

## 2. Human Rights and public policies: how to guarantee women with disabilities

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Before dealing with the condition of vulnerability of the disabled woman and her human rights, I would like to say something about the causes of disability and formulate a criticism against those with prevention refer to methods that historically belong to eugenics. The dominant scientific, genetic and behaviouristic paradigm neglects in a culpable way the environmental causes of disability and those socially created - it doesn't want to prevent them but points out that we can solve the problem by avoiding that carriers of impairments are born.

Instead, we should face the Aetiology theme, related to the preventable causes of severe malformations: think of the pharmacopoeia of the 60° and the anti-abortionists that caused severe foetal and genetic damages. Today we still produce gene-toxic, gene changeable substances and we daily consume chemical and physical cancerous genes. The problem of our western way of thinking is that we consider genetics and environment as separate things. But actually they are two interactive entities, what is genetics today will be environment tomorrow: there is a correlation between genetics and environment.

Considering the present and future causes of disability, it would be interesting to deal with the multiple chemical sensibilities that, in America and in Germany, has recently been identified as the real cause of disability, while in Italy people affected by Mcs due to environmental exposure are considered as intolerant or psychologically disturbed.

Another factor that causes disability is the workplace: in Italy a lot of accidents happen at work, some serious and some fatal. Every day 3-4 persons die in work accidents. I'd like to tell you an episode that happened at the end of the 70°, beginning of the 80°, at that time I was a worker at the assembly line in a factory- one day, after this company



was bought up by Barilla, four fingers of my friend Juliana flew into the Mulino Bianco cookies. This made me understand that in the productive processes, profit is more important than the life or the well-being of human beings. These "accidents" are beyond any doubt avoidable. As we wrote years ago in the Inter-Ministry Commission "Women and Health" (promptly cancelled by Minister Prestigiacomo and Sirchia), the measures against accidents, were made to measure men's needs, not women's and the accidents that regard women are increasing - and only recently the domestic accidents have also been taken in consideration, since home is a place where all women work. We should reflect on the aetiology of disability starting from these, often neglected, elements that regard diversity.

What is the relationship between inequality and diversity? Often diversity causes disparity. A lot in our way of acting and also in the symbolical and cultural field needs to change. As university teacher I noticed that the theses dealing with the margin phenomena are increasing, i.e. those that are at the bottom of the ladder of institutional priorities or those that nobody talks about. This margin is becoming more and more important to understand the whole. Bell Hooks, the American poetess, said in her 'Elegy of the Margin' that everything that from the centre out is considered marginal actually represents the point of view of change, everything that from above is considered below represents the critical thought. Being able in one single thought to overturn centre and margin, turning upside down what is above and what is below is a necessary action of social subversion. We want to put the individuals and their health central. In a democracy health is either for everybody or for nobody.

Think about the historical dimension of diversity, about how it changed throughout the years; think about the countries where diversity is a value. In the West we weren't able to face this topic and discuss it in depth. In the Maya culture, people with a morphological diversity were kept inside the temple and they were worshipped for their diversity: they were believed to have some extra gift and not to lack some quality. Our society that appreciates functionality tends to hide diversity and considers it a deficiency, a handicap. I would like to recall a quotation from the magazine "Health and Society", a monographic number of 2005, under the title *Disability between creation of identity and citizenship*. It doesn't talk about gender dimension but it

explains the origins of the word handicap, because, according to me, we can't talk about human rights if we don't break down the wall of words built around the persons. The word handicap indicates the measures of length during horse races; "hand in cap" was the money of the bets, they used to place the fastest horses behind and those that were not so fast in front, to give them the same possibility to run the race and win. The word handicap actually indicated the strongest and the aim of equal opportunities. In time, the meaning changed and today the word denotes what a person "doesn't have" and not the same possibilities for everybody. In recent times, when talking about diversity some talk about the sociology of diversity and some about the sociology of the deviation/ abnormality, which includes an idea of normality firmly rooted in our culture and also in our religion.

