterilisation. The government committed itself to preventing such harm in the future (Czech Republic Statement, 2009), without however adopting any legal framework.

In **Slovakia**, no government acknowledgement has been forthcoming after exposure of the practice by civil society and the Council of Europe's Commissioner for Human Rights (2003). Slovakia revised its legal framework governing sterilisation in 2004, including a requirement that sterilisation be performed on the basis of a written request and written informed consent, and that the information provided to a patient requesting sterilisation must include information on "alternative methods of contraception and family planning, possible changes in life circumstances leading to the request for sterilisation, medical

[105] In Norway, during the same period, about 2,000 Norwegians, mostly those deemed mentally handicapped or insane, were sterilised (Borberg, 1996).

[106] In Sweden, between 1935 and 1976, doctors forcibly sterilised approximately 62,000 "genetically inferior" people, 95% of whom were women with mental disabilities (Kaban, 1998; Sweden Country Report on Human Rights, 1997).

consequences of sterilisation as a method aimed at the irreversible prevention of fertility and the possible failure of sterilisation" (Zampas and Lamaková, 2011). The legal framework also removed medical indications for sterilisation, which were often used to justify sterilisation without informed consent. It has been reported that the implementation of the informed consent regulation has been rather inconsistent in practice (Committee on the Elimination of racial Discrimination, 2010), leading to the UN Race Discrimination Committee's 2010 recommendation to the Slovak Government to "establish clear guidelines concerning the requirement of 'informed consent' and to ensure that these guidelines are well-known among practitioners and the public, in particular Roma women".

In **Slovenia**, women with mental retardation have been sterilised (Zavirsek, 1998[107]). Contrary to assertions by the Slovene media that the sterilisation of disabled persons ended in 1994, a study of group homes for persons with disabilities showed that sterilisation is still used to prevent unwanted pregnancy (Zavirsek, 1998). In **Belgium,** Servais et al. (2004) found that prevalence of sterilisation of women with intellectual disability was three times higher (22%) than in the whole of Belgian population (7%) and correlated with institutional factors. If they lived in institutions where sexual intercourse was allowed or contraception was required, they were more likely to be sterilised. In **Denmark** until 1945, 78% of those sterilised had intellectual disability (Roy, 2012). In **Hungary,** women reported that some medical personnel intentionally over-medicated pregnant women with psychiatric disabilities, then recommend abortion, claiming that the high medication levels endanger the foetus (Raye, 1999). In **Switzerland,** a 1928 law incited a campaign of forced sterilisation of mostly women with mental disabilities, a law which is suggested to be the one that Adolf Hitler used as a model to establish the Nazi eugenics legislation (Kaban, 1998).
From an international perspective, predominantly in **Australia**, women with mental or intellectual disabilities are commonly administered menstrual suppressants and are involuntarily sterilised. Even though the issue of forced sterilisation has received widespread policy attention, there is little information about the extent of the practice. A 2001 report on sterilisation argues that although there has been a lot of controversy about the findings of the previous report and data from other sources, the actual cases of non-medical sterilisations have substantially decreased over the past years (Brady et al, 2001). In the **United States**, forced sterilisation was compulsory for disabled girls for many years, although such practices have been challenged there since the 1980s (Roy, 2012). Things are slowly changing (Roy, 2012).

4.3.2. Support mechanisms

In several European countries, best practices and policies to safeguard the human right of women with disabilities have been established, through agencies, authorities, groups or NGOs.

In **Ireland**, the Ministry of Justice established a Working Group on Equality Proofing in accordance with a national social partnership agreement, which includes representatives of Government Departments, Agencies and the Social Partners. The Working Group started its work in 2000 and aims to provide an on-going focus on **equality proofing** issues. Equality proofing is similar to gender mainstreaming strategies where the equality perspective is incorporated into policies and legislations and entails impact assessment and compliance. Another authority in Ireland, the Equality Authority, with a statutory mandate that covers

[107] Although dated, no more recent data on Slovenia could be found

nine different grounds, has identified the situation and experience of people at the intersections between these grounds as an important focus in their work.

In 2003 the **Danish** Institute for Human Rights established the Equal Treatment Committee, consisting of civil society and governmental organisations and independent experts representing the six grounds of race and ethnic origin, gender, religion and belief, age, disability and sexual orientation. The purpose of setting up the Committee was to create a platform to promote equal treatment and combat discrimination from a **horizontal cross-ground perspective**. In 2006, after a study mapping the status of equal treatment in Denmark, the Committee embarked upon an action plan for an inclusive society. The Declaration for an Inclusive Society was signed by 22 different NGOs and has led to a new action plan (2007-2010) to fulfil the objectives of the Declaration and make it operational. Several organisations are now working at the intersection of their grounds and cooperate on common projects.

The National Council for Combating Discrimination (NCCD) is **Romania**'s national equality body. Through its case work, the body became aware of a disproportionate number of cases involving **Roma** women. NCCD found that it was difficult to handle these cases because it was not clear whether the person was discriminated on the ground of race and ethnic origin or on the ground of gender. NCCD found that the grounds were so interrelated that they advised the Government to amend the Equal Treatment Act. The Act was amended to the effect that if an individual was found to be discriminated on two or more grounds it would be considered as an "aggravating circumstance".

The Equality and Diversity Forum (EDF) in the **United Kingdom**, is a network of national organisations committed to progress on age, disability, gender, race, religion and belief, sexual orientation and broader equality and human rights issues.

In spite of some encouraging policies in place to eliminate and eradicate the intersectional discrimination against women with disabilities regarding the unobstructed exercise and enjoyment of their reproductive rights, there is still a lot to be done on that front.

4.4. Conclusions - The way forward against forced sterilisation

It is an imperative for policies to address the underlying reasons[108] that are used to justify forced sterilisation of women with disabilities. Eugenic policies and practices aimed at eliminating certain groups and features can only be eradicated by law. On the other hand, justifications for coerced sterilisation that stem out of regarding disabled women who wish to reproduce as a "burden" for the community, the society and its resources or attitudes of an "incapacity" of women with disabilities for parenthood, can be eliminated by fundamental changes in policy frameworks and organisation of society to ensure and support inclusion and non-discrimination, as well as to empower and enable them to make informed choices and decisions.

For example, regimes which remove decision-making and the exercise of rights from the individual need to be carefully revised, as behind them lies the presumption that a guardian is better placed to make choices in the "best interest" of the individual concerned, a practice that often leads to abuse.

[108] It cannot be said that an underlying reason is the prohibition of intersectional discrimination. Up to now, forced sterilisation has been prohibited (when it was prohibited) on grounds on fundamental rights.

⇒ *Base actions on international consensus to prohibit forced sterilisation*

As a conclusion, it appears that numerous texts on the international and the EU level illustrate the various challenges concerning the practice of forced and coerced sterilisation, and set forth recommendations on how States can address them in order to comply with their international human rights obligations. They have established that States have obligations to strengthen laws to ensure free and informed consent, to include provisions of clear definitions of informed consent in cases of sterilisation, to review legislations that permitted forced sterilisation with parental consent, and finally to train health professionals on patients' rights. States have also obligations to fairly and effectively investigate reports of forced and coerced sterilisation, to prosecute perpetrators, and to provide effective remedies and compensation for victims of forced and coerced sterilisation.

⇒ *Ensure informed consent*

Instead, women and girls with disabilities should be educated and informed of their sexual and reproductive rights, on how to protect themselves against sexual abuse and unwanted pregnancy. Comprehensive steps ought to be taken as a common practice to ensure that information, education and services on sexual and reproductive health are available in accessible formats and languages, including sign languages, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication (IDA, 2013).

⇒ *Empower women with disabilities*

Women should also be specifically encouraged to question or at least to ask questions about what is suggested as being in their best interests (McCarthy, 2009), safeguarding that way their reproductive autonomy. At the same time, health professionals who deal with the reproductive issues of women with disabilities need to be adequately informed, educated and aware of the special needs and attention required to serve this group of patients (Hogg, 2000). Policies on contraception use and alternative to sterilisation methods of contraception need to be developed by disability services and authorities, to ensure that appropriate measures are being taken in the case that use of contraception is deemed necessary and not enforced (McCarthy, 2009). Negative perceptions of women with disabilities being unable to comprehend the concept of motherhood and care for their children need to be rigorously challenged (Booth & Booth, 1998).

