European Conference

Recognising the Rights of Girls and Women with Disabilities

An Added Value for Tomorrow's Society

Madrid, November 2007

CERMI
Comité Español
de Representantes
de Personas
con Discapacidad

Ediciones
Cinca

CERMI.ES Collection
Number 32
Collection Director: **Luis Cayo Pérez Bueno**

With the support of:

Fundación ONCE
para la cooperación e integración social
de personas con discapacidad

european disability forum

MINISTERIO DE TRABAJO Y ASUNTOS SOCIALES
SECRETARÍA DE ESTADO DE SERVICIOS SOCIALES, FAMILIAS Y DISCAPACIDAD
IMSERSO

MINISTERIO DE TRABAJO Y ASUNTOS SOCIALES
SECRETARÍA GENERAL DE POLÍTICAS DE IGUALDAD
INSTITUTO DE LA MUJER

MINISTERIO DE TRABAJO Y ASUNTOS SOCIALES
REAL PATRONATO SOBRE DISCAPACIDAD

2007 — European Year of Equal Opportunities for All

Direction: Luis Cayo Pérez Bueno
Technical Direction: Ana Peláez Narváez
Co-ordination and Supervision: Beatriz Martínez Ríos
Tecnical Support: Maria Nyman
Translation: David Stirton
Cover photo: Eduardo Gragera

1.st Edition April 2008

Edition, technical co-ordination & printing by:
Grupo editorial CINCA
Avda. Doctor Federico Rubio y Galí, 88. 28040 Madrid
grupoeditorial@edicionescinca.com

ISBN: 978-84-96889-22-4
Depósito legal:

European Conference

Recognising the Rights of Girls and Women with Disabilities

An Added Value for Tomorrow's Society

Madrid, November 2007

CD-Rom included with Spanish version of the text

Incluye CD-Rom con versión del texto en español

cermi
Comité Español
de Representantes
de Personas
con Discapacidad

Ediciones
Cinca

Contents

PRESENTATION

On the occasion of the 10th anniversary of the *European Disability Forum Manifesto by Girls and Women with Disabilities*, the Spanish Disability Forum (CERMI) and the European Disability Forum (EDF) took the initiative to host a European conference to promote equality and improve the quality of life for girls and women with disabilities in Europe.

The conference, which took place as we celebrated in 2007 the European Year of Equal Opportunities for All, aimed to provide a forum for an in-depth study of the key issues affecting girls and women with disabilities as they seek to achieve full participation as citizens, raising awareness within the European disability movement on the need to develop specific measures to ensure girls and women with disabilities are able to participate under conditions of equal opportunities and promoting the creation of and support for women's commissions within national and regional bodies in order to facilitate dialogue on the key issues that directly affect them.

To achieve this goal, all EDF members were invited to take part in the conference (National Councils and full and ordinary European NGO members). In addition, individuals were able to attend as observers. Representatives were asked to submit a report clearly outlining the situation regarding girls and women with disabilities in the different countries, national disability councils or European NGOs.

When drafting their reports, representatives were invited to follow a set of guidelines issued to make their work easier. To be more precise, they were asked to provide an overview of the situation (including statistics and information on women's participation in the movement), outline the main barriers (access to employment, involvement in decision-making, differences with respect to the two main reference groups – men with disabilities and the overall female population, etc.) and describe the measures and solutions put in place regarding this issue (legislation, positive action measures, specific action plans, etc.).

All this was made possible thanks to support, on the one hand, from the ONCE Foundation and, on the other, from the Spanish Ministry for Employment and Social Affairs through the Royal Board on Disability, the Institute for the Elderly and Social Services (IMSERSO) and the Women's Institute. Thanks to their backing, around 200 experts —mostly women— were able to gather at the conference. In total 23 European organisations and 21 National Disability Councils were represented.

This publication brings together the work carried out at the conference, including not only the key speeches and workshop conclusions but also the reports submitted on the specific situation in different countries and European organisations. The original working language for the conference was English, and since this was not the native language of many of the participants we have proofread and tidied up the documents, without modifying the message, in order to correct any grammatical mistakes.

This publication concludes with the ***Declaration on Recognising the Rights of Girls and Women with Disabilities***, a key instrument that will surely guide the disability movement as it moves towards full participation, equal opportunities and non-discrimination for women who form part of it. We dedicate this book to ALL WOMEN engaged in the disability movement.

PROLOGUE

2007 was designated European Year of Equal Opportunities for All. The objectives of the European year were to celebrate diversity, raise public awareness about everyone's right to equality and freedom from discrimination, promote equal opportunities for all and stimulate the debate about the benefits of diversity.

Throughout the year, the European Disability Forum (EDF) has been working to ensure disability is high on this year's agenda. We all know that disabled people today do not have equal opportunities in most areas of life, and our Forum is working tirelessly to dismantle these discriminatory barriers at European level.

However, EDF is also very aware of the inequalities in our European society between women and men. Compared to men, women continue to face disadvantage and discrimination. We all know that being a woman with a disability makes this picture even more complicated, leading to a situation where women with disabilities are among the most marginalized groups of our society, and subject to double or multiple discrimination.

The issue of multiple discrimination is very real and serious, and therefore requires addressing urgently. Multiple discrimination occurs when a person is facing discrimination on the basis of two or more grounds. The experience of discrimination can be compounded, thus the impact is more than simply adding together two types of discrimination. This means that multiple discrimination can present situations where an individual faces greater exclusion and disadvantage. Often people who experience multiple discrimination are even prevented from accessing their basic human and civil rights and are subject to social exclusion to a greater extent.

Unfortunately, European legislation as it stands does not recognize the increased hardship faced by women with disabilities —or any individual facing multiple discrimination— and therefore women with disabilities have to choose one type of discrimination (usually the one which is easier to prove or more blatant) when they present a case in court, for instance. Therefore there is a need for raised awareness and concrete solutions on how to tackle the particular problem of multiple discrimination at all levels.

In addition, mothers to children with disabilities often face discrimination and are at a disadvantage compared to their partners or spouses. They often also have to take on an unreasonable responsibility due to society's failure to provide support to the boy or girl with disability.

When the European Disability Forum statutes were signed and an independent European organization of people with disabilities was born ten years ago, our new membership expressed its firm commitment to gender issues and the promotion of gender equality in our governing bodies and in every aspect of our policy work. This is a fundamental premise inherent within our statutes and by laws – not purely an aspiration or statement of intent.

What has happened during these ten years of EDF existence in the policy area of the rights of women with disabilities?

EDF has a permanent Women's Committee, made up of very experienced women activists with disabilities from our membership, which is supporting the work of EDF and is raising awareness on the situation of women with disabilities within the organisation.

EDF has also been able to become a member of the European Women's Lobby, EWL, which is the largest umbrella organisation of women's associations in the European Union. This membership of the European Women's Lobby has been very positive and it has been of mutual value. The EDF representative within the European Women's lobby has been a member of their Board since we joined.

The Manifesto on Women and Disability was adopted ten years ago and is currently in the process of being revised, not least due to the recent adoption of the UN Convention on persons with disabilities and the twin-track approach to women which it guarantees.

The European Parliament adopted a report on women and disabilities this spring, including many amendments from EDF, not least an invitation to Member States to always include the situation of women with disabilities in their country reports on the *Convention on the Elimination of All Forms of Discrimination against Women* (CEDAW). A European Commission study on the situation of women with disabilities in the European Union is also being launched, intending to provide the EU Institutions with a more complete picture on the situation of women with disabilities within the EU.

Our Forum will do as much as possible to support this project in order to make sure that the outcomes of the study reflect the reality. Once the results of this project are published there will be an evidence-based report to refer to in policy work on women and disability.

These initiatives taken by EDF, the EWL and the European institutions respectively are all positive.