Leviticus said that those who are abnormal shouldn't be allowed to enter the Temple. The 4th Table of the Roman Laws allows euthanasia for deformed babies. Christianity introduced the idea of fraternity, however, with a lot of ambiguous interpretations because imperfection, ugliness, illness were considered as curses, divine punishments or worse as the sign of the devil.

I would like to read a small contribution of my former student Priscilla Berardi, she is a tetraplegic psychotherapist today - she also collaborated in a research on disability and homosexuality (<http://www.lelleri.it/report/abilidicuore.pdf>). Priscilla sent me some lines by e-mail that talk about visibility and sexuality, about affection and social integration: "As a psychotherapist I can say that undeniably there are gender differences in the way a disabled person experiences his/her disability and in the way it is perceived by the others. Consider that there is more pressure on women as regards aesthetics; therefore the disabled woman has to do more for her femininity and for the credibility of her femininity compared to what disabled men have to do for their virility. This also strongly conditions sentimental and sexual relationships. Girls are taught, from childhood on, to look after, to take care of and to accept the other with his/her difficulties, whereas boys are taught to protect, to defend and to use force. That is why I think it is difficult for a disabled woman to find a male partner, but easier for a disabled man to find a female partner."



The disabled man is accepted by women, the disabled woman has more difficulties because of the aesthetical aspect. Obviously relationships start anyway and when you have accepted yourself as you are, you know how to use your disability when you present yourself.

Another differentiating element is the double discrimination against disabled women: they are disabled and also women, meaning that all kinds of clichés are applied to her, from her job to her family." What Priscilla writes can be linked perfectly to a reflection taken from : A possible autonomy: itineraries of women between empowerment and advocacy<sup>10</sup>, a courageous book that contains an important international tendency. Among other things it says: "Being a woman with disability means undergoing a double discrimination: firstly as a person with impairments and then as a woman with impairments. Being the most excluded among the excluded, she doesn't enjoy equal opportunities as other women or as the category of disabled men" (page 13). The last fragment of Priscilla's letter reads: "There is no mention of sexuality, or better, little is said and what is said is bad. Once it is discussed, it is considered as a problem and not as something natural. And it is always considered as a separate sexuality as if there is a difference between the sexuality of the disabled person and the one of the non disabled person. No one understands or wants to understand that we are all in the same boat; the non disabled person needs to distinguish himself by saying I am not like you, what is happening to you is not happening to me. Practically we all make love in the same way; we only have to be a bit more inventive to overcome some physical difficulties." According to me, Priscilla's message transmits the idea of the right to happiness, to physical contact, to sexuality.

We carry the burden of not being loved without elaborating it: what are the disabled woman's specific wounds of not being accepted? We should do some research on this topic – and see to it that research informs policies, behaviour and culture.

In fact, experiences, publications and debates on disability contain information that is diffused among only few specialists, whereas we need to create transmission channels between those that produce this information, including in the production of this knowledge/information both the persons concerned, that have to be involved as the

<sup>10</sup> Marina Galati , Rita Barbuto, Marisa Meduri, Emilia Napoletano, Nunzia Coppedè A possible autonomy: itineraries of women between empowerment and advocacy Ed. Rubettino Soneria Mannelli (CZ) 2005 page. 13

subjects/protagonists of the research and not as its objects; and the world of politics, of mass media, of education and employment. For example, some Tuscan women wrote to me about Law n° 68 of '99.

They underlined how art. 3 remains a limit, mostly for the south, in finding a job. Also art 2: a person with technical skills, working in a factory, who at a certain age finds out to have muscular dystrophy, might loose his job. These Tuscan women are collecting signatures to change these and other Law articles, they have also created an agency and networks to show the condition of those that are "differently able" in our country.

I would like to conclude with the words of a wise Indian, who lived in a cave in the jungle: "We are all drops in the same ocean".

Part Two