

# Comments to UN Committee on the Elimination of Discrimination against Women

## 58th session

with regards to its review of Lithuania in its session

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## Introduction

Nixon (2009<sup>1</sup>) claims that it is important to understand the discrimination mechanisms operating against women who have disabilities by revealing their individual experiences and reactions to their situation. Following this notion authors of this report pursue the ‘post-social model<sup>2</sup>’ of disability which stresses the sensitivity of personal life experience, which will be differentiated according to the different kinds of impairments and disabling conditions (Shakespeare 2006). The report is mainly based on findings of the qualitative research conducted in 2014 “Quality of Life of Women Who Have Disabilities<sup>3</sup>” (hereafter – Research)<sup>4</sup> which provided in-depth analysis of personal experiences related to health, family, housing, education, labor participation, income, civic and political participation, security and other aspects of life of women who have disabilities.

## Access to justice and legal complaint mechanisms

Women who have intellectual or psychosocial disabilities and reside in care institutions experience major violations of their rights, including gender – specific rights violations, like forced abortions, involuntary sterilization, baby removal immediately after giving birth. Unfortunately they virtually have no access to justice and legal complaint mechanisms inside or outside these institutions. Although there formally exist complaint procedures they are never used by residents since they cannot secure anonymity and impartial complaint review mechanism.

Individual efforts to protect rights of women who have disabilities should be enhanced to an institutional level, f.i. by approaching Equal Opportunities Ombudsman’s Office. This initiative would solve individual problems of a particular woman who has disabilities; moreover prerequisites for changing existing discriminative practices would emerge.

## Stereotypes

The system of assistance to women who have disabilities is driven by stereotypes itself since it perceives them as incapable, passive and unmotivated persons. There are many active, motivated and ambitious women whose willingness to contribute to the welfare of the society is hindered by inflexible and not individualized disability policy. Women who have disabilities are not invited to

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<sup>1</sup> Nixon, J. (2009). "Domestic violence and women with disabilities: locating the issue on the periphery of social movements." *Disability & Society* 24(1): 77-89.

<sup>2</sup> Social model conceptualises disability as a product of social and material environment and emphasizes discrimination against people who have disability.

<sup>3</sup> Šumskienė, E., Augutienė, R., Jonutytė, J., Šumskas, G. 2014 „Negalią turinčių moterų padėties tyrimas“. Atliktas Lygių galimybių kontrolieriaus tarnybos užsakymu. Vilnius.

<sup>4</sup> <http://www.lygybe.lt/download/325/negalią%20turinčių%20moterų%20padėties%20tyrimas.pdf>

express their opinion and communicate their needs during the decision making process. This approach diminishes them to service recipients and passive observers, whereas politicians and officials make judgments on what is needed.

The abovementioned pattern is supported by societies' disbelief in femininity of women who have disabilities. Disability is perceived as their first, foremost and dominating identity over other aspects of personality, even including gender. This narrow approach obtains primitive and rude forms, f.i., publicly women who have disabilities are often blamed for their appearance (for using make up, wearing fashionable clothes, even for their open smile). On the other hand, this stereotyping may obtain a completely different shape which demonstrates society's unawareness of the health condition and needs of individuals who have disabilities: *Woman with physical disability goes to work on foot since public transportation is not adjusted to her needs. She falls down and is unable to stand up by herself. What she hears from passerby is blaming: "stop using drugs and rouging"*.

## **Violence against women**

Women who have disabilities are at extremely high risk to experience violence both its 'traditional' forms and particular forms related to their disability (sexual abuse by care givers or other residents in care institutions, neglect of their medical, care, psychological needs, forced abortion and sterilization, involuntary placement to psychiatric or social care institutions, deprivation of legal capacity, etc...).

In 2011 Law on Protection Against Domestic Violence was passed. This Law is important as it protects women who have disabilities on equal grounds with the rest of society; nevertheless it lacks special measures addressed for women who have disabilities. Police or other professionals lack knowledge how to communicate to victims who have particular disabilities, whereas women themselves are unaware of their rights and opportunities in accessing relevant services, they fear of institutionalization or forced placement in psychiatric hospital. Furthermore they find themselves in the dependant position in the power relations with the perpetrator. Thus the important and progressive mainstream measures should be tailored to the specific safety needs experienced by women who have disabilities. Women who have disabilities should be provided with necessary knowledge and measures to

## **Participation in public and political life**

There is no official data on women with disabilities in public positions, or on their political participation. Nevertheless there exists a problem of multiple discrimination on the grounds of gender (limited participation of women in policy making) and disability (limited participation of persons who have disabilities), since women with disabilities encounter institutional barriers, lack of support and understanding from the society as well as face stigmatizing confrontation.