When it comes to the representation of women with disabilities within the EDF structure, the balance between men and women is increasingly becoming more equal. However, the EDF structure only reflects the structure and balance —or rather imbalance— of women and men within membership. Insofar as members do not nominate an equal number of women to the decision-making bodies of EDF, EDF will have difficulties in getting a balanced structure. This imbalance will inevitably have a repercussion on policy work. This is why it is so important that we are all working together on solutions and to bring results to promote a change at national level, and in this sense it is worth mentioning an example of good practice that has been carried out by the Spanish National Council of People with Disabilities (CERMI).

Women with disabilities are one of the priority groups within CERMI, and throughout the past years it has been working hard on this issue to secure highly satisfactory results. So since 2000 CERMI has enjoyed support from its Women's Commission, one of its most active governing bodies, and its work is backed up by the figure of Commissioner for Women with Disabilities, created in 2004.

The concurrence of these two developments has facilitated a prolific work rate, as demonstrated by actions in specific areas of importance to the group.

Outstanding among them are numerous speeches in the Spanish parliament to advocate on behalf of women with disabilities in several policy areas, and CERMI participation through the Women's Commission in a number of public decision-making bodies. These include not only representation in several government-sponsored observatories, or in the Royal Board on Disability's working group on women with disabilities, but also the major achievement of securing a place for the disability movement on the Governing Council of the Spanish Women's Institute, a long-held demand.

To this long list of actions should be added the initiative to set up a network of female experts in gender and disability and drawing up the *First Action Plan for Women with Disabilities 2005-2008*. The Action Plan is a comprehensive document and invaluable working tool when gauging the situation of women with disabilities in different policy areas; in addition, it forms the basis of the political agenda in the field of women with disabilities for the period it covers (it was used as a guiding document in drafting the Spanish Government's Action Plan on Women with Disabilities, on which you can find more information in this book). All this work in Spain goes alongside CERMI's active involvement in and commitment to the EDF Women's Committee.

We will conclude this introduction by citing one of the most important articles from the *United Nations Convention on the Rights of Persons with Disabilities*:

> ***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.*

Yannis Vardakastannis
EDF President

Mario García Sánchez
CERMI President

Women and Disability

SITUATION OF GIRLS AND WOMEN WITH DISABILITIES WITHIN THE EUROPEAN DISABILITY FORUM (EDF) AND ITS MEMBER ORGANISATIONS

MARIA NYMAN
European Disability Forum

When we were discussing the organization of the conference we realized that it would be very useful to get a better knowledge on how members of all EDF member organizations experienced the situation of women and girls in their national council or European NGO and in their country.

Only with this background knowledge it is possible to get a fruitful discussion on how to improve the situation of women with disabilities and mothers of girls and boys with disabilities within the EDF structure and within our own countries. Because there was a feeling that there was no comprehensive overview of the situation of women with disabilities in Europe.

We have received about 30 reports from you all and this those reports contain an extremely valuable source of information for us all for our work, not only during this conference, but also for our work in the future within EDF and in our own countries and organizations. It is a quite unique collection of data and information which is hopefully a first step towards filling the current gap of statistics and information on women with disabilities, and mothers of girls and boys with disabilities, in Europe. The reading of those reports was very interesting, although sometimes very discouraging and sad. In the following pages you will find a brief overview or summary of the reports, but as the around 30 reports contain a lot of information this overview will be far from complete.

Representation and Structures

When it comes to the representation of women in the decision-making bodies of EDF member organizations, the situation is described in a quite similar way in most of the reports: women are under-represented. Sometimes the difference is flagrant, sometimes it is less obvious. The leading positions are much more often occupied by men than women. The situation seems to be more unequal the higher you come in the structure – meaning that the representation of women is in many countries better in organizations at local level than at regional and national level.

Denmark gave very detailed information in its report on the representation in its member organizations, and it was interesting to see that the over-representation of men in the decision-making bodies and among the chairpersons was very clear, but that in the Danish national Youth disability council the situation was the inverse; there were more women in chair positions than men. This reading gave a bit of hope for the future.

Most of the participants, with a couple of exceptions, explained through their reports that there was not a clear gender equality policy in their organizations work or statutes. It also seems to be rare to have a women's committee or women's "wing" in the national councils and European NGOs (although a few have one). More often, there is instead one or a couple of organizations or networks set up of women with disabilities which have had to take on the whole responsibility for equality work.

Some organizations state however in their reports that they are now considering focusing more on the issue of equality between disabled women and men and the need for an equal representation, as a consequence of their investigations behind the report. So hopefully these reports will be a starting point for positive initiatives in practice!

When it comes to national legislation and action plans, there are many positive initiatives on the equal rights of women on the one hand and of disabled persons on the other hand, but the perspective of disabled women seems to be lost in as well in the disability policies as the gender equality policies. However, Finland is citing as a good example that disability is now a part of the CEDAW country report. The *Spanish Action Plan on Women and Disability* is another positive exception.

There seems also to be a lack of reliable and systematic statistics in most countries on the situation of women with disabilities.

Disabled Women compared to Disabled Men

Many reports stated that disabled persons are considered as "people" instead of women or men. The words sexless or "third sex" was frequently used, meaning that the disability is what society seams to see and not the fact of being a woman or a man. This prejudice seems to be more frequent towards disabled women than men.

Another inequality is that there is a feeling that disabled women needs protection whilst men don't – for example if it is considered that working would have a positive impact on the life quality of a disabled man it is often felt that disabled women should be "protected" from working, despite that all evidence show that working can have a major positive impact on the quality of life of disabled women or women with chronic illnesses.

When it comes to employment, it is obvious that disabled men work to a much greater extent than disabled women despite the fact that in many countries it appears that the education level is reported to be higher among disabled women than men. The exclusion of disabled women seems to constitute a vicious circle: as women have not got the opportunities of acquiring experience due to discrimination/barriers, they do not get the required experience to take up certain positions and therefore they continue be discriminated compared to their male counterparts.

Sweden explains that women with disabilities mention to a greater extent that they need personal technical aids at work than disabled men do, but despite this it appears that men to a greater extent than women have their needs met. There was another interesting and clear example of different treatment between men and women in Sweden, that disabled men more often get subsidies for buying a personal adapted car, whilst women get subsidies to use public transport.

Poland gave an example of the parents of disabled women who sometimes hinder the woman to try to get a job, as a result of an economic calculation, as the system is such that you lose your social benefits if you do.

Malta gave another example in the same direction, that once a woman with a disability gets married she loses all benefits she received before getting married.

The portrayal of persons with disability in media is generally absent or very low, but when men is being portrayed it is often as courageous persons who succeeded in doing things despite their disability, whilst women with disabilities more often are being portrayed as victims.

There were many more examples than this and I am not going to mention them all now, but at least I hope that this gives some kind of indication on the kind of unbalance that exists.

Barriers specific for Women with Disabilities compared to Non-Disabled Women

Many reports mentioned the complete lack of accessible health services and gynecology services in particular.

Here again it seems clear that a person is generally being considered as either a woman or a disabled person and the services and support proposed are not being adapted to the fact of being a “disabled woman”.

Sexual and physical and psychological violence is incredibly high among disabled women, compared to non-disabled women and disabled men. Despite this the bitter reality is that most women shelters are inaccessible and that the staff is completely untrained on disability awareness and how to welcome disabled women in the centers.

Slovenia reported that their organization of women with disabilities has decided to buy a couple of accessible apartments for women with disabilities who are subject to violence, as the State does not provide any such accessible centers. Luxembourg on the other hand reported that there are now finally public projects to construct a certain number of accessible rooms in the shelters.

Estonia gave a very sad example of a case that had been a hot topic in Estonian media of a woman using a wheelchair who was married and a mother of three children. Afterwards the husband turned out to be violent. In the discussions on this case it was stated all over again that "*this situation was the fault of the disabled woman, she should never have accepted to marry and to have children. And when the issue of who should take care of the children after the divorce came up, it was considered that the father, who just came out from jail, was a better option than the mother as she had a disability…*"

France and ENUSP were two of the organizations highlighting the fact that disabled women and in particular women with mental health conditions are sometimes subject to the situation of their child being taken away at birth as they are considered as not being good mothers for them.

