



**LOBBY EUROPEEN DES FEMMES  
EUROPEAN WOMEN'S LOBBY**

**Disabled women – non-disabled women  
Strategies of action within the European context  
by  
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When speaking about disabled women it should always be done in relation to all women and the inequality that exists in our society between women and men.

But to understand the position and difficulties of disabled women as citizens in the European Union, but also as participants in both the Disability and the Women's movements we have to understand a little bit more of the historical structures in society and the causes for inequality and discrimination that women face on a day to day basis.

**Discrimination of women**

Despite the considerable progress made since the last century, equality between women and men is far from being a reality and signals of backlashes reach us from countries that were more advanced in reaching their goals for equality between women and men. The many inequalities that still exist in Europe are particularly obvious when the girl-child starts school or when women begin to work and/or start a family. Moreover if we look especially to the situation of young black, migrant and refugee women, we see similarities with women and girls from extremist countries. One of the biggest concerns remains the violence against women that takes many forms (domestic violence, street violence, sexual harassment, rape, gang violence, slavery, etc.) and concerns all women all over the world regardless of age, disability or social background. The number of women in the European Union dying as a result of domestic violence is growing rather than decreasing and it is estimated that one woman in five in Europe experiences some form of violence.

The fight for real equality between women and men is clearly not over and needs even more emphasis to tackle the present backlashes for the position of women in countries like Sweden and The Netherlands, for a long time being regarded as exemplary models for equality between women and men.

Inequality between women and men is based on a long tradition of paternalistic, cultural and religious dominance of men over women. The decision-making structures and the financial world are male dominated and it is still men who decide on war and peace.

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But what has this to do with disabled women you may wonder? Well let me be very clear the position of disabled women in the world is on gender grounds no different from non-disabled women. On the basis of their impairments they face however disabling factors that restricts them in a larger context than non-disabled women.

### **Position of disabled women**

If we look to the participation in decision-making structures of disabled women and mothers of disabled children we see an even lower to zero percentage. The same is applicable within the disability organisations and women's organisations. Although there are approx. 53% of disabled women of all disabled people with a growing number to approx. 58% in 2015, most disability organisations are run by men and gender mainstreaming of policies and decisions is not a fact or even a topic. The same can be said for mothers of disabled children. A large number of parents with disabled children are divorced leaving the mother with the sole caretaking of her child. Her chances to active participation in politics (within GO's and NGO's) is very limited in comparison to mothers of non-disabled children.

Society often questions whether the situation of disabled women is so very different from the situation of disabled men. The notion of multiple discrimination, on grounds of gender and disability is (and has proven to be) very complex. The situation as I described it for non-disabled women is the same or I could say even worse for disabled women.

### **Is disability gender neutral?**

To answer this question we have to first explore what we mean with *disability* and *gender*. Both are so-called social concepts and often inextricably linked with the medical/biological concepts of *impairment* and *sex*.

There is a clear difference of the usage of the word *disability* within the medical and political discourses (e.g. disability organisations) and the way the word is used within the social discourse on disability (academic approach).

*Sex* and *gender* are two concepts often used as synonymous, which as a rule is OK in daily life, but it is not good enough in science or in politics, as *sex* refers to the biological aspect of women and men, and *gender* is the social concept that is femininity/female and masculinity/male. What is female and male is socially constructed - the proof of this is the big variations between women and men depending on time, space and class.

By analyzing the social discourse on disability and on gender, we can perhaps more clearly understand how misunderstandings have occurred within the disability movement both in relation to disability as well as in relation to gender in combination with disability.

Disabled women are often seen as sex-neutral beings, as beings without a sexual identity. They are most likely referred to as **The Disabled** with no reference to being people, let alone to being a woman or a man.

This reference, often a result of the medical model, has separated the needs of the women or men in the first place from the needs related to the impairment.

Disabled women are born first as girls/women and their impairment is a secondary dimension, which is exacerbated by environmental factors. It cannot be seen as unimportant but certainly not the only distinguishing feature in an individual. Moreover it is society itself who creates (social) barriers for women with impairment that hampers them to act fully in society.