5. CONCLUSIONS AND RECOMMENDATIONS

KEY FINDINGS

- All Member States should enact EU legislation recognising the existence and prohibiting multiple and intersectional discrimination. They should also ensure efficient and easy access to justice for all, especially disabled women (via tribunals and ombudsman).
- Policy measures informed by an intersectionality approach to discrimination should promote the quality of life of the women with disabilities. Disability mainstreaming needs to be combined with positive actions, such as quotas in employment, "universal design" programmes, the raising of awareness of the population to challenge stereotypes, the removal of structural and cultural barriers through joint work by the disability and the feminist movements, the relevant training of relevant professionals (health professionals, carers, teachers, social workers, staff in day centres), business incentives, and increase of the visibility of disabled women in the public arena.
- Specific measures can include education in mainstream schools as a vehicle to achieve greater acceptance of disabled pupils; a less discriminatory labour market, which would increase employability of disabled women, coupled with generous benefits, workplace accommodation and incentives for employers; anti-poverty measures explicitly tackling the link between poverty, disability and gender; health policies to address inequalities at the intersection of gender and disability; rigorous studies and strict measures against institutional and domestic violence; prohibition of forced sterilisation, unless there is informed consent and acknowledgement of necessary responsibilities and conflicts of interests.
- Research is not only necessary as a means of evidence-based policy making but also as a way to raise awareness and is therefore of paramount importance. Funding for targeted research to provide more accurate qualitative and quantitative data is imperative and urgent for efficient policy design which will address intersectionality.

This section brings together the conclusions of the particular chapters, so that the interrelation of all the dimensions of the problem and recommended forms of action become more evident.

5.1. Recommendations regarding multiple discriminations

5.1.1. Recommendations from a legal point of view

- All Member States which have not already done so should ratify and implement the CRPD.
- EU legislation should be enacted recognising the existence and prohibiting multiple and intersectional discrimination. This should be a statement of principle. For instance, in line with the proposed EP amendment, it could be included in the preamble of the pending horizontal equal treatment Directive.

- Efficient and easy access to justice has to be ensured generally, in line with the Victims rights' package, and especially for disabled women as a particularly vulnerable group (via tribunals and ombudsman).

5.1.2. Recommendations from a social point of view: Promoting the quality of life of women with disabilities

- The intersectionality approach shows that **disability mainstreaming** might, similarly to the gender mainstreaming, lead to less discriminatory practices. This derives from the idea that laws in general do not take into account the diversity of the population. Even anti-discrimination laws have limitations. There is thus a need to include a positive element to counteract possible discriminatory outcomes.

- However, **positive actions** have been shown to be more effective in reducing inequalities than anti-discrimination legislation because there is no need to find a comparator. As it has been shown in the section on employment, quotas could only make a difference, if they targeted disabled women explicitly, so as to address the intersectionality of discrimination in employment.

- **"Universal design" programmes should be developed through** laws, regulations and 'culture', integrating the inclusive dimension in the design of buildings, products, and services from the start.

- For the mainstreaming of disability and gender issues, **awareness-raising of the general population** is needed as an overarching priority. Disability should be seen as common, multiform experience, related to the ageing process, which will eventually afflict most people who will live long, especially women who live longer. Given the demographic conditions, it will be on the increase in the years to come. Possible actions could be challenging stereotypes through art, science, media, visual representations, sport, advertisement, activism, and language, notably if related to contribution of eminent scholars, artists and thinkers. Awareness and presentation of the disability movement claims in terms of social citizenship and human rights is essential in changing attitudes of the public and of policy makers.

- **Disability and feminist movements should work together** to remove both structural and cultural barriers.

- The social model of disability and findings of disability studies scholars should be included in the **education and training curricula of professionals** dealing with people with disabilities (health professionals, carers, teachers, social workers, staff in day centres etc.) to make them familiar with the relevant issues and updated information related to their work.

- **The potential of public procurement** as a powerful tool to provide business with an incentive to develop accessible goods and services whilst stimulating innovation should be further developed.

- **The visibility of disabled women** in the public arena needs to be increased. Breaking stereotypes in the way disabled people are portrayed by the media and making linguistic adjustments in a non-simplifying and non-stigmatising way is an imperative. In this way, a more accurate representation of the conditions and the experience of disabled people are ensured. It leads to more inclusion.

5.1.3. Specific measures

- EDUCATION: **Inclusive education** is a vehicle to achieve greater acceptance of disabled pupils in early years by their peer group, cultivate the sense of belonging, change stereotypes and give the chance to able-bodied pupils to appreciate disabled pupils' contribution, abilities and commonalities. Disability needs to be better mainstreamed into vocational training.

- EMPLOYMENT: **A less discriminatory labour market** will lead to greater social inclusion and alleviation of some of the negative material and psychological consequences of disability. As seen in Chapter 2, the existing comprehensive EU anti-discrimination framework does not address intersectional discrimination. Measures adopting an intersectional approach would aim at increasing employability of disabled women and thus enable them to become less dependent on their family (parents or partners) and capable of having a more autonomous lifestyle. In the meantime, it is down to welfare states to introduce benefits which would increase autonomous living.

- EMPLOYMENT: **Adaptation of the workplace** to the needs of disabled women workers will increase participation of the disabled in the labour market. It is down to the Member States to encourage employers to provide reasonable accommodation with a view to hire disabled women.

- POVERTY: The **link between poverty, disability and gender** must be taken into account in any anti-poverty measures. Poverty is inextricably linked with disability, either as a cause or an outcome of it. Many impairments are caused or exacerbated by malnutrition, poor living conditions, lack of access to health care services and alternatively. Additionally, when impairment exists, the disabling social conditions and barriers to education or employment for women with disability result in poverty.

- HEALTH: Health inequalities at the intersection of gender and disability need to be acknowledged and included as a priority into the research agenda of governments, as this dimension has been neglected.

5.1.4. Need for more research

Research is not only necessary as a means of **evidence-based policy making** but also as a way to raise **awareness** and is therefore of paramount importance. The current dearth of studies, even statistics, on people with disabilities and especially disabled women is not acceptable and must be remedied. Funding for targeted research to provide qualitative and quantitative data is imperative and urgent for efficient policy design which will address intersectionality. The EU can be instrumental in funding such studies, as disabled women have not been prioritised in the national context, while the current economic climate in many Member states has affected funding for research of this type.

- **Statistics** should be disaggregated so that the percentages of persons with disabilities and their different situations become obvious so that the problem can be seen in its true dimensions. These statistics should also be gender-disaggregated.

- Qualitative research is required to shed light to the **different experiences** of disabled women of all classes, ethnic origins, income levels, sexual preferences and

religions and mainly different forms of disabilities, so that intersectionality can be empirically demonstrated but also disparities among the disabled can become evident.

- In particular, additional evidence especially with regard to less visible and less-known forms of disability in relation to gender is necessary. This can also only be achieved through qualitative research, mainly through the **use of narratives** which are seen as the most appropriate research method to provide accounts of personal experiences. The Union could finance extensive surveys to collect this type of information and form **databases** in all EU languages.

- **Feasibility studies** will help to design legislation and other policy measures more appropriately for persons with disabilities when taking into account external constraints such as affordability, competing priorities, availability of human resources, availability of knowledge and technology, and cultural differences.

- In this context, separate studies need to be made on **each dimension** of an intersectional approach so that the effect of each aspect can be separately assessed as to the impact a policy has on

    - disability,
    - gender,
    - poverty, and
    - any other ground of discrimination.

5.2. Recommendations regarding forced sterilisation

5.2.1. Recommendations

- The Commission should consider proposing a directive on the basis of Article 19 prohibiting sterilisation as a serious form of discrimination or as threat to human rights and women's dignity except where there is a serious threat to life. In any case and regardless of whether the particular girl/woman has a disability, fully-informed consent is required.

- Member States should ensure access to justice, psychological and financial reparation, including access to specific support mechanisms aiming at vulnerable categories of people, such as disabled women (for example through a regional or national bureau or centre for disabled women and their tutors). This could be linked to the implementation of the victim's package.

- Member States have to ensure special training of all professionals involved in these cases.

- Member States should make sure that all law and practice should be in line with the CRPD and account for the disabled person's consent to medical procedures and take

into account parental responsibilities and powers and their restrictions in certain circumstances. In all cases, the following questions should always be answered:

  - Is the sterilisation performed for other than therapeutic purposes?
  - Was it preceded by due inquiry and adequate consideration?
  - Is there a conflict between the interests of the disabled persons and her carers?

- In the framework of its obligations from the CRPD, the Commission should proceed to a complete and exhaustive comparison of the Member States legal provisions and their implementation in practice in relation to forced sterilisation.

REFERENCES

- Ahtonen, A. and R. Pardo (12 March 2013) "The Accessibility Act – Using the single market to promote fundamental rights". European Policy Centre.

- Albert, G. (2011) "Forced sterilisation and Romani Women's Resistance in Central Europe", *Different Takes* (71), summer 2011.

- Alborz A, McNall R, Swallow A (2003) *From the Cradle to the Grave: A Literature Review of Access to Healthcare for People with Learning Disabilities Across the Lifespan*. National Co-ordinating Centre for NHS Service Delivery and Organisation, London.

- Alborz A, McNally R, Glendinning C (2005) "Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence". *Journal of Health Services Research and Policy*. 10, 3, 173-182.

- Anand, S. (2012) "Public Health, Ethics and Equity", OUP Catalogue. www.ideas.repec.org.

- Anderson Snyder, L., J. Carmichael, et al. (2010). "Perceptions of discrimination and justice among employees with disabilities." Employee Responsibilities and Rights Journal **22**: 5-19.