The lack of acceptance of the motherhood of a disabled woman is underlined in most reports. Disabled women are often supposed to not have families and it seems like there is a complete lack of information on family planning, sexuality etc in accessible formats or information taking into account the situation of disabled women.

Austria is also mentioning two laws on the reproductive health of disabled persons, which are behind the clear differentiation between the handling of non-disabled and disabled women. One is the law on eugenic indication to abortion, which allows abortion of disabled children until nine month pregnancy. The consequence of this is that disabled women often have to argue with the doctors that that they actually want to keep a baby.

Another example comes from Belgium, stating that society sometimes try to limit the social contacts of disabled women with men in order to avoid a possible pregnancy. This leads to isolation and exclusion and even confinement of disabled women.

EDSA was giving evidence that sterilization of women with learning difficulties is still common, without their consent or without them understanding the exact purpose of the surgical operation.

The number of women who are victims of violence from someone who is close to them is also probably far higher than in official statistics. To quote from the the DPI Italy report, "…*how can a woman with a disability accuse the perpetrator if she depends on him for her survival? How can a woman with a disability who suffers from violence accuse the relative she depends on to get up, wash and go to the toilet if she doesn't have the economic independence to live on her own?*"

To conclude with a sentence taken directly from the report of the Estonian representatives, "*Improving the life quality of disabled women needs joint effort of disabled and non-disabled persons, men and women, young and old, and wisdom and tolerance to move from misunderstandings to mutual understanding and cooperation. In other words, improving the world starts with yourself".*

FACING MULTIPLE DISCRIMINATION - BEING A WOMAN WITH A DISABILITY

LYDIA LA RIVIÈRE-ZIJDEL[1]
International Consultant on Gender and Disability

My second life: born a feminist, became a disability and gender activist!

Introduction

Just two weeks ago I celebrated my 25th anniversary of disability activism. Becoming a paraplegic through a car accident in 1982, was a great momentum as it was right in the midst of the 1st disability emancipation wave. As activism against social injustice and discrimination has been part of my entire life, it was a logical step to enter this new vibrant world of the disability movement.

I was born as the first girl after three older brothers in a family of in total 7 children. My parents, both with a working-class background, were true socialists and Christian, a rare combination at the time, but it had a great influence on my activism later in life. I was born in the grey years of post-WWII social reconstruction,

---

[1] Social Scientist (MA's in Disability Studies; Social and Community Studies and Gender Studies) and International Consultant on Gender, Disability and Sport; Steering group member of the International Working Group on Women and Sport (IWG); President of the Dutch Coalition on Disability and Development, Co-ordinator of the W-IDC.

(3rd Degree Black Belt Shuri Ryu Karate, 1st Degree Black Belt Aikido, Licensed Feministic Self-defence Teacher/Trainer) with a severe lack of housing and most houses were in a dilapidated state. There was widespread poverty in those years and a glaring absence, where once the Amsterdam Jewish population had lived. My father had played a heroic role during the war and was still active as such in the years thereafter. My mother was running her household with four little children and the driving force behind the empowerment of women in their neighbourhood.

Most women played an active and independent role during the war, either in factories, hiding Jewish refugees, walking for days to find food, as most men were deported to the factories of the war industry or imprisoned. But in the years thereafter they were pushed back again in their traditional role as housewives with no real say in the new society. Women engaged disproportionately in unpaid labour in comparison with men. This labour has gone unnoticed for centuries and we should not knowingly repeat this gesture in our policies of today in regard to women and women and those with disabilities in particular.

I am painting this picture of my family to make you understand that in my family and class the role of women became part of the general conceptual thinking about women after the WWII, being primarily housewives and mothers. Paid employment —in part or fulltime— was more apparent in higher classes than strangely enough in the so-called working class, unless it was low paid and invisible cleaning work in the houses of others or in offices. Class is one of the variables that needs to be taken into account, when we think about women and disability. We should not fall into the trap that we regard all disabled women working-class, neither only heterosexual nor white to mention a few identities. This is what tends to happen in commonsense thinking about the various variables gender, disability, ethnicity, class, sexual orientation, nationality and/or religion that together give meaning to our lives, to our identities and to the way society is structured and saturated with inequalities along these various dimensions.

When we refer to disability we are neither linking it in the first place to women or men, but to non-sexual beings as persons with a disability. Moreover, unless we say purposely that we are talking about women with disabilities, it is disabled men who are the implicit subjects of the term. Sometimes even only the impairment, the disability come into our minds (the blind, the deaf, the learning disabled).

Intersectional Theory

This particular style of arguing that I am unfolding here is an instance of intersectional theory; while talking about class, immediately disability and gender come into my picture. As can been done for sexual orientation, ethnicity, age and so on. In other words, I am not considering the various dimensions of difference, as is the case in much commonsense thinking, as separate and having nothing to do with each other. The underlying logic in commonsense thought is that something either has to do with disability or with gender, but not with both at the same time, and often even more focused on the first than on the second element. This binary logic constructs and splits the world in two categories, —e.g. "non-disabled" vs. "disabled"; "man" vs "woman"; "heterosexual" vs "homosexual"; "white majority" vs "ethnic minority"— which are not only mutually exclusive, but which stand in a hierarchical position toward each other, with the first term demarcating a more favourable, a more valued positioning.

Moreover, in dominant thought-patterns the more powerful and valued term is mostly bracketed; it is "normalized", i.e. made into the "normal position" and implicitly defined as non-marked and thus non-problematical.

I will highlight this with my own experience. Born a feminist and active throughout my life in the women's movement, especially in the seventies during the 2nd feminist wave, I never considered, like many others around me, disabled women as part of our movement. Although I had an open eye for difference, having worked at my early twenties in Africa that broadened my perspective in race and ethnicity thinking, disability was regarded as a medical aspect that differred the sick from the healthy. Not realising that there are many social dimensions and in and exclusions attached to disability as well. So when I became disabled myself it was for the first time that I was struck by the fact that suddenly I was not very welcome anymore in the women's movement. Environmental but very much so attitudinal barriers blocked my way back into the women's organisations.

The astonishing effect of still looking the same, talking the same, feeling most of my body the same as prior to my accident, now society at large including the women's movement, regarded me as an alien, as an outcast. Diminishing my prior *her* story, my ability, my career, my feminist work to nearly zero.

The solidarity that I had always cherished so much within the women's movement was not apparent for women with disabilities.

This made it clear to me that in most policies and debates about emancipation or about diverse society, ableness, masculinity and whiteness are simply not taken into account as particularly powerful positions and it is only ”them”, i.e. women or disabled people who are targeted as being in need of transformation.

Intersectional thinkers, on the other hand, believe that the axes of differentiation that structure our lives are always already connected to each other. Class, for instance, has already gendered and disabling manifestations; correspondingly, when we talk about gender, we are also and simultaneously making statements about class and disability and the same goes when one takes disability as the entry point of an analysis.

I want to highlight today this particular way of thinking about the differences that come together in the positions of disabled women and girls in various European metropolitan centers. Their positions warrant our serious attention in terms of their fundamental rights and living circumstances now and in the future.

Intersectional theory is one of the contributions that women-of-colour have made to feminist thought during the 2nd feminist wave. Gradually others like women with disabilities and lesbian women alike have taken up their insights.

As gender equality has been such an intrinsic part of my life in combination with class, the element of disability became just another intersectional aspect from a sociological viewpoint, even though it had a major impact on my personal and physical life as well. But as disability scientist I have taught myself to distinct the medical from the social model, and to keep the physical pain and dilemma's of my body as a private issue, unless there is a causal link to environmental, social or economic barriers created by society as a whole.

It was not common in my class that girls went to higher education or university, and I was one of the first exceptions in my family. Already at the age of 20 I had this urge to go beyond borders and went for 3 years to Tanzania to build a secretarial school for women and girls and supported the Flying Doctors Service on their weekend flights with my secretarial skills. A time wherein I learned about difference, about hunger and pain, but also about the contradictory combination of suffering and happiness.