When society recognises that there is a human element in all of us, they see us as disabled women and again not distinguishing a disabled woman from a disabled man.

Society believes that disabled women and men have the same needs, based primarily on the impairment and not based on human potential and values.

But let me explain first what we mean with Medical and Social Models and why it is so important to understand its concepts in order to understand the double discrimination that disabled women face?

### **The Individual (personal tragedy) or Medical model**

This model places the causes of the problems directly by the individual and her/his impairment. Within this model, a woman's functional limitations (impairments) are the root cause of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure. The individual or medical model views an impairment as an 'abnormality', that needs to be 'corrected', 'cured', 'overcome'. The Medical Model has value in certain contexts, but when it is used as the only model for approaching disability, it is seriously defective: based on the concepts of 'normality' and 'abnormality', it sees the human body as flexible and alterable and the social environment as fixed and unalterable: if a woman does not fit the social environment, then that woman -not the environment- must be changed.

So if all disturbances in a disabled woman's life are all attributed to the impairment it can effect her life-circle (communication, relationships, sexuality, employment, wealth, etc.).

This approach puts disabled women right away in a dependent position and even degrades them to second-class citizens position. They are caught within a care system that is lead by dominant professionals. Disabled women in these situations are expected to integrate into the care system and to adjust to the systems rules. Many of the interventions of these professionals are also focussed on the integration of that disabled woman or man into the system and society in general.

The model uses labelling and the attached objectified characteristics. They try to capture women and men by their label and attached characterizations. All blind women should be provided with a guide-dog; deaf women should learn to read lips; women in wheelchairs need push handles on their wheelchairs; learning disabled women cannot decide for themselves.

This labelling -as so poignantly mentioned by Goffman (1968) - is food for stigmatisation.

This individual or medical model does not go hand in hand with concepts as *growth, possibilities and self-determination*. It is more based on a line of thought that resembles a pessimistic-fatalistic attitude of the professionals involved whereby barriers and obstacles cannot be demolished.

It often leads to oppression and overpowering as they -the professionals- have all the knowledge about the impairment. It further leads to government controlled policy regulations for entitlement to services and benefits, rather than legal based disability rights. Within such attitudes and policies disabled women hardly find space to escape the scripts laid out for them and consequently it effects their self-esteem and they oscillate between acceptance and resistance. With the latter they risk deprivation of the care and services they need and also face the results of negative government decisions based on economic or political grounds.

### **The social model on disability**

This model is from a scientific theoretical discourse completely the opposite of the former model. The Social Model, shifts the focus from impairment onto disability, using this term to refer to disabling social, environmental and attitudinal barriers rather than lack of ability. Thus, while impairment means the functional limitation(s), which affects a woman's body, disability is the loss or limitation of opportunities resulting from direct and indirect discrimination.

According to this model it is society, which disables women with impairments and therefore any meaningful solution must be directed at societal change rather than individual adjustment and rehabilitation (Barnes et al, 1999).

Disabled Peoples International defined the Social Model of Disability as follows:

**Impairment:** is the functional limitation within the individual caused by physical, mental or sensory impairment.

**Disability:** is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (DPI, 1982; Barnes, 1991,1999,2000; Oliver, 1990, 1996; Rivière-Zijdel la, 2001)

The Social Model makes a clear distinction between impairment and disability; the former refers to *biological* characteristics of the body and mind, and the latter to society's failure to address the needs of disabled women. The Social Model therefore, is a concerted attempt to focus on those aspects of disabled women's lives which *can* and *should* be changed (Barnes, 2000: 38). The Social Model signals a radical shift in thinking about disability, recasting disability as a form of social oppression. As Abberley (1987) argued in the late 1980s, disableism joins sexism, racism, homophobia and ageism in the catalogue of social oppressions. The Social Model throws the spotlight on the need for societal change and the removal of socially created barriers and all forms of institutional discrimination (Barnes, 1991 in Thomas, 1999) in contrast to the "help the unfortunate disabled person to adjust to their limitations" (Thomas, 1999: 15) perspective that has dominated for so long.