- Arenas Conejo, M. (2011). "Disabled women and transnational feminisms: shifting boundaries and frontiers " Disability and Society **26**(5): 597-609.

- Bacchi, C. (1999). *Women, Policy and Politics: The Construction of Policy Problems*. London: Sage.

- Banda, F. and Chinkin, C. (2004) *Gender, minorities and indigenous peoples*, London, Minority Rights Group.

- Barile, M. (2002). "Individual-systemic violence: disabled women's standpoint." Journal of International Women's Studies **4**(1): 1-14.

- Beigi, A. and K. Cheng (2010). "Rethinking gender in disability issues." Sexuality and Disability **28**: 205-207.

- Bell, M. (2003). 'The Right to Equality and Non-Discrimination', in T. Hervey and J. Kenner (eds), *Economic and Social Rights under the EU Chatter of Fundamental Rights: A Legal Perspective* (pp. 91–110). Oxford: Hart Publishing.

- Bell, D. and Heitmueller, A. (2009) The Disability Discrimination Act in the UK: Helping or hindering employment among the disabled? *Journal of Health Economics vol. 28, no. 2*, pp. 465-480

- Berthoud, R. (2011). Trends in the Employment of Disabled People in Britain, University of Essex, Institute for Social and Economic Research.

- Beveridge, F. (2011). '"Going Soft"? Analysing the Contribution of Soft and Hard Measures in EU Gender Law and Policy', in E. Lombardo and M. Forest (eds), *The*

Europeanisation of Gender Equality Policies: A Discursive-Sociological Approach (pp. 28–48). Basingstoke: Palgrave Macmillan.

- Booth W. & Booth T. (1998) Advocacy for parents with learning difficulties. Brighton: Pavilion Publishing.
- Borberg, Roll-Hansen (1996) Eugenics and the Welfare State: Sterilisation Policy in Denmark, Sweden, Norway and Finland. Michigan: Michigan State University Press; 1996.
- Bradley, H., Healy, G., Forson, C. and Kaul, P. (2007) Moving on up? Ethnic minority women and work, Manchester, Equal Opportunities Commission.
- Brady, S., Briton, J., & Grover, S. (2001) The Sterilisation of Girls and Young Women in Australia: Issues and Progress. A report commissioned by the Federal Sex Discrimination Commissioner and the Disability Discrimination Commissioner; Human Rights and Equal Opportunity Commission, Sydney, Australia. Available online at: www.wwda.org.au/brady2.htm
- Browne, Irene Misra Joya (2003) The Intersection of Gender and Race in the Labour Market, Annual Review of Sociology 29Jun 2003 487–513. 29 Nov 2007, http://arjournals.annualreviews.org/doi/abs/10.1146/annurev.soc.29.010202.100016.
- Burri Susanne and Schiek Dagmar (2007) European network of legal experts in the field of gender equality.Report to the Commission on *Multiple Discrimination in EU Law, Opportunities for legal responses to intersectional, gender discrimination?*
- Burnett, G., P.T. Jaeger and K.M. Thompson (2008)"The social aspects of information access: the viewpoint of normative theory of information behaviour". *Library and Information Science Research* 30: 56-66.
- CEDAW. 1 March 2013. Concluding Observations on the combined seventh and eight periodic reports of Hungary adopted by the Committee at its fifty-fourth session (11 February – 1 March 2013).
- Center for Civil and Human Rights, People in Need Slovakia. Written Comments concerning the sixth, seventh and eighth periodic reports of the Slovak republic under the Convention on the Elimination of All Forms of Racial Discrimination. Geneva: Committee on the Elimination of Racial Discrimination. Seventy-sixth Session, 2010.
- Centre for Reproductive Rights, "Hungary" in *Women of the World*. 2003.
- Center for Reproductive Rights, Porada. Body and Soul, Forced Sterilisation and Other Violations of Roma Women's Reproductive Freedom in Slovakia. New York: CRR; 2003.
- Chance for Children et al. *Hungary - Submission to the UN Universal Periodic Review 11th session of the UPR Working Group of the Human Rights Council,* November 2010.
- Chenoweth, L. (1996). "Violence and women with disabilities." Violence Against **2**: 391-411.

- Coleman D. (1998) The Seattle Compromise: Multicultural Sensitivity and Americanization, Duke Law Journal, 45, 717-783.
- Connelly M. (2008) *Fatal Misconceptions*. Cambridge, MA/London., England: Belknap Press of Harvard University.
- Crenshaw, Kimberlé W. (1991) Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color, *Stanford Law Review*, Vol. 43, No. 6., pp. 1241–1299.
- Davaki, K (2001) Women in the Labour market and the Family: Policies in Germany and Greece, PhD thesis, University of Kent.
- De Francisco, V. P. and Palczewski, C. H. (2007) Communicating Gender Diversity: A Critical Approach. Los Angeles, Sage Publications.
- Department of Health (2008) Healthcare for All. Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. DH, London.
- Disability High Level Group (2008), Beyond EU competence Co-operation of 'added value', 1st report.
- Disability Rights Commission (2006) How to Use Easy Words and Pictures. http://tinyurl.com/8y7ar7g (Last accessed: November 29 2012.)
- Douzinas, C. (2006). Humanitarianism and politics. Re-public: Re-imagining Democracy. http://www.re-public.gr/en/?p=30.
- Dowse Leanne (2004) 'Moving Forward or Losing Ground? The Sterilisation of Women and Girls with Disabilities in Australia'. Women with Disabilities Australia (WWDA).
- Dowse Leanne (2004) Moving Forward or Losing Ground? The Sterilisation of Women and Girls with Disabilities in Australia'. Women with Disabilities Australia (WWDA) rights. Geneva: CESCR; 2010.
- Emerson E, Baines S, Allerton L et al (2011) "Health Inequalities and People with Learning Disabilities in the UK: 2011". http://tinyurl.com/3p32luy (Accessed: 29 March 2013.)
- Emmett, T.and E.Alant (2007) "Women and disability: exploring the interface of multiple disadvantage". Development South Africa. 23:4, 445-460.
- Erevelles, N. (2011). Disability and Difference in Global Contexts. New York, Palgrave Macmillan.
- European Training and Research Center for Human Rights and Democracy (2012) Locating Intersectional Discrimination, A detailed report on the Conference of 18th/19th October 2012 in Graz on "Intersectional disadvantage and discrimination - social realities and legal practice", http://antidiscrimination.etc-graz.at/cms/index.php?id=22.
- European Union Agency for Fundamental Rights (2012), Multiple discrimination in healthcare, http://fra.europa.eu/en/project/2011/multiple-discrimination-healthcare (accessed on 5/2/13).

- European Commission, Unit G4 (2007) Tackling multiple discrimination: practices, policies and laws / LSE.

- European Disability Forum (2011) "Freedom of movement of goods and services: The need for accessibility". Brussels: EDF, December 2011.

- European Disability Forum (2011). 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union: A Toolkit for Activists and Policymakers. Budapest, General Assembly of the European Disability Forum.

- European Roma Rights Center. Shadow letter to Committee on the Elimination of Discrimination Against Women on the Czech Republic. Geneva: CEDAW Committee. Forty-seventh Session, 2010.

- Fennell, P. (2007) *Mental Health: the New Law*, Bristol: Jordans, 2007.

- Fennell, P. (1996) *Treatment without consent*: *Law, Psychiatry, and the Treatment of Mentally Disordered People Since 1845*. Routledge.

- Ferree, M.M., W.A. Gamson, J. Gerhards and D. Rucht (2002). *Shaping Abortion Discourse. Democracy and the Public Sphere in Germany and the United States*. Cambridge: Cambridge University Press.

- FIGO (2006) *Ethical issues in obstetrics and gynaecology.* FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, Ethical Considerations in Sterilization, November 2006., available at: http://www.figo.org/files/figo-corp/docs/Ethics%20Guidelines%20-%20English%20version%202006%20-2009.pdf

- Final Statement of the Public Defender of Rights in the Matter of Sterilisations Performed in Contravention of the Law and Proposed Remedial Measures. JUDr. Otakar Motejl, Public Defender of Rights, Brno, 23 December 2005. Motion of the Council of the Government of the Czech Republic with respect to sterilisations performed in contravention of the law, 13 December 2007. Resolution of the Government of the Czech Republic 1424 from 23 November 2009.

- Fleischmann, K.R. (2010) "The public library in the life of the Internet: How the core values of librarianship can shape human-centered computing", in J.C. Bertot, P.T. Jaeger, C.R. McClure (eds.), *Public Libraries and the Internet: Roles, Perspectives, and Implications*. Westport, CT: Libraries Unlimited, 91-102.

- Fredman, S. (2005). 'Double trouble: Multiple discrimination and EU Law'*European Anti-discrimination Law Review* 2: 13–21.

- Frohmader Carolyn (2012) Briefing Paper: Sterilisation of Women and girls with disabilities: an update on the issue in Australia for Women With disabilities Australia (WWda) http://www.wwda.org.au/Sterilisation_of_Women_and_Girls_with_Disabilities_UpdateDec2012.pdf (accessed on 5/2/13).