Participation in NGOs activities is very common among women who have disabilities. This offers meaningful time spending, provision of charity, and socialization. Some women actively participate in human rights actions, f.i. Living Library<sup>5</sup> helping people to meet vulnerable groups, to fight discrimination and stereotypes.

Disability NGOs are well known and important also for their non-members. It is important to notice that women who have disabilities mainly are involved in disability organizations, there is no data of their civic engagement in other spheres of public life.

## Education

In the system of education individuals who have disabilities face many barriers due to unadjusted physical and informational environment; nonetheless many of them successfully graduate from schools and universities. Programs of higher education are not adjusted to the needs of persons with particular disabilities, especially hearing and sight impairments. Professors are not flexible enough, unprepared and unaware of special needs of their students who have disabilities.

The research revealed an interesting phenomenon of social capital created by and for the students who have disabilities. Women who have disabilities usually choose to study helping profession, f.i., social work, social/special pedagogic, and psychology. During their studies they enjoy ongoing support from their study mates who have also chosen helping profession due to their sympathetic nature. Students who have disabilities find this help and understanding more relevant than adjusted environment.

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<sup>5</sup>Living Library is method of informal education, encouraging social awareness, tolerance and respect for human rights. Living library consists of Living books, librarians and readers. Living Books are people from vulnerable social groups, experiencing discrimination or stereotypes in society. Living books have a lot to say about discrimination, social inequality, answer a lot of deep and intimate questions concerning lifestyle of different social groups. <http://gyvojibiblioteka.lt/en/kas-tai-yra/>

After graduation women who have disabilities frequently choose a carrier in the field of disability: *women with physical disability works as a trainer of physical rehabilitation, women with hearing impairment trains interpreters of the sign language.*

## Employment

Women who have disabilities mainly experience discrimination in the labor market on the grounds of their disability, not on the grounds of gender. When they want to (re)enter the labor market they use programs addressed to individuals who have disabilities, not gender oriented employment measures.

Women who have disabilities have to overcome many obstacles on their way to employment. Part of these obstacles are related to the disability, health condition or personal situation, like lack of experience or education, isolation, limited social ties, lack of initiative. Nevertheless most important obstacles exist in the environment. The system of integration should function as an empowering factor; however there exist major contradictions among its segments. Financial motivation to work is diminished by the system of social assistance, which is bound to the income level. F.i., higher salary withdraws the right to social housing; women with low working capacity level<sup>6</sup> withdraw the right for employment support services.

Important obstacle is negative attitude by employers and their mistrust towards employee who has disability. This lack of trust is based on the health status, not on the gender. Importance of gender issue has shown up during the research as an interesting phenomenon: women with disabilities feel very comfortable in the male – dominated working environment since they can ask for their colleagues' assistance as "a weak woman" not as a person who has disability. It reveals a ridiculous situation when women who have disabilities deliberately choose to be discriminated on the grounds of gender.

The oversimplified differentiation between those capable and those incapable of work rules out a wide range of conditions between, including personal motivation which is the most important inducement to participate in the labor market. The research has revealed that motivation and willingness to work are more important driving forces than objective criterions of setting the level of employment capacity. Respondents who dedicated most efforts to join the labor market value work for reasons of self-realization, social integration more than remuneration. *One woman who has physical impairment works as a lawyer and enjoys adjusted working environment, possibility to work*

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<sup>6</sup> Nustatytas darbingumo lygis

*from home, warm and supportive atmosphere. Unfortunately she has to resign to an unfair treatment regarding pay.*

This picture proves opposite to stereotypes of women who have disabilities as dependant, unproductive and preferring social isolation.

Women who have disabilities report rare cases of positive discrimination as a result of employers' consciousness: employers choose between employee with and without disability for the good of an employee who has disability. Nevertheless these cases are rare, and women who have disabilities constantly feel like they must prove being worth employment: *On my very first day at work I was crying. You feel really grim when they throw you like a fly into the soup. And they observe you through a reading glass, if you succeed swimming or you drown.* This example reveals that women who have disabilities are widely perceived as unreliable employees and there is a gap of systemic, state level efforts presenting the opposite.