It is important to note that *disability is temporarily, culturally and situationally variable*. *Temporarily* as it can change in time; *culturally* as it depends on where women live, in which culture with its attached perspectives and demands. *Situationally* because different work and living environments may have other influences on disability. When barriers are diminished, consequently the oppression resulting from it can diminish too.

The social model coalesces with the *inclusion-philosophy* (Hove, van, 1999). No longer choices for separatism - putting women aside in special care institutes -. Recognizing the power of natural networks, the present social and community structures obtain an enlarged role above specialised care. Support no longer means taking over but enabling. So in this concept we should talk about rendering services to disabled women on the basis of legal rights and entitlements not of taking care of them as a charity-based or colonial attitude.

Disabled women should be enabled to obtain space and possibilities to grow, to organise themselves and become more determinant about their lives. This can also mean that they ask for support to learn to break with the old passive and submissive attitude that they incorporated within the old structures. This emancipating process has an enormous effect on the personality and self-esteem of disabled women (Williams & Shoultz, 1982; Charlton, 1998; Goodley, 2000; Shakespeare, 2000).

Like other oppressed movements disabled women too revolted against this segregation of society. The first groups 'fought' their way through further education and the first disabled academics set the tone for the 'radical' change in sociological thinking on disabled women resulting in European and member states legislation and in the social model on disability.

The social model thinking, i.e. looking at societal created barriers, is therewith ancillary to the feeling of tragedy in relation of the impairment itself. Yet the social model thinking, or human rights based approach to disability has a more binding factor for women with various impairments than focussing on obstacles in society from an impairment specific approach.

(Instead of thinking I cannot enter a building because I am paralyzed and in a wheelchair thinking why does society not create accessible buildings for all).

This is also why it should be avoided to speak of women with disabilities, although the desire to focus on women first can be understood (but we should be clear that we distinct ourselves as humans from plants, and animals anyway!), it is incorrect language as we should see disability as the social obstruction (construct) and not the impairment as an obstruction. Dis-able, means no more than being unable to participate fully in society on the basis of our impairments, or through the stigma that society attaches to a specific impairment, like they do to ethnicity, gay and lesbian and gender.

## History

To understand more of the exclusion of disabled women in society and the negative images that society has about us, I would like to make a little trip with you in the history. We discover there common patterns. In the past this exclusion took the form of abandonment of infants who had apparent impairments. Some societies not only killed children with deformities; they also killed their mothers.

Enough is known of ancient Greek philosophy and customs to provide a reasonably clear record. To quote the famous Greek writer Plato who suggested that "the offspring of the inferior, or of the better when they chance to be deformed, will be put away" and Aristotle's plea for "a law that no deformed child shall live" as examples of that philosophy.

The Spartans threw unwanted infants with impairments from a cliff at Mt. Teygetus to die. Spartans considered these infants unlikely to make significant contributions to their society, and so they simply disposed of them. The site of these killings is still marked by a public historical sign declaring that these children were killed "for the good of the development of the human race".

Athenians typically viewed as more humanistic than the Spartans also practised infanticide. They placed unwanted infants in jars and put them by temples where they could be removed by anyone who might choose to adopt them. Infants who were female or seemed to have impairments were particularly likely to be destroyed in this manner.

Infanticide was also common practice during much of the Roman era. Some of these abandoned children were rescued, only to be mutilated by their rescuers in order to make them more effective beggars.

Even now, in some parts of the world, mutilations for this purpose still occur. With the growth of Christianity, women with impairments were sometimes executed as devils. Martin Luther, for example, recommended drowning because "idiots are men in whom devils have established themselves".