- Geiger, B. et al (2011) "The Healthy Web – Access to online health information for individuals with disabilities". *International Electronic Journal of Health Education* (14), 93-100.

- Gibbs S, Brown M, Muir W (2008) "The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study". *Journal of Intellectual Disability Research.* 52, 12, 1061-1077.
- Gleeson, B. (1999). Geographies of Disability. London Routledge.
- Gonzales L et al. Accessible rural transportation: an evaluation of the Traveler's Cheque Voucher Program. *Community Development: Journal of the Community Development Society*, 2006, 37:106-115. doi:10.1080/15575330.2006.10383112
- Graham, H, (2009) *Understanding Health Inequalities,* Open University Press.
- Hall, E. and Wilton, R. (2011) 'Alternative spaces of 'work' and inclusion for disabled people', *Disability and Society*, 26:7, 867-880.
- Hanna L, Taggart L, Cousins W (2011) "Cancer prevention and health promotion for people with intellectual disabilities: an exploratory study of staff knowledge". *Journal of Intellectual Disability Research.* 55, 3, 281-291.
- Hawthorne, S., J. Denge, N. Coombs (1997) "The Law and Library Access for Persons with Disabilities" *Information Technology and Disabilities* (4:1)
- Hogg J. (2000) Improving essential healthcare for people with learning disabilities: Strategies for success. Dundee: White Top Research Unit.
- Hooks, Bell, (1984) Feminist Theory: From Margin to Center. 2nd. Cambridge, Massachusetts, South End Press.
- Howieson J and K. Clarke (2012) "Ensuring service users can access crucial information" *Learning Disability Practice* (16:1)
- Hughes, K., M. Bellis, et al. (2012). "Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies." Lancet **379**: 1621-1629.
- Human Rights Watch (2012). Human Rights for Women and Children with Disabilities. New York, Human Rights Watch.
- Human Rights Watch (2011) Briefing Paper Sterilisation of Women and Girls with Disabilities: A Briefing Paper, November 10, 2011
- Jaeger, P.T. (2012) *Disability and the Internet: Confronting the Digital Divide*. Lynne Rienner publishers.
- Jaeger, P.T. and C.A. Bowman (2005) *Understanding Disability: Inclusion, Access, Diversity and Civil Rights*. Westport, CT: Praeger.
- Johnson, C.A. (2010) To public libraries contribute to social capital? A preliminary investigation into the relationship, *Library and Information Science Research* 32: 147-155.
- Jones C. and Shorter Gooden K. (2003) Shifting: The Double Lives of Black Women in America, NewYork: HarperCollins.

- Jones, M. and Basser Marks, L. A. (1999) Disability, Divers-Ability and Legal Change, Martinus Nijhoff Publishers.
- Jones, M.K. and Latreille, P. (2010). Disability and earnings: Are employer characteristics important ? *Economic Letters 106*: 191-194.
- Information and Refugee Board of Canada, *Hungary: Reports of the forced sterilisation of women (2000-2011)*, correspondence with the European Roma Rights Centre (18 October 2011), 4 November 2011
- International Disability Alliance (2013) IDA submission to the CRPD Committee's General Discussion on women and girls with disabilities, 17 April 2013, 9th session
- International Labour Organisation (ILO) (2010). Including People with Disabilities in Crisis Response. Geneva, ILO.
- INWD (2010). 15-year Review of the Beijing Declaration and Platform for Action, International Disability Alliance.
- Issac, R., D. Raja, et al. (2010). "Integrating people with disabilities: their right-our responsibility." Disability and Society **25**(5): 627-630.
- Kaban, Elif (1998) Nazi-Style Sterilization Report Shocks Swiss, Reuters, Geneva, August 27, 1998.
- Kim, C.-K. (2011). "Comparative perspectives on disability employment policy." International Review of Public Administration **15**(3): 27-35.
- Kirschbaum, M. and R. Olkin (2002). "Parents with physical, systemic or visual disabilities." Sexuality and Disability **20**(1): 65-80.
- Knudsen, Susanne (2006) Intersectionality—A Theoretical Inspiration in the Analysis of Minority Cultures and Identities in Textbooks. Caught in the Web or Lost in the Textbook, 61–76, http://www.caen.iufm.fr/colloque_iartem/pdf/knudsen.pdf (accessed on 5/2/13).
- Korpi, W. (1994). Class, gender, and power in the development of social citizenship. World Congress of Sociology, Bielefeld, Germany.
- Krizsan, A. Skjeie, H. Squires J. (2012), A Theoretical Framework in *Institutionalizing Intersectionality The Changing Nature of European Equality Regimes*, Palgrave Macmillan, p. 34.
- Kuhlmann Ellen and Annandale Ellen (2012) The Palgrave handbook of gender and healthcare Edition 2.
- Lawson, A. (ed.). (2005). *Disability Rights in Europe: From Theory to Practice*, Oxford: Hart Publishing.
- Lentin, A. and G. Titley (2008). More Benetton than barricades? : the politics of diversity in Europe. The Politics of Diversity in Europe Brussels, Council of Europe**:** 9-30.

- Leonardi M et al. *MHADIE background document on disability prevalence across different diseases and EU countries*. Milan, Measuring Health and Disability in Europe, 2009 (http://www.mhadie.it/publications.aspx, accessed 21 January 2010).

- Lister, R. (2003). Citizenship: Feminist Perspectives. Houndmills, Palgrave Macmillan.

- Locating Intersectional Discrimination (2012) A detailed report on the Conference of 18th/19th October 2012 in Graz on "Intersectional disadvantage and discrimination - social realities and legal practice", http://antidiscrimination.etc-graz.at/cms/index.php?id=22.

- Lombardo, E. and L. Rolandsen Agustín. (2011) "Framing gender intersection in the European Union: What implications for the quality of intersectionality in policies?". Social Politics **19** (4): 482-512.

- Lombardo, E. and M. Verloo. (2009). 'Institutionalizing Intersectionality in the European Union? Policy Developments and Contestations'. *International Feminist Journal of Politics* 11: 4, 478–96.

- Lombardo, E. and M. Verloo. (2009). 'Institutionalizing Intersectionality in the European Union? Policy Developments and Contestations'. *International Feminist Journal of Politics* 11: 4, 478–96.

- Lopez Gonzalez, M. (2009). "Getting to know reality and breaking stereotypes: the experience of two generations of working disabled women." Disability and Society **24**(4): 447-459.

- Loprest P, Maag E. *Barriers to and supports for work among adults with disabilities: results from the NHIS-D*. Washington, The Urban Institute, 2001.

- Malo, M. and R. Pagan (2012). "Wage differentials and disability across Europe: discrimination and/or lower productivity?" International Labour Review **151**(1-2): 43-60.

- Marshall, T. H. (1992) *Citizenship and social class*, London, Pluto perspectives.

- Martin M. (2012) 'Disability Identity – disability-Pride'. Perspectives **16**:1, 14-18

- Marzo, C. (2009), La dimension sociale de la citoyenneté européenne, PUAM, Aix-Marseille.

- McCall, L. (2001) Complex inequality [electronic resource]: gender, class, and race in the new economy, New York: Routledge.

- Mayes, R., G. Llewellyn, et al. (2011). ""That's who I choose to be": the mother identity for women with intellectual disabilities." Women's Studies International Forum **34**: 112-120.

- McCall, Leslie (2001) Complex inequality [electronic resource] : gender, class, and race in the new economy /

- McCall, Leslie (2005) The Complexity of Intersectionality, Journal of Women in Culture and Society, Vol.30, No. 3, Spring 2005, pp. 1771–1800, http://www.journals.uchicago.edu/doi/pdf/10.1086/426800

- McCarthy M. (2009) "I have the jab so I can't be blamed for getting pregnant": Contraception and wome with learning disabilities. Women's Studies International Forum 32 (2009), 198-208.
- McIlfatrick S, Taggart L, Truesdale-Kennedy M. (2011) "Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective". European Journal of Cancer Care, 20:412-20. doi:10.1111/j.1365-2354.2010.01221.x PMID:20825462
- Mencap (2007) Death by Indifference. Mencap, London.
- Mencap (2012) Death by Indifference: 74 Deaths and Counting. Mencap, London.
- Moller Okin, Susan (1997) Is Multiculturalism Bad for Women? Boston Review of Books.
- Moore, M. et al. (2011) The vocational wellbeing of workers with childhood onset of disability: Life satisfaction and perceived workplace discrimination, *Journal of Vocational Behavior 79. 681-698.*
- Nations Unies (2001) Background briefing on intersectionality. Groupe de travail sur les femmes et les droits humains, 45e session des Nations Unies.
- Nixon, J. (2009). "Domestic violence and women with disabilities: locating the issue on the periphery of social movements." Disability & Society **24**(1): 77-89.
- Oliver, M. (1990). The politics of disablement. London, MacMillan.
- Oliver, M. (2009). Understanding Disability: From Theory to Practice. New York, Palgrave Macmillan; 2nd edition
- Ombudsman (2009) *Six Lives: the Provision of Public Services to People with Learning Disabilities.* The Stationery Office, London.
- Open Society Foundations (OSF), 22 November 2010. *From judgement to justice: Implementing international and regional human rights decisions.*
- Orloff, A. S. (1993). "Gender and the social rights of citizenship: The comparative analysis of gender relations and welfare states." American Sociological Review **58**(June): 303-328.
- Parodi, G. and F. Pastore (2012). "Young people, the disabled, and immigrant workers." International Journal of Manpower **33**(1): 4-8.
- Pascoe, E.A.., and Smart Richman, L. (2009) Perceived Discrimination and Health: A meta-Analytic Review, Psychological Bulletin, 135:4, 531-554.
- Plummer, S.-B. and P. Findley (2012). "Women with disabilities' experience with physical and sexual abuse: review of the literature and implications for the field." Trauma, Violence & Abuse **13**(1): 15-29.
- Producing better information for disabled people: A toolkit for local authorities. Office for Disabled People, HM Government. November 2008.
- Rao I. (2004) Equity to women with disabilities in India. Bangalore, CBR Network (http://v1.dpi.org/lang-en/resources/details.php?page=90, accessed 6 August 2010).