After my return to the Netherlands I decided to enter university to find skills that could be even more useful when returning to Africa or into other developing countries. Marriage, the in the last year unfinished psychology study (as I had doubt about its contents from a feminist perspective), my political activism and feminism and on top of that in 1982 the car-accident never made me return for long to the developing world. All of the sudden I had to add another dimension to my existence: becoming disabled. Just a few years before I already had to add another —till then hidden— intersectional aspect to my life as I discovered being a lesbian.

The question arises then: did I become a multiple oppressed person and if so is that condition permanently present? My answer on this is a clear No and I will explain this further with a discourse on intersectional thinking.

Intersectional theory is based on thinking about “difference”, which involves and implicates all of us. This thinking goes against the grain, it complicates things, but it is more inclusive. It says: we are all in this society together and it does not favour particular positions, as is the case in commonsense thought. I will be paying attention to differences of gender, disability and class but could as well have added here sexual orientation, “race”/ ethnicity and age. All these dimensions structure the ways in which society is organized; that is why they are called social ordering principles.

They are operative at different levels: a personal, a symbolical and an institutional level. First, I will illustrate how these important differences operate at different levels. Subsequently I will make a far reaching proposal for policy making and how to work towards an attitude change in European society.

Gender

In the eighties, under the influence of theoretical developments within the English-speaking region, the concept of gender gained increasing acceptance in

Women's Studies. When compared to sex, 'gender' allowed for a broader and more dynamic perspective. The concept of gender, which lacks a suitable equivalent in many European languages, refers to social interpretations of biological differences between men and women. These biological differences do not speak for themselves; what is important are the meanings given to these differences in a particular culture. In Western societies biological difference is coupled to the idea that masculinity is superior and femininity is inferior. Gender is the complex and ever changing system of personal, social and symbolical relations through which men and women are created socially and through which they enter roles, identities, status, power and material resources available in society.

Both men and women have gendered identities and experience gender relations, but they experience them differently, because of the a-symmetrical social processes through which men and women become men and women.

The analytical category gender has fulfilled a paradigmatic role in the development of a constructivist vision on women, men and relations between the sexes (Bosch 1999, p. 19). Where the monolithical category 'sex' paid attention to women as a homogenous group of 'victims' and men as 'oppressors', excluding them from education and research, gender refers to the social interpretation of masculinity and femininity. The abandonment of the concept of sex also meant a distancing from a model which has disadvantage at its centre, imprisoning women and femininity, requiring special measures.

Interpretations of masculinity and femininity are no longer fixed, but may vary according to historical periods, social contexts, culture, class background, disability, ethnicity, sexual orientation and/or other factors. As a consequence, gender offers possibilities for change and variation. Women are no longer seen as a disadvantaged 'group' only, men are no longer unilaterally seen as oppressors; there is too much variation between women and too much variation between men to make such a one-sided classification relevant.

Yet at the same time we have to realise that although we need to focus on the gender consequences of men as well this cannot be seen apart of the unequal situation that women with and without disabilities are still subjected too. The dominance of the patriarchal structures in our societies today still disadvantages women. Moreover violence against women and girls is still a great problem and most perpetrators of such violence are men.

The paradigm change from sex to gender and an increasing insight into the differences between various women made the emergence of disability as an issue on the feminist agenda unavoidable. Like gender, disability[2] is created, it is a social construction or ‘invention’; disability refers to the personal, social and symbolical meanings given to (dis)abling differences between people. Those meanings are not fixed for ever. We could imagine disability as an unfinished process of the contradictory social formation of groups in which the boundaries between ‘us’ and ‘them’ are constantly defined, fought and repositioned (Hall, 1991, Van Houten, 1999, Pattynama and Verboom, 2000).

Disability

Disability is the social system that gives meaning to the disabling circumstances of people – to those disabling factors that can be made on the basis of a persons physical or sensory impairment, mental health situation, learning disability or chronic illness. But is also linked to that person’s history, culture, language, sexual orientation, ethnicity and religion.

When “disability” is being discussed in a European common sense context, but also in many academic discourses, it is predominantly “they”/ The Other/ “the disabled” that come to mind.

Like gender, disability is played out at three levels which influence each other: the personal, the social and the symbolical level. At the personal level the assignment of disability to individuals plays a role in every society that is structured by ableism and, therefore, organised hierarchically.

Just like boys and girls find out very quickly that being a boy has advantages and offers possibilities, research done shows that when they have reached the

---

[2] Not to mistake this with impairment as disability is the direct social consequence of impairment.

age of 3 or 4 children know that the non-disabled position is most desirable (Williams, P., 1997).

At the social level we find a whole system of ideas and expectations concerning disabilities: which types of behaviour, qualities and skills are ascribed to different groups and how are they appreciated? The discussions that disabled people cannot be reliable employees as they tend to be more often sick than non-disabled people; that higher education is mostly not possible as their IQ must be affected by their impairment and consequently institutionalisation. And disabled people need to be cared for and are mostly unable to take their own decisions, creating therewith a dominant and more desirable position for non-disabled people.

Finally, symbolically ‘able’ and ‘disable’ represent complete opposites. ‘Able’ still represents capability, talented, strong, powerful, healthy, skill, opportunity, while ‘disable’ represents, ineffective, unfit, incapable, and sick. (See for instance Collins Concise Dictionary, 1999).

Disability structures, like gender our personal experiences, it gives content to the symbols surrounding and constructing different positioning, and it gives rise to institutionalized inequities in society. It is clear that these dimensions structure meanings for people at the personal and symbolical levels; one only has to think of the differential consequences of applying for a position when one reveals being blind, deaf or wheelchair user. The diverging percentages of joblessness for non-disabled and disabled people or the discrimination faced by the latter in a variety of social settings, is quite telling.

At first I was also under the impression that there is no difference in relation to paraplegic men or paraplegic women, but practical situations proved otherwise. Most of my male colleagues are more often referred to as ‘Sir or Mister’ while I am named by my first given name only. Disabled men face lesser employment problems than disabled women do. Also the road to higher education is easier for disabled men than for disabled women. In most aspects I see similar discrimination as my non-disabled sisters’ experience, and some are related to my disability and sometimes the combination is true. Within the disability movement the male dominance is as apparent especially in leadership roles as can be seen within other organisations or political institutions. The same can be said for homosexual disabled women and men and from ethnic minority background.

Social Inclusion or Exclusion

In policy today, we see a shift toward client centred-thinking. In other words, there is a change to centrally situate the questions, need and demands of citizens. This is also evident from an instrument like gender and/or disability mainstreaming. Of course, it is important that gender and disability are part of the process of policy development and implementation, but it is not enough. It is a missed chance when policy makers foreground instruments that are only targeting gender or disability, while the other axes of signification are left to the side, as if they had no meaning. It is important that all policies, whether in the field of poverty eradication or health care should take the relevant differences that exist between people into account.

Furthermore we have to realise that also organisations of generally marginalised people exclude those people that are not part of their ‘culture’. The disability movement has proven to be very homophobic and has still difficulty to include disabled persons from ethnic minorities (black and Roma for instance) and to have women in leadership positions. The same can be said for the Lesbian, Gay, Bisexual and Transgender (LGBT) movement that have difficulty including LGBT disabled persons as well as persons from ethnic minorities. And there is hardly any difference within ethnic minority and other groupings in relation to exclusive behaviour. This stresses the importance of including and celebrating difference from a positive rather than from a negative or problematic angle. Within all movements men are mostly the norm and women play a subordinate role in leadership positions.

My radical proposal is that, if one wants to reach as many people as possible with a policy, then the imaginary subject should not be the norm, but a person who deviates in many respects from that standard. The implicit subject in most policy is a heterosexual white non-disabled man or woman, who speaks fluently the national language, is autonomous, can take care of him- /herself financially, can make choices, and does not suffer from racism, homophobia or ableism.

I want to highlight the principle that what is good for a subordinate group is also good for the groups and individuals who are situated in more favourable positions. What is good for disabled women, i.e. new ways of thinking about labour, less —domestic— violence, economic independence, better support with reproductive health issues, is also good for other women and men. The reverse is not true.