The history of past atrocities committed against disabled women may seem remote. Certainly attitudes have become more benevolent and enlightened, but how much has really changed? Even to-day, living in the 21st century, the fallacies of the reasoning behind the eugenics movement are widely recognised. The issues surrounding the elimination of disabled women through incarceration, death, and sterilisation, however, still remain.

Though the rhetoric and rationales have changed, the means are more subtle. The actual numbers may have been reduced, but efforts to eliminate disabled women continue. The human beings who were sterilised as threats to racial purity, burned as witches, or sent to the gas chambers in the past are now being "allowed to die for their own good" or sterilised for "hygienic reasons" or the alleged "inability to raise children" in this era.

Recent research has exposed the way that doctors in the Third Reich held that the quality of life for disabled women was, inevitably, so poor that to end such lives was 'mercy killing'. Such a judgement is also at the heart of the recent 'assisted suicide' cases in the USA, Canada and, using a variety of sources of material, I explore such attitudes in European member states as well.

### **Disabled women versus non-disabled women**

Within a society that has historically regarded disabled people as (economic) burdens<sup>2</sup>, it is not easy to grow up with a great self-esteem. This is even more difficult for disabled women as women in general are regarded as second class citizens. Disabled women are valued even less than non-disabled women in relation to beauty, motherhood or parenthood, sexual attractiveness as a woman, the chance of being a wife or for instance a disabled lesbian, etc. If you are a woman with a learning impairment, or a woman with high dependency needs, you face even more discrimination as other women do. This is based on the fact that society in general, including non-disabled women who are often the care-takers, have the feeling they alone can make judgements about your ability as a woman. A linked phenomenon with the mother-daughter relationship.

Disabled women throughout the European Union form the highest rate of unemployment. They are more often deprived of good education and further education. They are not stimulated in their development towards womanhood.

When institutionalised or being a person with high dependency needs you do not receive the special attention or dignity you need as a woman: for instance there is no time for personal care such as putting on make-up if you wish so. Clothes are always chosen from a practical viewpoint rather than from a fashionable one. Intimate care is -if given- undertaken by male assistants without consent, etc.

But greater dangers exist.

- Disabled women face very often and in many countries of the European Union forced sterilisation.
- Learning disabled women have an even greater chance to become victims of forced sterilisation or abortions without consent.
- Disabled women are in many cases discouraged to become pregnant; false information is given about their physical capabilities to bear children.
- The medical world denies the right of conception by highlighting to disabled potential mothers with an inheritable impairment/disease, their criminal behaviour if they would become pregnant. In many cases further medical care is refused.
- Disabled women and women with mental health problems in particular are often experimented upon by the pharmaceutical and medical industry. Drugs are tested on them as well as undefined medical treatments, operations, and therapies. A recent research in the UK on treatments with Electro Convulsive Therapy showed that 68% of people treated with ECT were women and only 32% men. 44% were women over 65! Moreover it is estimated that only about 25% of uses of ECT have been properly reported.

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<sup>2</sup> Therewith not recognizing the economic profit that is derived from the various impairments that disabled people have (pharmaceutical, medical and care industries)

## **Violence towards disabled women**

Through major researches in the Netherlands, Austria, Germany, the United Kingdom, Sweden and recently in Spain, it has been proven that nearly 80% of disabled women become a victim of various forms of (sexual) violence.

This rate is far higher than the (sexual) violence rate for non-disabled women or disabled men.

Perpetrators of such violence are in most cases men **and** disabled men.

Whereas for non-disabled women family-members score highest as perpetrators, in the case of disabled women of which 68% live in institutions, the perpetrators are more often service providers, medical doctors, psychologists, priests, physiotherapists, drivers of special transport, group leaders, personal assistants and other care takers, etc.

Violence, like sexual violence against women is a power issue. From the power theory we have to admit that disabled women are a group with the least power, whether these women are white disabled women, learning disabled, disabled ethnic minorities, refugees, disabled lesbians, etc.