- Radhika Coomaraswamy (1999), Report of the Special Rapporteur on Violence Against Women, its Causes and Consequences: Policies and practices that impact women's reproductive rights and contribute to, cause or constitute violence against women, (55th Sess.), E/CN.4/1999/68/Add.4 (1999), [para. 51].

- Ratzka A. *A brief survey of studies on costs and benefits of non-handicapping environments*. Stockholm, Independent Living Institute, 1994.

- Raye, Karin L. (1999) Esq. Director, Women's Rights Advocacy Initiative Mental Disability Rights International *Revised August 4, 1999* - Mental Disability Rights International Women's Rights Advocacy Initiative *Violence, Women and Mental Disability*

- Recommendation of the Commissioner for Human Rights Concerning Certain Aspects of Law and Practice relating to Sterilization of Women in the Slovak Republic. Strasbourg: Council of Europe; 2003.

- Redley M. Citizens with learning disabilities and the right to vote. *Disability & Society*, 2008,23:375-384. doi:10.1080/09687590802038894

- Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak. Geneva: Human Rights Council. Seventh Session, 2008, para 38.

- Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt. Geneva, Commission on Human Rights. Sixty-first Session, 2005, paras 9 & 12.

- Report by Thomas Hammarberg, Commissioner for Human Rights of the Council of Europe, following his visit to the Czech Republic from 17 to 19 November 2010. Strasbourg: Council of Europe; 2011. paras 82–88.

- Ross, T. "Woman with learning disabilities could be forcibly sterilised", *The Daily Telegraph*, 14 February 2011.

- Sassen Saskia (1997) Culture Beyond Gender: A Reply to Susan Moller Okin, Boston Review of Books.

- Savell, K. (2004) "Sex and the Sacred: Sterilization and the Bodily Integrity in English and Canadian Law". McGill Law Journal (49).

- Schiek D. and Chege V. (2009) European Union non-discrimination law : comparative perspectives on multidimensional equality law London ; New York : Routledge-Cavendish.

- Schroeder S, Steinfeld E. *The estimated cost of accessibility*. Washington, United States Department of Housing and Urban Development, 1979.

- Scullion, P. (2009). "Models of disability: their influence in nursing and potential role in challenging discrimination." Journal of Advanced Nursing **66**(3): 697-707.

- Servais L, Leach R, Jacques D, Roussaux JP. (2004) Sterilisation of intellectually disabled women. European Psychiatry 2004;19:428-32.

- Shachar Ayelet (2000) On Citizenship and Multicultural Vulnerability, Political Theory, Vol. 28-1, 64-89.
- Shakespeare, T. (2006). Disability: Rights and Wrongs. London and New York, Routledge.
- Shakespeare, T., L. Iezzoni, et al. (2009). "Disability and the training of health professionals." Lancet **374**: 1815-1816.
- Solanke I. (2009) Putting Race and Gender Together: A New Approach To Intersectionality, *Modern Law Review*, 72(5) 723/749.
- Solanke I. (2011) Infusing the silos in the Equality Act 2010 with synergy, *Industrial Law Journal*, 40(4), 336-358. See also Iyiola Solanke**,** Tackling multiple discrimination: Delivering equality in the 21st century, LSE blog, 7 September 2011, http://blogs.lse.ac.uk/diversity/2011/09/tackling-multiple-discrimination-delivering-equality-in-the-21st-century/ (15/4/13).
- Sterilisation of Women and Girls with Disabilities, A Briefing Paper, October 2011, http://www.hrw.org/news/2011/11/10/sterilisation-women-and-girls-disabilities (accessed on 5/2/13).
- Steven Winter Associates. *Cost of accessible housing*. Washington, United States Department of Housing and Urban Development, 1993.
- Stone, E. and M. Priestley (1996). "Parasites, pawns and partners: disability research and the role of non-disabled researchers." British Journal of Sociology 47(4): 699-716.
- Study on The Situation of Women with Disabilities in the framework of the European Year of Equal Opportunities for All and in view of the UNCPRD (VC/2007/317)/ Etude sur la situation des femmes handicapées à la lumière de la CNRDPH VC 2007/317, Rapport final pour la DG Emploi.
- Svenonious, E. (2000) *The Intellectual Foundation of Information Organization*. Cambridge: MIT Press.
- Sweden Country Report on Human Rights Practices for 1997, Bureau of Democracy, Human Rights and Labor, 1/30/98.
- Taylor-Gooby, P. (1991). "Welfare state regimes and welfare citizenship." Journal of European Social Policy **1**(2): 93-106.
- Thiara, R., Hague, G and Mullender, A. (2011) Losing out on both counts: disabled women and domestic violence, *Disability and Society*, 26:6, 757-771.
- Thomas, Q. (26.04.2013) "La "silver economy" veut mettre la high-tech au service des seniors" in *Le Monde.*
- Turner, B. (1992) Outline of a theory of citizenship, in Mouffe, C., *Dimensions of radical democracy: pluralism, citizenship, community*, London, New York, Verso, pp. 33-63.
- UNESCO (November 2011) Consultative Expert Meeting Report, "Accessible ICTs and personalised learning for students with disabilities" (17-18 November 2011)
- UNESCO Global Report (February 2013) "Opening New Avenues for Empowerment: ICTs to Access Information and Knowledge for Persons with Disabilities"

- United Nations. 12 October 2011. Human Rights Council, *Summary prepared by the Office of the High Commissioner for Human Rights in accordance with paragraph 15 (c) of the Annex to Human Rights Council Resolution 5/1.* (a/HRC/WG.6/11/HUN/3) (ecoi.net)

- Utah University, Centre for Persons with Disabilities. Constructing a POUR website. Putting People at the Centre of the Process; 2010. http://webaim.org/articles/pour

- Verloo, M. (2006) "Multiple inequalities, intersectionality and the European Union". European Journal of Women's Studies.**13**: 211

- Waddington, L. (2009) "A Disabled Market: Free Movement of Goods and Services in the EU and Disability Accessibility". *European Law Journal* (15:5), 575-598.Walby, S (1994) Is citizenship gendered? Sociology 28 (2): 379-395

- Walby, S (1994) Is citizenship gendered? Sociology 28 (2): 379-395

- Warner, D. and Brown, T. (2011) 'Understanding how race/ethnicity and gender define age-trajectories of disability: An intersectionality approach', Social Science and Medicine, 72, 1236-1248.

- Williamson, K., and J. Roberts (2010) "Developing and sustaining a sense of place: the role of social information". *Library and Information Science Research* 32: 281-287.

- World Health Organization (WHO), Medical Eligibility Criteria for Contraceptive Use, 4th edition, 2004.

- World Health Organisation (WHO) (2011) World Report on Disability. Geneva: WHO.

- Yuval-Davis, N. (2006) "Intersectionality and Feminist Politics" European Journal of Women's Studies.**13**: 193

- Zampas C. and A. Lamačková, (2011) "Ethical and legal issues in reproductive health: forced and coerced sterilization of women in Europe". *International Journal of Gynaecology and Obstetrics* (114), 163–166.

- Zavirsek, D. (1998) Disability as a Gendered Taboo, Women Participating in Global Change, International Association of Schools of Social Work, Women's Symposium (Hong Kong) Publications Committee (1998).

ANNEX 1: NATIONAL LEGAL FRAMEWORKS REGULATING STERILISATION OF WOMEN WITHIN THE EU

This section aims at presenting a comparative description of the legal framework for the sterilisation of women, not only disabled women, in some member states of the European Union and an analysis of the compatibility of these legislations and practices with the obligations arising from the CRPD.