Closing Remarks

Looking back of nearly 60 years of being a feminist, 25 years as disability activist and 30 years as lesbian and gay activist and the accomplishments I have been able to achieve, I look back at overcoming the obstacles and seeing the intersectional aspects that sometimes hamper me as clear variables that do not add up to my daily life as three or four layers of clothes. Being a feminist and activist paved a way into the European Women's Lobby to become their first disabled woman president ever, and even as far as we know in history of the women's global movement. I became active within the International Lesbian and Gay associations, who are —despite of the HIV/AIDS survivors movement— are still coping with ableism, but fortunately to a lesser extent as the disability movement does regarding homophobia. All my positions within these civil society movements created open doors within European and international civil and government organisations and it supported me in my later work with the drafting of the *UN Convention on the Rights of Persons with Disabilities* and specifically the women, girls and gender paragraphs. My sport and academic career (as disability, gender and social scientist) added to my expertise as international gender and disability expert. Always taking into consideration what aspect of my self was hampering, often it is being a woman, sometimes my disability and in rarer cases being a lesbian. The latter plays a greater —negative— role in my current activities as expert in sport for women in particularly Muslim countries and developing countries than gender, and disability do.

For all disabled women and girls, regardless of their age, sexual orientation, ethnicity, nationality, religion etc. it is essential to deviate what element is predominantly discriminating you at a certain time. When among disabled women the disability is not the first hampering element, neither is gender in a women's setting. To regard intersectional aspects as a variable that changes with time, place, environment, group etc. By doing so we can distinguish better the way to deal with the various aspects and to create adequate policies for women and girls with disabilities.

- It is important that intersectional thinking becomes part of the toolkit of policy makers all across Europe, not only to do justice to the complexities of their changing populations, but also to make European data about disabled women and girls and non-disabled women and girls and disabled men comparable, including all other intersectional aspects like class, sexual orientation, ethnicity, age, religion, nationality etc.
- Connections should be forged between organizations of disabled women, and of non-disabled women, policy makers and Women's Studies in various European nations in order to make good policies for disabled women and girls especially in relation to poverty, violence, reproductive rights and health, ethnicity, religion, nationality and sexual orientation.
- In the light of a European history that is interlarded with inequities and ultimate violence against groups of people (mostly women) who were deemed to be inferior, we should be aware that to make good policies is not just a matter of correcting some obvious flaws here and there, but that we are prepared to look the systematisation of exclusions, asymmetries and hierarchisations straight in the eye. Only in that way will we be able to overcome the devaluation of disabled women and girls.

I am now nearly at the threshold of a third life: that of ageing, or I rather like to call it becoming part of the '*Eminence Grice'*, but if I listen or read the negative connotations that the ageing population in the European Union is subjected to, I fear that my work as an activist is not over yet and more decades of activism have to be added to the nearly 60 years of being a feminist, 25 years of disability activism and 30 years of fighting homophobia.

Literature

ACKER, JOAN (1992) ‘Hierarchies, Jobs, Bodies: A Theory of Gendered Organizations’. In *Gender & Society* 4.

ALVESSON, MATS & YVONNE DUE BILLING (1992) ‘Gender and Organization: towards a differentiated understanding’. In *Organization Studies*, 13, I.

BARNES, C. (1991) ‘Disabled People in Britain and Discrimination’, in THOMAS, C. (1999) *Female Forms; Experiencing and Understanding Disability.* Buckingham-Philadelphia: Open University Press.

BARNES, C., MERCER, G. AND SHAKESPEARE, T. (1999) *Exploring Disability: A sociological introduction.* Cambridge: Polity Press.

BARNES, C. (2000) ‘The Social Model of Disability: Myths and Misconceptions’ in *Definitions and Theories of Disability.* Reader MA in Disability Studies, Leeds: DRU Press.

BARTON, L. and OLIVER, M. (eds.) (1997) *Disability Studies: Past, Present and Future.* Leeds: The Disability Press.

BOTMAN, M., N. JOUWE EN G. WEKKER RED. *Caleidoscopische Visies. De geschiedenis van de zwarte, migranten- en vluchtelingen vrouwenbeweging in Nederland.* Amsterdam: KIT, 2001.

BRÜCKNER, M. (2004) ‘Changing Europe and the Relevance of Care and the Caring Professions’, *Social Work and Society* 2 (1): 28-39.

CHARLESWORTH, H. (1994) What are “Women’s International Human Rights?” In R.J. COOK (ED.), *Human Rights of Women - National and International Perspectives,*pp.58-81. Philadelphia: University of Pennsylvania Press.

CONNELL, R.W. (1987) *Gender and Power: Society, the Person and Sexual Politics.* Cambridge: Polity Press.

CONNELL, R.W. (1995) *Masculinities.* Cambridge: Polity PreConnell.

CORKER, M.(1998) *Deaf and Disabled, or Deafness Disabled?* Buckingham: Open University Press.

COCKBURN, CYNTHIA (1991) *In the way of Women – Men's Resistance to Sex Equality in Organizations.* London: Macmillan.

CRENSHAW, K. (2000) 'Background Paper for the Expert Meeting on the Gender-Related Aspects of Race Discrimination'. Paper presented at Zagreb, Croatia (November 21-24).

CRENSHAW, KIMBERLE WILLIAMS (2000) "Intersectional Discrimination" Background paper and Training Workshop Prepared for Expert Group Meeting on Gender and Race Discrimination. New York.

DAVIES, K. (1996) 'Capturing Women's Lives- A Discussion of Time and Methodological Issues', *Women's Studies International Studies* 19(6): 579-588.

DOORN, L.G. (1998) 'Universality and Women's Human Rights- an Artificial Connection?', *SIM Special* 21: 401-419.

ESSED, P. (2002) *Cloning Cultural Homogeneity While Talking Divesity: Old Wine in New Bottles in Dutch Work Organizations?* Transforming Anthropology.

ESSED, P. & D.T. GOLDBERG (2002) 'Cloning Cultures: The Social Injustices of Sameness. A Discussion Piece'. In *Ehtnic and Racial Studies,* Vol 25, nr. 6 (November 2002).

FRENCH, S. (ed.) (1994) *On Equal Terms: Working with disabled people.* Oxford: Butterworth-Heinemann.

HALL, S., (1991) Het minimale Zelf en andere opstellen. Amsterdam: SUA.

HOBSON, B. AND R. LISTER. (2001) Keyword: Citizenship, in J. Lewis, B. Hobson and B. Siim (eds), *Contested Concepts; Gender and Social Politics*. Edward Algar.

HOUTEN, DOUWE VAN (1999) *De standaardmens voorbij. Over zorg, verzorgingsstaat en burgerschap,* Humanistische Bibliotheek, Maarssen: Elsevier / De Tijdstroom.

MAKKONEN, L.L.M.T. (2002) *Multiple, Compound and Intersectional Discrimination: Bringing the Experiences of the Most Marginalized to the Fore*. Institute for Human Rights, Åbo Akademi University.

OLIVER, MICHAEL (1996) *Understanding Disability: From theory to practice.* Basingstoke: Macmillan.

OLIVER, M. (1990) *The Politics of Disablement.* Basingstoke: Macmillan.

PARSONS, T. (1951) *The Social System.* New York: Free Press.

PATTYNAMA, P. EN M. VERBOOM (2000) *Werkboek 'Kleur in het curriculum'. Interculturalisatie in het hoger onderwijs*. Utrecht: (NGV/Gem).

RIVIÈRE-ZIJDEL la, LYDIA (2000) *What is missing in the divisions of welfare for disabled Women*. Amsterdam: ITAR Publ.

RIVIÈRE-ZIJDEL la, LYDIA (2001) *How can the under-representation of disabled women and mothers within the European Disability Forum (EDF) be diminished?* Amsterdam: ITAR Publ.

RIVIÈRE-ZIJDEL la, LYDIA (2001) *The relevance of the Social Model of Disability within various cultures.* Amsterdam: ITAR Publ.