Disabled women face double oppression. Oppressed by disabled men (forming a -slight-minority in the European Union but having a lead in the representation of the disability movement). And oppressed by non-disabled women, who on the one hand form the largest group of professional carers or as I call it the disability industry, and who on the other hand ignored for a very long time the existence of disabled women within their own movement.

Through this oppression disabled women are deprived of their voice in the decision making process and their rights as women.

Within many member states, where women's emancipation took place to a greater or lesser degree, disabled women were for a long time excluded. The women's movement did not reach out to disabled women, having the same prejudices as society in general: the impairment (the stigma) is the biggest element of discrimination and not the gender. They should have known better!

## **Disability or gender issue**

If I look to the situation of disabled women throughout the European Union I see similarities and differences. Unemployment, low payment, low education, less opportunity to develop an adult relationship, poor participation in decision making processes, is also seen in countries like the Netherlands, Finland and Germany. Some member states might have laws that forbid forced sterilisation without consent, but who will adequately defend a woman with a learning disability if the legal world does not have a clue about disabled women? Some member states are highly influenced by for instance the Roman Catholic church (Ireland, Austria, Spain, Italy), or Orthodox Church as in Greece. As the church was the first institute to take care of disabled women and men, their influence is still visible in the charity-oriented organisations for disabled people. 'Doing good for the disabled' was for a long time (and in many countries still is) a Samaritan act. In many cases this has led to less autonomy for disabled people in general and disabled women in particular.

Also the values of family life, the cultural and historical backgrounds of member states have influenced the development of women in general and disabled women in particular. If you live in a member state where women's rights are diminished to being the barer and carer of children and where men are the sole decision makers and by law the head of the household, you can understand that disabled women's rights are not even taken into consideration.

And as I said earlier on, if a woman is only judged on being a fit mother, disabled women will never be accepted as full citizens if they are physically or otherwise unable to do so or facilitated to do so.

This means we have to recognize that the gender based violence is even more salient in society than the violence based on disability or impairment as the first is structurally and the latter a variable that could change over time if enough resources are available. But what we cannot change is attitudes. Attitudes towards disabled women in general and towards women in particular. As long as society stigmatises disabled women as sick, non-worthy, poor suffering persons, which is often stipulated by the words used to describe disabled women by (cripples, suffers, bound to wheelchairs, invalids, deaf and dumb, etc.) and women are stigmatised as being weak, emotional, unable to do a men's job, dependent, objects to please men, etc. we will have as disabled women a long way to go to change the attitudes of a male dominated society.

This does not mean that we should only focus on the gender based discrimination but also stipulate over and over again the discrimination on the grounds of disability or impairment. As long as society does not recognize the plea for a human rights approach to disability, disabled women and men and mothers and fathers of disabled children will need to beg for their entitlements. Because on the long run it does effect disabled women's daily lives. Not being allowed into decision making, or not being able to earn your own money with employment are minor problems in comparison to the fact that you cannot get out of your bed because the support services are inadequate, staff do not turn up, money is not available for personal assistance, you cannot afford to hire PA's. This means that many disabled women throughout Europe are solely or for the majority of their daily personal care dependent on family members (their mothers –sometimes fathers -, their children, neighbours etc.). For some disabled women it means when their mother (or other family caretakers) die or move out that they have to go (back) into an institute after having lived independently for most of their adult life.

I have never understood that in countries where one is blessed (or cursed) with Royal Families the caretaking of these royalties has never formed a problem and provided for by the state, but when it comes to disabled women it seems that regulations are numerous and care has to be given at low cost, therewith hardly considering the self-esteem and dignity of the women involved.

Within the European Union and its Member States the main focus is on employment. Disabled women and men are also included in the various employment policies. But over and over again I we have to stipulate that employment is not the sole solution. First of all it is questionable if all disabled women are able to be fully employed and if only part-time what does this mean for their economic independence. We are well aware that the economic independence of non-disabled part-time working women is not guaranteed and that life-long poverty often occurs within groups of low-educated and/or part-time working women. The same can be said for disabled women. Moreover if their expenditure for living with an impairment is high and benefits low.