Women who have disabilities face additional obstacles in the labor market due to intersectional discrimination when both forms of oppression are interacting simultaneously. Research shows that they have either to demonstrate an extraordinary persistence while competing for a workplace; to be employed in a social enterprise; or to postpone their working ambitions to an indefinite time span.

Parents (first and foremost mothers) of children with disabilities face the challenges of financial stress, lack of transportation alternatives, few supports for household tasks, lack of care services within the community, and high levels of strain. Care giving usually also means opt out of the paid labor force and of the system of social insurance. Moderate nursing allowances paid to caring parents partially amend the financial loss; nevertheless caregivers lose their social insurance record and are deprived of social insurance benefits. Attempts made by disability organizations urging to include caregivers to the system of social insurance appropriately amending the Law on State social insurance pensions unfortunately were rejected by reason of financial burden.

## **Health**

Women who have disabilities are objected to regular medical monitoring, even if their diagnosis is stable and they do not have other complaints. Obligatory visits to in-patient and out-patient facilities are rather associated with control than with care. This is a major difference between women who have disabilities and those without disabilities, who can decide themselves if and how to care about their health.

Reproductive rights are often not granted to women who have disabilities: gynecologists perfunctory react to their gynecological problems; moreover they don't possess necessary equipment (special

chair with adjustable height) for gynecological examination of women who have physical impairments. These women perceive gynecological check as the least accessible medical service.

Women who have disabilities are perceived as asexual and deprived of sexual education. Very often they are urged to terminate their pregnancy without a particular health-related reason. Research shows that many women who have disabilities object to this incitement, give birth and raise their children. Women who have intellectual or psychosocial disabilities and reside in care institutions frequently are imposed on forced sterilization<sup>7</sup>, or forced abortion. These institutional practices are officially not documented; sometimes women themselves are not informed about real consequences of the procedures they undergo.

## Disadvantaged groups of women

### INCOME

Research revealed that women who have disabilities and raise children experience most severe financial difficulties. For the sake of their children women refuse meeting their own requirements, sometimes even postpone purchase of the necessary medication. Income is less important for young unmarried women without children, who are supported by their own parents. These women can do volunteering, participate in stereotype-breaking projects, etc...

Women who have disabilities prefer being independent, exposing to difficulties neither their families nor the state; they want to work, to make their own plans, and to save money for their needs. They are ready to raise bank credit; unfortunately banks deprive them of this opportunity because of their disability. One woman tried to raise credit and approached four banks. She calculated her needs and expenditures: *“I found a house in Salininkai for 60.000 Litas and calculated accurately. If I consume only grits and water, never get sick and never need medication, I can pay it in 10 years. It is absolutely realistic”*. Unfortunately every bank rejected her request.

### HOUSING

There is a long waiting list to receive social housing in big cities. Women who have disabilities calculate that waiting may take over 30 (thirty!) years. Individuals who have disabilities are put in the same list with persons who don't have disabilities; moreover if their income increases they lose their place on the waiting list. A woman who has disability in emergency case could be placed in temporary accommodation hostels. Unfortunately they are not (or just partially) adjusted for the needs of persons who have physical impairment. Even if the entrance door is wide enough, toilets are

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<sup>7</sup> 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 (Discrimination generated by intersection of gender and disability. Study, 2013. Directorate Generale for Internal Policies. Policy Department. Citizens Rights and Constitutional Affairs).

not adjusted, bedrooms have narrow passing and two-storey beds which are inaccessible for someone moving with a wheelchair. Due to this inflexible institutional framework women who have disabilities usually end up in residential social care institutions although they could live in the community with a moderate social and financial assistance.

## CHILDREN

Society doesn't perceive pregnancy and maternity of women who have disabilities as blessing, rather as burden and load of care. Consequently their sexuality, pregnancy and maternity become objects of social control. The usual strategy employed both by professional and informal care givers is to prevent birth instead of helping potential mothers who have disabilities to overcome any difficulties to raise their children. The same pattern continues after the birth of the child, especially in the case of maternity of women who have intellectual disabilities: there is a strong tendency to place it to institutional care instead of assisting and developing her maternal competencies.