RIVIÈRE-ZIJDEL la, LYDIA (2003) *Is disability gender-neutral?* EWL Publication: Brussels.

SEIDMAN, STEVEN, ed. (1997) *Queer Theory/Sociology.* Blackwell Publ.: Oxford.

SUNDIN, ELISABETH (2003) 'Changing Work Organisation in the Knowledge Economy for improved Gender Equality'. Speech at the European Congress and Ministerial Conference on *'Gender and Information Society'*, Athens: 5-6 May 2003.

SWAIN, J., FINKELSTEIN, V., FRENCH, S. and OLIVER, M. (eds.) (1993) 'Disabling Barriers Enabling Environments'. London: Sage In RIVIÈRE-ZIJDEL la, LYDIA (2001) *From Rucksack to Attaché case: Towards a new vision on disabled people's employment.* Amsterdam/Leicester: ITAR Publ.

WEKKER, GLORIA "Building nests in windy place, thinking about gender and ethnicity in the Netherlands": oration, april 2002 WEKKER, GLORIA (RED.) Lover 2002/ 2: "Kruispuntdenken – Over gender & etniciteit. Een staalkaart van kwesties".

WEKKER, GLORIA EN HELMA LUTZ "Een hoogvlakte met koude winden. De geschiendenis van het gender- en etniciteitsdenken in Nederland" In: Botman, Jouwe & Wekker (red.), *Caleidoscopische visies. De zwarte, migranten- en vluchtelingenvrouwen-beweging in Nederland*. Amsterdam, Utrecht, Den Haag: KIT, GEM, E-Quality, 2001, p. 25-50.

The English translation (A wind-swept plain; the history of ideas on gender and ethnicity in the Netherlands / by Gloria Wekker and Helma Lutz (2001)) you can find via: http://www.iiav.nl/epublications/2001/windswept_plain.pdf

WILLIAMS, PATRICIA J. (1991) *The Alchemy of Race and Rights. Diary of a Law Professor*, Cambridge, Massachuetts, and London: Harvard University Press.

WILLIAMS, PATRICIA (1997) Seeing a Color Blind Future. London (Virago).

WING K. (ED.), *Critical race feminism. A reader*, New York 2003.

HUMAN RIGHTS PERSPECTIVE ON GIRLS AND WOMEN WITH DISABILITIES

KICKI NORDSTRÖM
World Blind Union

Women and the United Nations Conventions

A United Nations Convention is an international law, to which each country member of the UN, is obliged to follow, if the country has ratified the convention.

There are 8 Human Rights conventions in force in the UN and all of them sort under the Office of the High Commissioner on Human Rights (OHCHR), in Geneva.

The 9th UN Convention which soon will come into force, is the Convention of the Rights of Persons with Disabilities, CRPD.

CRPD is the convention that will ensure full human rights and fundamental freedom and equal opportunities for persons with disabilities of all ages, nationalities, social status, religion, ethnic background, sex or sexual orientation.

We have now a document which will be legally binding for States which ratify it. It takes 20 ratifying countries until the convention can come into force. Most likely will the convention come into force during 2008.

We hold our countries accountable for ratifying the CRPD very soon, together with the Optional Protocol and without any reservations.

As soon as the convention has come into force, a monitoring committee will be established. The committee will monitor the convention and receive complaints from individuals and organisations. The condition is however that countries also ratify the Optional Protocol to the convention.

This convention is not a social declaration nor is it a convention on development. It is a pure human rights based convention, nothing more, nothing less! For the first time in history will persons with disabilities be seen in the context of human rights, this is why CRPD is so important. Persons with disabilities will no longer depend on medical professionals or care givers and their justifications for getting our rights insured.

The convention will not only constitute an international law, but also become national laws, as all national laws must be adjusted and apply to international laws or conventions.

This convention is not a toothless convention without power. CRPD is the most powerful convention of all human rights treaties in the UN system.

CRPD has several new rights, among one of them is that EU as a regional body can ratify the convention beside each of all EU states. That means that EU must form a new directive on disability rights – finally.

Women with disabilities are recognised at several places in the CRPD. We have our own article (number 6). In article 6 it is acknowledge that women with disabilities suffer from multiple discrimination.

We all know that women with disabilities (WWD) suffer from neglect, isolation and invisibility by the society at large. But if we keep together and form a common front and make ourselves visible and heard, we may get countries to listen to our voices and demands for justice and non-discrimination! We must now learn how to use our legal instrument so as we can put an end to discrimination of all persons with disabilities, but in particular WWD.

One mistake has been committed by women mainstream activists, - they have forgotten women and girls with disabilities in their work. It seems that WWD are not seen among the public society, as women at first, but rather a sexless and neutral body with a disability.

This is obvious if we just look around and seek for information about women with disabilities. Very little is to be found. If you happen to find something, women and girls with disabilities are often made helpless and dependent. WWD are marginalised and made invisible in international surveys, national data collections and in social and legislative programs and actions. Women and girls with disabilities are made inferior and unknown by not being noticed of their existence in any kind of publicly addressed investigations, gender policies, women's programs or laws of protection.

Statistics from Canada, Finland and Sweden reveal that up to 50% of women in general may have been physically abused in their lifetime and this is probably just the tip of the iceberg. What do we know about WWD? Among women with disabilities the numbers may be even higher

There are however some NGO's, which have made investigations on violence, and it is not a nice reading at all. The perpetrators are often the support givers, family members or professionals. When will government acknowledge that WWD also can experience severe violence and make a national study of the problem? Or is this not interesting enough?

We must admit that there is a need to assist battered and abused women with disabilities and make them visible! What do we know about this area? What are we, ourselves doing for getting violence against WWD seen? What support do sheltered homes for battled women give WWD?

Violence against women is a criminal act and agreed on as such by the UN Human Rights institutions. We must learn to use our legal documents. That also includes WWD.

All these neglect and lack of interest in the living conditions of WWD was the reason why we from the International Disability Caucus (IDC), so strongly fought for a stand alone article on women with disabilities in the CRPD.

We had mainly EU opposing us. EU took the stand that there are already a convention which prohibit discrimination against women, namely the *Convention on the Elimination of All Forms of Discrimination against Women* (CEDAW).

Our reply was that we, women with disabilities have never been recognised, reported on or mentioned in connection to CEDAW. That convention would never protect WWD.

The worse countries in opposition to us were the UK and Sweden.

After a long fight, women with disabilities were recognised in the CRPD within our own article and at a number of essential areas, even if not directly spelled out in the text.

Articles there WWD are directly or indirectly mentioned are:

- Women with disabilities, Article 6;
- Right to life, Article 10;
- Equal recognition before the law, Article 12;
- Access to justice, Article 13;
- Freedom from torture or cruel, inhuman or degrading treatment or punishment, Article 15;
- Freedom from exploitation, violence and abuse, Article 16;
- Freedom of expression and opinion, and access to information, Article 21.
- Education, Article 24;
- Health, Article 25;
- Rehabilitation, Article 26;
- Work and employment, Article 27;
- Participation in the political and public life, Article 29;
- Participation in cultural life, recreation, leisure and sport, Article 30.

Then we drafted the CRPD, we realized that we had to demonstrate consensus and have to support each other in order to gain what we wanted. I believe it is in that way we, women with disabilities shall continue to do, so as we can form a sustainable network of WWD in Europe.

But this is not enough, we ourselves must be proactive and let us make use of what is available. We will soon have legal means, we must learn how to use them.

We must take initiatives to work with some of the following:

- International women's organisations;
- Different international Disability Persons' Organisations (DPO)'s;
- UN body and its agencies.

We must prepare and perform an international advocacy campaigns in order to raise awareness of the existence of WWD. We need all allies we can find, in order to be effective at the international level.

At the national level we should work with the following tools:

- Awareness raising;
- Education of the civil society;
- Networking between national women's organisations;
- National DPO's which could be beneficial to us;
- Financial support structures and fundraising;
- Capacity building and leadership training of WWD.

These tools could help to make women with disabilities visible, heard, noticed and taken into account.