In many member states disabled people are punished through stopping their allowances if they are not accepting employment. And if they are accepting employment and they are only able to work part-time they are living below the bread-line. This is the case for many disabled women as it is harder for them to reach the employment market in general. On top of that research show that disabled women have often lower education than disabled men.

Focusing on economic independence is a better instrument to guarantee a dignified life for disabled women than to focus on (full) employment only, which is a very paternalistic approach to the problem.

A clear shift from the medical model thinking in the European society is needed to embed in all the policies/ directives and legal measurement the human rights that disabled women and men are entitled to. Not *caring for* should be the guiding principle, but *inclusion of*.

### **Strategies for action**

What can the European Parliament do for disabled women and what can national member states do? Changing attitudes towards oppressed groups in society needs often many generations. This process can however be stimulated by the right legal measurements. It is therefore essential that new directives are created to stimulate member states to progress with the emancipation of both women and disabled women.

- Women across Europe have been waiting for 3 years for the adoption of a new European directive aiming at achieving gender equality outside employment. Despite numerous political commitments to equality of women and men, despite strong Treaty provisions and international texts signed by all EU Member States, the European Commission has only taken a first step to address the unequal status of women and men in society. Women in Europe of course welcome the adoption of the draft directive but strongly hope it is only the first of a series of legal texts covering all areas of life, which will truly make a difference for women in Europe. Especially to guarantee the full inclusion of disabled women demands for a directive that goes much further than the present one.
- Despite wide-spread discrimination against women in all areas and a very strong mobilisation of women in favour of comprehensive legislation, the proposal adopted by the Commission on 05.11.2003 is very limited in scope (it covers only goods and services) and it appears to allow for narrow interpretation on many instances; it contains many exceptions and introduces a long transition period for gender equality in the area of insurances. The position of disabled women is not explicitly mentioned within this directive and can lead to further misinterpretation or direct exclusion in relation to discrimination in the provision of goods and services.
- Apart from strong legislation to further stimulate equality between women and men there is a need for a more comprehensive legislation - towards a European non-discrimination disability specific directive. Discrimination does not occur in the field of employment only. The field of employment is closely linked to several other areas such as for example education, transportation and access to services and goods. Therefore a legislation within the field of employment only, is not enough. In order for the disabled woman or man to be an active member of the society in all areas and to enhance a broad non discrimination approach, a new disability specific directive is needed. Such a directive should be directly linked with a new gender directive that goes further than discrimination on the grounds of goods and services only.
- It is further essential that the European Union strives for a European Disability Act which goes further than discrimination towards disabled people as mentioned under Article 13 of the present Treaty. Such Disability Act (in comparison with the Disability Act of the United States and recommended by the United Nations within their Human Rights Act) encourages full civil rights and access to these rights for all citizens regardless of their disability or impairment and it encourages specific regulations to improve the situation of disabled women and men.
- Research focussing on the position of disabled women is needed to learn and understand more about the complexity of gender and disability. It is therefore essential that more universities in Europe have specific social sciences focussing on women studies and on disability studies. Resources should become available to create academic

departments for gender studies and for disability studies to encourage students and researchers to increase the knowledge on both topics.

Legal provisions are needed to guarantee a dignified life for disabled women and disabled men and for mothers and fathers of disabled children. When disabled women and mothers of disabled children are able to participate fully and with dignity in society, as a consequence negative attitudes towards them will decrease. But also more in-depth knowledge of the academic values of disability and gender are needed to stimulate the discourse and to work towards paradigm shifts in the thinking about disabled and non-disabled woman.

As women we are strong and as disabled women we are even stronger as we have learned to overcome daily struggles and barriers. We make a difference every day again, now it is time that the other half of the world learns to understand that the world is created much better if we are both taking part in that world: women and men, shoulder to shoulder, disabled women and non-disabled women, disabled women and disabled men all together can change the world into a world wherein equality of women and men has become a true reality and wherein dignity of all its citizens: women and men becomes a true reality.

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