Giving birth and raising children are very special experiences of mothers who have disabilities. They worry about health of their children and are afraid of heredity of disability; they constantly need help taking care of their children. Children are also a major stimulus to work, to fight and to have a goal in their lives. One of the most painful experiences is their children' admitting that they suffer from bullying due to their mothers' disabilities. Children disclose that they are ashamed of their mothers and it is a reflection of stigmatizing attitudes that are widespread all over society.

Reproductive rights of women who have psychosocial disabilities are ignored; moreover, the society in general and professionals in particular doubt their maternal capacities. It is believed that women who have psychosocial disabilities 'lose' these skills and forget their children during the relapse of their mental condition. Research data shows the contrary: women do care of their children and their wellbeing even when they are hospitalized. Therefore it is necessary to inform mothers about who and how takes care of their children, even if mothers' condition appears to be very severe.

There exist only scarce data on this situation therefore it requires in-depth analysis about violation of sexual, reproductive and maternity rights of women who have disabilities. Society (including politicians, officials, and caregivers) lacks understanding and awareness; journalists tend to depict maternity of women who have disabilities as a plague. Lack of knowledge, stereotype-driven understanding and absence of system of specialized services are the main gaps that need to be targeted.



## Recommendations

Gender discrimination oriented programs should include disability aspects; disability programs and strategies should also contain gender issues. This ‘synergy’ would contribute to greater gender and disability awareness and mainstreaming which are needed in order to increase the participation of women who have disabilities in community and national processes of decision making.

Research on the scope of the problem and best practice analysis, qualitative and quantitative data collection is necessary for planning evidence based and needs oriented policy as well as for awareness rising.

Government should ensure access to justice, professional assistance, psychological and financial reparation for victims of crime, including access to specific support mechanisms aiming at women who have disabilities. Preventive measures to diminish potential vulnerability of women who have disabilities should also be taken into account.

Training of relevant professionals is needed, including:

- University teachers: on educational needs of women who have disabilities, flexible and inclusive forms of teaching;
- Employers and representatives of employment services: on workplace adjustment, special programs for employment, special needs towards working environment experienced by women who have disabilities;
- Policy officers: about communication with women who have disabilities (e.g. speech, hearing, sight impairment, intellectual disability, psychosocial disability during the period of relaps) and are victims of abuse;
- Journalists: about ethical writing about disability and gender issues. Journalists should obtain a wider perspective on these sensitive issues, being critical and analytical instead of stereotypes-driven. Awareness and presentation of the multiple discrimination claims in terms of human rights is essential in changing attitudes of the public and of policy makers;
- Care givers: about sexual and reproductive rights of women who have disabilities.

To amend appropriate legislative acts (mainly Law on State social insurance pensions) to include caregivers (mainly mothers caring after the their children with disabilities) to the system of social insurance.

Lithuanian NGOs have necessary knowledge and practice in the abovementioned fields which has been piloted during national or international projects. This capacity is easily disposable and it should be applied providing trainings for professionals and developing new services for women who have disabilities.

## Annex I

About submitting organization:

### **Association Lithuanian forum for the disabled (LNF)**

Lithuanians Forum for the Disabled (LNF) (Reg. 125703071).- the Lithuanian Umbrella organization for Disability Organizations and was founded in 2001. At the moment it has 15 national member organizations representing about 280 000 Lithuanian people with disabilities and their families. The mission of LNF is to strive toward state policy that promotes human, social and economic rights of disabled. LNF follows the principles of equal possibilities for all and nondiscrimination for people with disabilities. Our organization is seeking to improve situation and equal realization of rights of Lithuanian disabled people likewise of Europeans, and to represent them in both national and European institutions. The work direction of LNF is: to promote disability in the governmental and local policy, as well as to influence process of adopting positively set legislation for people with disabilities, to promote policy, which protects rights of people with disabilities, to cooperate with different agencies on national and local level, to provide systematic monitoring of legislative proposals concerning people with disabilities, to promote participation in the decision making process on all levels, to protect interests of member organizations, to participate in drafting laws and other normative acts, provide consultations and opinion on those. LNF is member of European Disability Forum and works in close cooperation with EDF, following its strategic priorities and policy on disability. Recently LNF work is mainly focusing on the implementation of United Nations Convention on the Rights of Persons with disabilities (CRPD) and is driven by the main principle of CRPD "Nothing about disabled - without disabled".

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