The *Convention on the Elimination of all forms of Discrimination against Women (*CEDAW), is another UN convention, which we should and can work with, perhaps with other women's groups or organisations.

CEDAW is ratified by about 160 UN member countries. UN has 192 members.

CEDAW is mainly addressing non-discrimination against women. CEDAW is silent concerning violence against women. CEDAW do not address any particular concerned group of women at all! But CEDAW highlight the equality between men and women: One can say that CEDAW is a rather narrow convention compared to CRPD.

However, what is stated in CEDAW does also apply to WWD, fully out and without any exceptions. We are the only ones that can demand this fact. Other women's organisations are not doing it on our behalf.

> ***CEDAW*: *Article 2. (b):*** *To adopt appropriate legislative and other measures, including sanctions where appropriate, prohibiting all discrimination against women;*

Why are we not using this article, ladies?

Another thing we can make use of through CEDAW, and should, if we need, is the issue about legal capacity.

In CEDAW Article 15 paragraph 2, states that:

> *States Parties shall accord to women,… legal capacity identical to that of men and the same opportunities to exercise that capacity.*

CEDAW states that legal capacity shall also cover women's influence in all aspects of life, equal to men.

In CRPD legal capacity states that:

> ***Article 12.***
>
> *Paragraph 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*
>
> *Paragraph 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their Legal Capacity.*

The text in CEDAW does not refer to men as it is understood that men carry legal capacity by nature. Men already possess the influence, power, socially, culturally and economically, therefore are guaranteed legal capacity after his 18th birthday.

The advantage WWD may gain from those two Conventions, is that the legal capacity is guaranteed to all women through CEDAW, without any exceptions. But this right is also guaranteed us through CRPD as CRPD guarantees legal capacity to all PWD, with out any exceptions.

But now we can hear that countries declared they wish to make reservations to this article on legal capacity. This reservation may at first address persons who have an intellectual or a psychosocial disability. But It is also said in some places that the reservation should also cover persons who are blind or death, or deafblind or persons who have speech problems.

If we refer to CEDAW instead of CRPD in the case we are deprived our legal capacity for any reasons, we should be covered by CEDAW convention as women. But poor men who fall under the CRPD and if the country has tabled a reservation, those poor men will not be covered and can be denied their legal capacity.

Women with Disabilities must be more active and successful in our human rights advocacy work and specifically around the issues of sterilization of women and children with disabilities. In particular sterilization of girl children with an intellectual disability, is now a big issue in some states.

The ironic situation is that in those states abortion is prohibited but it seems OK to sterilize a girl or a woman, and deprive her of her legal capacity, her full and informed consent and the right to keep her fertility!

All forms of sterilization without full and informed consent, must be seen as violence. We must admit that all sterilizations without full and informed consent are an act of violence committed by the State.

The main step forward now, towards the realisation of a world without discrimination, a world in peace and freedom for all, is to put an end to all forms of violence and discrimination of women and in particular of WWD.

All legal measures must be followed up by monitoring and implementation policies at the international and on national levels.

No excuse for inactivity or lack of resources should be tolerated. A change in attitude and behaviour would not cost much money, but may take a bit of personal and political will from some.

Mainstreaming policies and particular mentioning of women's equal human rights have not brought about any changes for women. This must be obvious for everyone now.

Maybe it was a mistake by the women activists during the last decades, to demand mainstreaming instead of anti-discrimination laws and particular rights for women. Or should we have demanded both – a twin track approach to gender equality? What is meant with a twin track, is that we can ride two parallel tracks at the same time. One on the mainstream track and the other on the anti-discrimination law track. We may be able to do both and thereby gain what we want, namely gender equality.

We must improve our representation and leadership skills. We must be active in the ongoing work regarding the development and implementation of the United Nations treaties. It is through those treaties we have been guaranteed our full and equal rights with others. But we have to tell them, the rights will not be given to us without us asking for it.

We must challenge our government so as they not only adopt new legislations without implementations. We will monitor that the rights are implemented.

The power of the dream is near. 650 million persons with disabilities, of which more than a half are women, can look forward to a better world and a better life in the future due to CRPD! But only if we press for changes ourselves. Government will not offer any changes in attitudes or resources to us, we must demand the changes to be made ourselves.

Let us, women with disabilities take the lead. We have the knowledge, we have the skills and we take the power.

Let us do it through our European network of WWD, let the network grow and let it become a world wide movement. Let us tell everyone:

Nothing about WWD, without us involved!

APPENDIX

Here are the texts in the CRPD that in particular concern women with disabilities:

> ***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.*

Further, it is stated in the preamble:

> *(q) Recognizing that women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation.*
>
> *(s) Emphasizing the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities.*

Article 3. General principles

This is one of the fundamental articles in the convention and it states that the principles of the present convention shall be:

(g) Equality between men and women.

Article 12. Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

Article 16. Freedom from exploitation, violence and abuse

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.

Article 25. Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

Article 28. Adequate standard of living and social protection

(b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes.

Article 34. Committee on the Rights of Persons with Disabilities

4. The members of the Committee shall be elected by States Parties, consideration being given to equitable geographical distribution, representation of the different forms of civilization and of the principal legal systems, balanced gender representation and participation of experts with disabilities.

EUROPEAN PERSPECTIVE ON GIRLS AND WOMEN WITH DISABILITIES

MARIA NYMAN
European Disability Forum

NATALIA BERAZA
CERMI Commission of Women with Disabilities

The purpose of this presentation is to give you an overview of the legislative instruments existing at European level of particular relevance for women and girls with disabilities.

It is to be recognized that multiple discrimination is an area that the European Union has showed some interest in and understanding for rather recently. Gender equality is generally dealt with within the Gender Equality Rights unit of the European Commission whilst disability is dealt with in the Disability Unit. There has been a gap in coordination, cooperation and mainstreaming on the specific area of women with disability between those two units, and even the more for all other units of the European Commission, which have not focused on this question at all.

Although the European Action plan on people with disabilities is recognising the need for a mainstreaming approach of disability, this has hardly been implemented in policies in proactive, with transport being the only clear exception. The specific situation of women with disabilities has until very recently not been highlighted or recognised at all, and is not even mentioned in the action plan on disability! There are no specific actions proposed on the situation of women with disabilities and mothers of disabled children, and not any actions are proposed to include a gender equality perspective.

However, the European Community signed on the 30th of March the *UN Convention on the Rights of Persons with Disabilities*. This is the first time the Community signs a core UN human rights convention.

This signature also shows that Europe wants to be at the forefront of strengthening rights for people with disabilities worldwide and is an important achievement in the European Year of Equal Opportunities for All.

The convention text also acknowledges, as you already know, that women with disabilities are more likely to face multiple forms of discrimination and accordingly calls for measures combining mainstreaming of gender issues and specific gender sensitive measures in the disability field.

Member States have given a mandate the European Commission to negotiate and sign on behalf of the Community on matters falling under Community competence, but the EU Member States themselves will also sign the Convention individually. Signature constitutes the first step of becoming formally part of the Convention.

Having the Convention signed by the EU also means that there will be an enforced legal basis for mainstreaming disability in all EU policy areas, and, as gender should be mainstreamed in disability policies —this is clear from the convention— in the end this means that the perspective of women with disabilities must be mainstreamed in all EU policy areas, beyond usual disability policies and usual gender equality policies.

The *European Commission Road Map 2006-2010 on the Equality between Women and Men in the EU* is recognising the issue of multiple discrimination and states that it must be combated.

The road map outlines six priority areas for EU action on gender equality for the period 2006-2010: equal economic independence for women and men; reconciliation of private and professional life; equal representation in decision-making; eradication of all forms of gender based violence; elimination of gender stereotypes; promotion of gender equality in external and development policies.

Despite slightly touching upon the issue of multiple discrimination, disability is not mentioned explicitly in the road map, despite the fact that it is dealing with the priorities that I just mentioned, in which there are clearly specific issues that need to be tackled for women with disabilities. Access to health care is an example —disability is not mentioned here, the same goes for the gender based violence and so on.