Overview

At present, the majority of European countries have legislation pertaining to sterilisation. Most of them have applied the international recommendations but some still do not have a legal framework. There is also variation in the wording of the legislations and the judges' attitudes towards cases of sterilisation. This reflects a difference in traditions and practices. For instance, a country adopts measures to ensure that all health care and services provided to children and adults with disabilities, including all mental health care and services are based on the free and informed consent of the individual concerned, and that involuntary treatment and confinement are unlawful. It ensures that reproductive health services are respectful of the dignity and integrity of persons with disabilities based on the free and informed consent of the individual concerned and that all non-consensual treatment including that for which consent is given by a third party, is forbidden by law. When it comes to traditions they vary considerably. For instance, in Slovakia, a tradition of sterilising Roma and disabled women is now fading[109].

Figure 3: Attitudes of the EU Member States to sterilisation

Country	Attitude
Austria	Standard sterilisation act (1974)
Belgium	Unclear Recommendations were made to repeal legal provisions allowing sterilisation of women and girls with disabilities and calling for its abolition in law and in practice.
Bulgaria	Unclear
Croatia	Unclear, but report last year claiming that women with disabilities in institutions have undergone abortions without their consent.
Cyprus	Unclear
Czech Republic	According to the report of the Czech Public Defender of Rights, the practice of 7-day waiting period before sterilisation is performed poses a legal obligation on healthcare providers to inform patients on the permanency of sterilisation and alternatives to sterilisation; provides training to health professionals on informed consent; and institutes a compensation scheme for women who have fallen victim to such practices.

[109] Centre for Reproductive Rights, Poradňa pre občianske a l'udské práva (Centre for Civil and Human Rights or Poradňa). Body and Soul, Forced Sterilisation and Other Violations of Roma Women's Reproductive Freedom in Slovakia.

	However, no legal framework yet, yet sterilisations widely performed
Denmark	Standard Sterilisation Act 1973, 1976 Recommendations to repeal legal provisions allowing sterilisation of women and girls with disabilities and calling for its abolition in law and in practice
Estonia	n/a
Finland	Evolution through a new legislation (1970, 1985)
France	Contraceptive sterilisation cannot be performed on an adult whose impaired mental faculties have created a handicap and justified a wardship / state guardianship order unless there is an absolute medical contraindication to usual contraceptive methods or an impossibility to efficiently administer them. The decision is taken by a wardship judge at the request of the person, his/her parents or the legal representative of the person, after hearing an expert committee. See Article L. 2123-2 Public Health Code.
Germany	Difficult history[110]. Standard sterilisation act (1976) According to German law, sterilisation is generally prohibited up to the age of 18 years (§ 1631c Bürgerliches Gesetzbuch - BGB). After that time, persons are free to decide for themselves. However, § 1905 BGB describes under which conditions sterilisation of persons deemed unable to consent is permitted by law. In this case, operations have to be approved by the guardianship court. Between 2002 and 2010 an average of 100 cases per year of sterilisation of individuals whose legal capacity has been restricted were approved, whereas an average of only 23 cases were denied[111]. Articles 2, 7, 23, 16, 26 Take steps to repeal § 1905 of the German Civil Code to abolish the forced sterilisation of women with disabilities whose legal capacity has been restricted.
Greece	Unclear
Hungary	Standard sterilisation act (1987), but many violations. Hungarian Civil Liberties Union has revealed widespread use of contraceptives given to women residents or in social care institutions for people with disabilities.
Ireland	Unclear
Italy	Standard sterilisation act (1978, 1982)
Latvia	n/a
Lithuania	n/a
Luxembourg	Standard sterilisation act (1978)
Malta	Unclear
Netherlands	Standard sterilisation act

[110] From nurturing the nation to purifying the Volk : Weimar and Nazi family policy, 1918-1945 / by Mouton, Michelle, 1965- Published 2007
[111] http://dejure.org/gesetze/BGB/1905.html

Poland	Unclear
Portugal	Standard sterilisation act (1984)
Romania	Standard sterilisation act (1989)
Slovakia	Standard sterilisation act adopted in 2004, difficulties of enforcement[112]. Exposure by the Council of Europe's Commissioner for Human Rights[113] and by the UN Race Discrimination Committee's 2010 who recommended to the Slovak Government to "establish clear guidelines concerning the requirement of 'informed consent' and to ensure that these guidelines are well-known among practitioners and the public[114].
Slovenia	Standard sterilisation act (1977)
Spain	Standard sterilisation act (1983)
Sweden	After a controversial history[115], Sweden has adopted a standard sterilisation act. There have been no present-day allegations of such practices.
UK	Standard Sterilisation Act. Under the Mental Capacity Act 2005, the Court has the power to decide on medical treatments for individuals judged by psychiatrists to lack mental capacity The case law on its application is very relevant as it shows the difficulties of interpretation of the law[116]. The court can also order "terminations of pregnancy" for women who lack capacity to consent, as well as "experimental or innovative treatment" and medical procedures that require the use of force to restrain the patient. See the English House of Lords decision in the Gillick case [1986] AC 112 regarding the circumstances in which contraceptive advice and treatment could be provided to girls under the age of 16 without parental consent.

Three examples: France, Hungary, the United Kingdom

France

Sterilisation is normally avoided in France.[117] According to Article 16-3 of the French civil code,[118] "there may be no invasion of the integrity of the human body except in case of medical necessity for the person or exceptionally in the therapeutic interest of others[119].

[112] http://reproductiverights.org/sites/default/files/documents/bo_slov_part3.pdf
[113] Recommendation of the Commissioner for Human Rights Concerning Certain Aspects of Law and Practice relating to Sterilisation of Women in the Slovak Republic. Strasbourg: Council of Europe; 2003.
[114] Committee on the Elimination of Racial Discrimination, Concluding Observations: Slovakia. Seventy-sixth Session, 2010, Para 18.
[115] Steriliseringsfragan i Sverige 1935–1975 Ekonomisk ersättning (The Sterilisation Question in Sweden 1935–1975. Economic compensation) Delbetänkande av 1997 ars steriliseringvutredning, Stockolm, 1999 (Zampas, Lamačková, 2011).
[116] See upon, section on the examples.
[117] There are exceptions. See for instance, Laurence Brunet, Stérilisation et changement de la mention du sexe à l'état civil : les atermoiements du droit français
[118] Article 16-3 du code civil (Créé par Loi n°94-653 du 29 juillet 1994 - art. 3 JORF 30 juillet 1994
[119] Act no 2004-800 of 6 Aug. 2004.

The consent of the person concerned must be obtained previously except when his state necessitates a therapeutic intervention to which he/she is not able to assent".

A report from the general inspection of social affairs (IGAS) considers that it is possible to sterilise a woman in very limited cases and with the judge's authorisation. These cases include the risk to the pregnancy, a clear parental incapacity, the impossibility to use efficient contraceptive means without putting the woman's life in danger. This report stresses the importance to allow disabled women to have a free sexuality and encourages the use of normal contraception.

Article L. 2123-2 of the public health code (code de la santé publique), modified by a law of 2001[120], forbids the tubal ligation with a contraceptive goal on minors and disabled adults under guardianship or curatorship, unless there is "an absolute medical contraindication to contraceptive methods or a proven impossibility to efficiently use them"[121]. It states that "contraceptive sterilisation cannot be performed on an adult whose impaired mental faculties have created a handicap and justified a wardship/ state guardianship order unless there is an absolute medical contraindication to usual contraceptive methods or an impossibility to efficiently administer them"[122]. The decision is taken by a wardship judge at the request of the person, his/her parents or the legal representative of the person, after hearing the opinion of a committee of experts. The judge should hear the person. If she is able to express his/her preference, her consent should systematically be requested and taken into account after "an information adapted to her degree of understanding" was given. The refusal or the revocation of her consent cannot be ignored. The judge should also hear the parents of the legal tutor as well as all persons whose audition is useful[123].

It must be said that France has ratified the CRPD. It is also part of the EU and the Council of Europe. This does not mean that there cannot be abuses. Practices of forced sterilisation were reported in the Gauer case in front of the ECtHR,[124] in a Senate report,[125] and press articles[126]. Even if these practices were deemed unlawful even at the time they were performed, it seems that France was reluctant to punish them and justice got delayed. The ECtHR judgement is expected[127].

Hungary

Sterilisation as a method of contraception is permitted in Hungary for family planning purposes or for health reasons under Article 187 of the Public Health Act[128] and Welfare Ministry Order no. 25/1998 (VI. 17)[129], but has been considered very unpopular in the past[130]. The specificity of Hungarian law is that its legal provisions do not provide for

[120] Loi n° 2001-588 du 4 juillet 2001.
[121] *Une contre-indication médicale absolue aux méthodes de contraception ou une impossibilité avérée de les mettre en oeuvre efficacement* .
[122] Article L. 2123-2 modified by Article 27, Loi 2001-588 du 4 juillet 2001 relative à l'interruption volontaire de grossesse et à la contraception.
[123] J. Juilhard, *Handicapés – Maltraitance Envers les Personnes Handicapées: Briser la loi du Silence*, TOME 1, RAPPORT DE COMMISSION D´ENQUÊTE, http://www.senat.fr/rap/r02-339-1/r02-339-15.html (accessed on 19/04/13).
[124] See above, ECHR section.
[125] J. Juilhard, *Handicapés – Maltraitance Envers les Personnes Handicapées: Briser la loi du Silence*, TOME 1, RAPPORT DE COMMISSION D´ENQUÊTE, www.senat.fr/rap/r02-339-1/r02-339-15.html (accessed on 19/04/13).
[126] As quoted in the Senate report.
[127] See upon, ECHR section.
[128] 1997. évi CLIV. törvény az egészségügyrOEl [Act CLIV of 1997 on Public Health Care], art.187 (JURIX).
[129] 25/1998. (VI.17.) NM rendelet a mıvi meddOEvételrOEl [Ministry of Welfare Order on Artificial Sterilisation] (JURIX).
[130] Centre for Reproductive Rights, "Hungary" in *Women of the World*. 2003.

enough checks to ensure the voluntary and informed consent of patients to the permanent act of sterilisation. Provisions of the Public Health Act indeed leave the door open for forced or coerced sterilisation through two main loopholes in the law:

- Misinformation of the patient: Article 187(2) regarding information on the sterilisation intervention to be provided by the doctor as a predicate to informed consent includes information on the "chances of reversibility". This is contrary to international definitions of sterilisation as a permanent procedure and contravenes standards of information during the counselling on sterilisation set by WHO and FIGO[131];

- "Emergency" decision of the physician: the Public Health Act allows a physician to perform sterilisation surgery without following any special procedure, or without following a rigorous information procedure, "when it seems to be appropriate in certain circumstances". The fuzziness of the definition allows for arbitrary decisions to be taken without prior consultation of the patient.

Hungary has ratified the CRPD, but the extent of its compliance to the Convention is unclear, as elements in its legal regime are not consistent with international regulations. Moreover, reports from civil society organisations denounce forced sterilisation practices on minority women, including foremost disabled women and women from the Roma community[132].

Hungary represents an interesting case in our analysis of forced sterilisation, as it sheds light on the legal regimes of Eastern European countries, in particular the discrepancy between law and implementation, as well as the treatment of minority women. Although there are fewer reported cases of forced sterilisation than in the neighbouring Czech Republic and Slovakia[133], one recent case was very mediatised. A.S. v. Hungary represents a landmark decision: it was the first time that an international body held a state responsible of violating a citizen's right to full information and consent on the sterilisation procedure[134]. CEDAW recommended the Hungarian state to compensate A.S. and make fundamental changes in its legal and policy procedures.

Consequences of the A.S. case in Hungarian law

CEDAW's recommendations for action have in consequence initiated some change in Hungarian law, which was cited as one of CEDAW's success stories for its thirtieth anniversary in 2009[135]. This comes at a time when the legislative regime is being reviewed at its core:

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[131] ETHICAL ISSUES IN OBSTETRICS AND GYNECOLOGY by the FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, Ethical Considerations in Sterilization, November 2006., available at: http://www.figo.org/files/figo-corp/docs/Ethics%20Guidelines%20-%20English%20version%202006%20-2009.pdf; Medical Eligibility Criteria for Contraceptive Use, World Health Organization (WHO), 4th edition, 2004, p. 8.

[132] Karin L. Raye, Esq. Director, Women's Rights Advocacy Initiative Mental Disability Rights International *Revised August 4, 1999* - Mental Disability Rights International Women's Rights Advocacy Initiative *Violence, Women and Mental Disability*.

[133] Gwendolyn Albert, "Forced sterilisation and Romani Women's Resistance in Central Europe", *Different Takes* (71), summer 2011.

[134] Open Society Foundations (OSF), 22 November 2010. *From judgement to justice: Implementing international and regional human rights decisions*; Christina Zampas & Adriana Lamačková, "Ethical and legal issues in reproductive health: forced and coerced sterilization of women in Europe". *International Journal of Gynaecology and Obstetrics* (114).

[135] See http://www.unifem.org/cedaw30/success_stories/#hungary (accessed 14 April 2013),

- The Public Health Act was amended by Hungary in 2008, to comply with the recommendations of the CEDAW on the legislation of sterilisation. Revisions include differentiating between persons of legal capacity, incompetent persons, and persons with limited capacity; waiting times between requests and procedure; stricter conditions before the procedure is authorised; provision of adequate information. The change operated by the Hungarian government following the recommendations of the international committee provide a stark improvement in the prevention of abusive sterilisation of women. However, in CEDAW's "Concluding Observations on the combined seventh and eight periodic reports of Hungary" of 1 March 2013, the Committee notes that additional changes are still needed. Some of the elements judged as crucial by CEDAW, such as the inclusion of the statement that a "patient has to be informed about the permanent nature of the operation" rather than "chances of reinstalling fertility", as well as the removal of the paragraph on sterilisation for medical reasons, which is contrary to WHO and FIGO concepts of sterilisation, was not adopted by the Hungarian government[136];
- In February 2009, the Ministry of Social Affairs and Labour announced that they would compensate Ms A.S. in line with CEDAW's recommendations – this appears to not have happened as of yet, however;

- On 18 April 2011, Hungary adopted a new Constitution (Fundamental Law), which entered into force on 1 January 2012. The Constitution has been subject of controversy, at is criticised for having been written without consultation of the population and for adopting the conservative Christian worldview of the ruling party. It is doubtful if in these circumstances, further compliance with international standards on sterilisation will be implemented in the near future.

Despite changes in the law, various human rights experts indeed assert that forced sterilisation is still occurring[137], as testified by a 2008 case represented by the European Roma Rights Centre[138], although they are difficult to document[139] due to a) lack of sex disaggregated data, in particular on women belonging to disadvantaged groups[140], b) a traditional patriarchal structure, which prevents women from speaking up about these issues for fear of exclusion, and of seeking redress with the relevant parties.

United Kingdom

The United Kingdom (UK) has a legal system based on common law, which means that the law is developed through court decisions cases. In the UK, the administration of non-consensual medical treatment is absolutely prohibited for all "conscious adults of sound mind" (per Sir Thomas Bingham MR in *Bland* [1993]). However, the Abortion Act of 1967 provided safeguards for the doctors involved in the forced sterilisation or abortion of mentally handicapped women, as was held in the case Re SG (Adult Mental Patient:

[136] Chance for Children et al. "Annex 1 – Recommendations", *Hungary - Submission to the UN Universal Periodic Review 11th session of the UPR Working Group of the Human Rights Council*, November 2010.
[137] United Nations. 12 October 2011. Human Rights Council, *Summary prepared by the Office of the High Commissioner for Human Rights in accordance with paragraph 15 (c) of the Annex to Human Rights Council Resolution 5/1.* (a/HRC/WG.6/11/HUN/3) (ecoi.net)
[138] Chance for Children et al. *Hungary - Submission to the UN Universal Periodic Review 11th session of the UPR Working Group of the Human Rights Council*, November 2010.
[139] Information and Refugee Board of Canada. 4 November 2011. *Hungary: Reports of the forced sterilisation of women (2000-2011)*, correspondence with the European Roma Rights Centre (18 October 2011); Chance for Children et al. *Hungary - Submission to the UN Universal Periodic Review 11th session of the UPR Working Group of the Human Rights Council*, November 2010.
[140] CEDAW. 1 March 2013. Concluding Observations on the combined seventh and eight periodic reports of Hungary adopted by the Committee at its fifty-fourth session (11 February – 1 March 2013).

Abortion) [1993] and Re E (a Minor) [1991]. As such, until the 1980s, urgent operations on an unconscious person were not prohibited on the basis that "the surgeon's action is acceptable in the ordinary conduct of everyday life" (per Croom-Johnson LJ in *Wilson v. Pringle* [1986]).

This system changed after a controversial case, Re F (Mental Patient: Sterilisation) [1989], which introduced a more substantial criterion than the "ordinary conduct of everyday life". At common law, from 1989, the legal justification for performing an emergency non-consensual medical treatment such as sterilisation on an adult had to be guided by the principles of "necessity" and "best interests" of the patient. It was held that these principles should be based on the *Bolam* standard, i.e. on the basis that a majority of a responsible body of medical opinion considers the treatment to be in the best interest of the patient. This criterion for determining the "best interests" of the patient was complemented by another safeguard in case Re A (Male Sterilisation) [2000], which held that the treatment should be judged to provide "significant credit" of probable advantages over disadvantages"[141]. In JS v a NHS Trust [2002], the concept of "best interests" was broadened to include the medical as well as *non-medical* benefits and losses, although the distinction between therapeutic and non-therapeutic had been rejected several years earlier in the case of Re B (A Minor) (Wardship: sterilisation) [1987], a minor ward sterilised without his consent[142].

The legal texts of England and Wales making provision for the treatment of patients with mental disorder without their consent are:

1) The Mental Health Act (MHA) of 1983, specifically part IV and section 58, which allow for patients to be treated without their consent if a second opinion doctor approves the treatment on the grounds that it is "for mental disorder" (B v Croydon HA [1995]) and "likely to alleviate or prevent deterioration in the patient's condition" (Reid v Secretary of State for Scotland [1999]);

2) The Mental Capacity Act (MCA) of 2005 codifies the common law doctrine of necessity in its sections 5 and 6. It provides that treatment can be carried out on mentally incapacitated adults without their consent for physical or mental disorder, without incurring liability in battery;

3) The Mental Health Act 2007, aimed at amending the 1983 Act and at introducing *"deprivation of liberty safeguards"* by amending the MCA[143].

The main arguments accepted to authorise sterilisation of women is a) their lack of sexual autonomy[144], and b) their inability to care for a child (see Re B., Re F., Re P., Re M., re H.G., Re W.).

No cases appear to have arisen on the *de facto* forced sterilisation of UK citizens. The English Courts, and since 2005, the Court of Protection specifically, have however been solicited several times to rule on the legality of sterilising mentally impaired individuals. The MCA and its supplemented Code of Practice indeed extended the jurisdiction of the Court of

[141] In this case, the male patient suffered from Down Syndrome. His mother sought his sterilisation to avoid his fathering of a child that he could not have cared for and protect potential partners from the consequences of an unwanted pregnancy. The Court refused the application on the grounds that there was no benefit for the patient but that the benefit would have been for a third party.
[142] Case cited in Kristin Savell, "sex and the Sacred: Sterilization and the Bodily Integrity in English and Canadian Law". McGill Law Journal (49) 2004.
[143] UK National Archives, accessed on 8 April 2013: http://www.legislation.gov.uk/ukpga/2007/12/contents
[144] Kristin Savell, "sex and the Sacred: Sterilization and the Bodily Integrity in English and Canadian Law". McGill Law Journal (49) 2004: 1140.

Protection, previously only competent in the area of financial affairs of people lacking capacity to manage their own affairs. Since 2005, the Court of Protection has indeed heard a handful of cases on request of non-consensual sterilisation.

Another recent and particular case of 2011 concerning a mentally disabled woman of 21 years' old, whose case brought to the Court by her mother, Mrs P., asking that her daughter be sterilised during the caesarean section she was due to have for her second child, raising concerns regarding her ability to use alternative forms of contraception. The case was picked up by the British press in February 2011 and the hearing by the Court of Protection was exceptionally scheduled as an open hearing because of the "overwhelming 'public interest' in understanding the case"[145]. It is unclear what the Court ruled.

In respect of the elements cited above, it appears the British law compliance to the requirements set out by the CRPD.

[145] Ross, Tim. "Woman with learning disabilities could be forcibly sterilised", *The Daily Telegraph*, 14 February 2011.

ANNEX 2: INSPIRING LEGAL FRAMEWORKS REGULATING STERILISATION – ONE EXAMPLE FROM A THIRD COUNTRY: AUSTRALIA

Australia has been the theatre of a heated debate about sterilisation. It was a precursor in the debate of sterilisation of disabled girls or women. A national report of 1997 followed heavy criticisms of the doctrine. It should lead to the adoption of an act this year.

It must be said that Australia is not the only interesting country. The US is a federal state which provides a fruitful case law[146] on the question of sterilisation of young disabled women such as the Ashley X case[147]. The diversity of systems in the States would make a comparison with the EU very relevant[148]. Similarly, Canada presents a special interest because of its history and evolution. For instance, in Alberta, the 1928 Sexual Sterilisation Act which legally provided for sterilisation of disabled persons was repealed in 1972. The Senate's debates and arguments of relevant cases such as the Leilani Muir v Her Majesty the Queen in Right of Alberta of 1995 shows the interests at stake (Jones, M. and Basser Marks, L. A., 1999).

But Australia has been chosen in this instance as important developments have taken place in this field and in this country. A legislation is about to be passed. A Senate Inquiry into Involuntary or Coerced Sterilisation of People with Disabilities in Australia started in late 2012. The Senate should report on the Inquiry by June 2013.

The Australian current approach relies on the "best interest approach". If some see it as a way to "perpetuate discriminatory attitudes against women and girls with disabilities, and [...] to facilitate the practice of forced sterilisation",[149] others see it as a way to balance the different interests at stake. A good example is given by the famous Marion case.

The case of In re Marion[150] originally came before the Full Court of the Family Court of Australia in June 1990. It involved the difficult issue of who may lawfully authorise the sterilisation of an intellectually disabled teenage girl, and therefore brought into sharp relief the debate concerning family autonomy versus state intervention sparked off in previous instances where decision-making over children's welfare has been contested[151].

By a 2 to 1 majority, the Full Court of the Family Court decided that the parents, as joint guardians of Marion, were able to authorise her sterilisation without a court order, although Strauss J considered that Family Court approval should still be obtained as a matter of prudence. McCall J found that the relevant provisions of the Family Law Act gave the parents responsibility for the long-term welfare of their child, and also independently granted them all the common law powers, rights and duties associated with guardianship. He concluded that these were sufficiently wide to enable parents to authorise sterilisation.

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[146] Better for all the world: the secret history of forced sterilization and America's quest for racial purity /by Bruinius, Harry. Edition 1, Published 2007

[147] the Ashley X case: http://www.nwabr.org/education/pdfs/PRIMER/PrimerPieces/Ashley.pdf.

[148] http://www.uvm.edu/~lkaelber/eugenics/.

[149] Senate Inquiry into Involuntary and Coerced Sterilisation of People with Disabilities in Australia (September 2012 - April 2013), http://www.wwda.org.au/senateinquiry2012.htm (see on 22/04/13).

[150] (1991) FLC 92-193.

[151] What's New in Family Law? Parental Authority and its Constraints, The Case of 'Marion', Margaret Harrison, http://www.aifs.gov.au/institute/pubs/fm1/fm32mh.html

They held that the parents could not lawfully authorise a sterilisation procedure to be carried out on their daughter without a court order. It remained unclear whether sterilisation could be authorised by the parents or by a judge[152].

Since then, as one can see in the Australian Government's response to the UN on 16 December 2011, 'sterilisations are authorised only where they are the last resort, as less invasive options have failed or are inappropriate, and where they are in a person's best interests'.

Australia ratified the CRPD in 2008. In June 2012, the Committee on the Rights of the Child, it expressed its serious concern that the absence of legislation prohibiting non-therapeutic sterilisation of girls and women with disabilities "is discriminatory and in contravention of article 23(c) of the Convention on the Rights of Persons with Disabilities". The Committee urges the State party to: "enact non-discriminatory legislation that prohibits non-therapeutic sterilization of all children, regardless of disability; and ensure that when sterilisation that is strictly on therapeutic grounds does occur, that this be subject to the free and informed consent of children, including those with disabilities". Furthermore, the Committee clearly identified non-therapeutic sterilisation as a form of violence against girls and women, and recommended that the Australian Government 'develop and enforce strict guidelines to prevent the sterilisation of women and girls who are affected by disabilities and are unable to consent.'[153]

To summarise, at an international level, it is thought that Australia should enact national legislation prohibiting the use of non-therapeutic sterilisation of children, regardless of whether they have a disability, and of adults with disabilities without their informed and free consent. But, the Australian Government has to date, argued that: "the Australian Government considers that the 'best interests' test as articulated and applied in Australia is consistent with Australia's international obligations[154]." On 10 December 2012, International Human Rights Day, the Australian Government released its National Human Rights Action Plan[155]. It states that "the Australian Government will work with states and territories to clarify and improve laws and practices governing the sterilisation of women and girls with disability".[156]

In any case, activism in Australia has mobilised people on the subject of sterilisation. If no law has been adopted yet, the voices raised around this question have started to create consciousness.

[152] 2 cases decided in each direction: Re a Teenager (1988) 94 FLR 181, Re Jane and Re Elizabeth (1989) FLC 92-023, and In re S (1988) 98 FLR 41.)
[153] UN Committee on the Rights of the Child; *Consideration of reports submitted by States parties under article 44 of the Convention; Concluding observations: Australia*; Sixtieth session, 29 May–15 June 2012; CRC/C/AUS/CO/4; UN Committee on the Rights of the Child; *Consideration of reports submitted by States parties under article 44 of the Convention; Fourth periodic report of States parties due in 2007: Australia*; 25 June 2009; CRC/C/AUS/4; see also Sterilisation of Women and Girls with Disabilities: An update on the issue in Australia, *By Carolyn Frohmader for Women* With Disabilities Australia (WWDA), Updated December 2012, http://www.wwda.org.au/senateinquiry2012.htm, accessed on 22/4/13.
[154] United Nations General Assembly, Human Rights Council (2011) *Report of the Working Group on the Universal Periodic Review: Australia; Addendum: Views on conclusions and/or recommendations, voluntary commitments and replies presented by the State under review.* Seventeenth session, A/HRC/17/10/Add.1.
[155] The National Human Rights Action Plan is available at: http://www.ag.gov.au/Humanrightsandantidiscrimination/Australiashumanrightsframework/Pages/NationalHumanRightsActionPlan.aspx
[156] Commonwealth of Australia (2012) *Australia's National Human Rights Action Plan 2012*.

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