During this summer, the European Commission came out with a call for tender for a “*Study on the situation of women with disabilities in Europe in light of the UN convention on the Rights of People with Disabilities*”. The background for the contract is indicated to be that “*there are inequalities existing in many spheres of life resulting from gender and disability. Women with disabilities are more likely to be exposed to multiple forms of discrimination. When accessing their human rights and fundamental freedoms disabled women face various obstacles, even more than disabled men. According to empirical evidence, they are often marginalised, isolated, abused and are situated at a great risk of poverty.*”

This is the first time that this is so explicitly recognized by the European Commission. The main field of this study will be the collection of the information and its analysis and interpretation on the situation of women and girls with disabilities in the light of provisions of the UN Convention

In April this year the European Parliament adopted a resolution on the situation of women with disabilities in Europe. The rapporteur of this report, which was elaborated by the committee on Women’s Rights and Gender Equality, was Ms Esther Herranz García. Among the important legislative instruments that it was building its position on, it was referring to the EDF manifesto of disabled women in Europe.

Through the resolution the Parliament was particularly calling on the Commission and the Member States to ensure the removal of existing barriers and obstacles, with a view to creating equal rights and opportunities for women and girls with disabilities to play a part in family, political, cultural, social and professional life, particularly through better implementation of Community anti-discrimination and gender-equality legislation. It was also calling the Member states and Commission to take all relevant measures and to undertake studies to eradicate existing violence against disabled women and better use of the opportunities provided by relevant Community programmes and funds.

Among the many rather positive suggestions that it includes —thanks to partly some lobbying action from the disability movement – it is demanding for the support to set up a network of women with disabilities in Europe and to include a disability perspective in the country reports on the CEDAW convention. These are very concrete points that the disability movement could use as support in their lobbying actions relating to women and disability.

Another important European stakeholder, the Council of Europe, has adopted an *Action Plan on People with Disabilities*, which is intended to serve as a roadmap for policy makers, enabling the design, adjustment and implementation of appropriate programmes and innovative strategies. It has a broad scope covering key areas for people with disabilities, reflected in 15 action lines including participation in political, public and cultural life, education, information and communication, employment, accessibility of the built environment and transport. It also draws attention to the needs of women and children with disabilities, and equality between women and men is one of the fundamental principles upon which this document is based upon.

You will have understood from my presentation that the legal documents and recommendations at European level which touch upon the fundamental question on the equal rights of women with disabilities are few. However, although there is a long way forward, we can see that at least the discussions are getting started.

Let’s contribute to these discussions, let ‘s ensure that there will be a disability perspective in all EU policies aiming at equality between the sexes and that equality between women and men becomes a part of all EU disability policies.

ACTION PLAN FOR WOMEN AND GIRLS WITH DISABILITIES IN SPAIN

LOLA LINARES MÁRQUEZ DE PRADO
General Directorate, Co-ordination of Sectorial Policies on Disability, Ministry of Labour and Social Affairs (MTAS)
Head of Planning

A plan is a political document adopted by the Council of Ministers since disability policy touches upon the work of different ministries. Having said that, the Ministry of Employment and Social Affairs puts forward and promotes the plan as it is the lead ministry in this policy area. A document of this type involves:

- A commitment made by the Government to citizens (the elections are there to make sure it is carried through) in a specific topic on the political agenda;
- A way to carry through actions for the governing bodies involved;
- Instructions for public servants on what may and should be proposed; in short, on how to act;
- Pedagogical aspects, given that it describes the situation at the outset and criteria and values are set out in goals to be reached to modify the situation, and actions and instruments —along with ways to relate to others and behave towards women with disabilities— aimed at changing the situation and the social imaginary society holds with regard to women with disabilities.

The *Action Plan on Women with Disabilities* arises from the invisible nature of the disadvantageous status that women with disabilities face as part of the wider grouping of people with disabilities. Women with disabilities themselves —leaders in the disability movements and experts— held the view that the discrimination they face is similar to that faced by the whole disability movement with an added element because they are women.

In drafting action policies, therefore, it would be enough to incorporate the point of view of disability in gender policies —approximately 9% of all women have a disability— or the gender perspective in policies on disability (in Spain 58 % of all people with disabilities are women).

Nevertheless, the 1997 *European Disability Forum Manifesto by Disabled Women in Europe* revealed that such policies, in addition to being insufficient, widened the existing gap between men and women with disabilities and women with and without disabilities due to their intention to remain neutral; policies in the field of disability have tended to favour men, while gender policies have overlooked the fact that the roles attributed by society to women with disabilities differ from those assigned to women in general.

Women differ from each other in that apart from the different types and degrees of disability, and changing situations throughout the entire life cycle —from girls to elderly women— they may belong to any of the social classes or cultural identities present in our country.

We are dealing with a reality that affects more than two million women; women who find themselves in a more vulnerable situation. Many face the risk of social exclusion and all share the risk of suffering from social rejection which can cause great damage to the self-esteem of women and girls with disabilities, although given their special circumstances, many of the barriers they share with all women, such as difficulties in finding a work-life balance or having to put up with family-based or institution-based gender violence, are exacerbated.

Around half a million of these women with disabilities in our country are confined to their homes. They have almost no decision-making power in their families, are not involved in employment or public activities, are unable to live an independent life and face a lack of care aggravated by their old age and the fact that they are largely and almost solely responsible for taking care of their parents.

The key facts in this field are as follows:

Women with disabilities make up 58% of the total number of people with disabilities, and those over 65 years old make up the majority. This difference becomes greater in people over 80 years old, 69% of whom are women and 31% men. (*Source: Survey on Disabilities, Handicaps and State of Health, 1999-INE, ONCE Foundation and IMSERSO)*

With respect to marital status, 39% of women with disabilities are widows, while 9% of men with disabilities are widowers. 45.2% are married, in comparison with 67.3% of men. (*Source: Survey on Disabilities, Handicaps and State of Health, 1999-INE, ONCE Foundation and IMSERSO)*

74.79% of women with disabilities have no qualifications or only a primary school education. In terms of illiteracy caused by factors unrelated to physical or mental problems, 6.74% (43 410) of all women with disabilities are illiterate in comparison with 3.66% of all men (23 463). (*Source: Survey on Disabilities, Handicaps and State of Health, 1999-INE, ONCE Foundation and IMSERSO)*

In terms of involvement in economic activity, the percentage of women with disabilities (21.7%) is lower than that of women in general (44%) and that of men with disabilities (34%). *(Source: EPA 2005)*

Unemployment among women with disabilities (19.7%) is three and a half percentage points higher than that of women without disabilities (16.2%), and almost seven points higher than that of men with disabilities (12.8%). (*Source: People with disabilities in relation to employment, using statistics from the Survey on Active Population, 2nd quarter 2002, INE 2003)*

There is a significant gap between women and men with disabilities in the impact of measures to boost employment. Of the 43 088 people with disabilities involved in such measures, only 12 731, that is to say 29.54%, are women. (*Source: Survey on Disabilities, Handicaps and State of Health, 1999-INE, ONCE Foundation and IMSERSO)*

A study of people receiving non-contributory allowances shows a clear majority of women (73.46% of the total are women: in other words, the number of women receiving such allowances is three times that of men). *(Map of non-contributory allowances, IMSERSO 2004)*

Among those receiving non-contributory retirement pensions, this difference is even more pronounced; 85.01% are women. The percentage of women among pensioners over 84 years old is even higher (89.95%). *(Map of non-contributory allowances, IMSERSO 2004)*

A cross-referenced study on ability to carry out both basic and instrumental activities in daily life shows a higher degree of dependence. Of all the people requiring assistance to carry out instrumental activities in daily living, 65.4% are women. (*Source: Survey on Disabilities, Handicaps and State of Health, 1999-INE, ONCE Foundation and IMSERSO)*

The main users of the health system are women with disabilities, 61% of all people with illnesses requiring high levels of assistance are women and they lack the accessible services needed to secure appropriate health care. (*Source: Survey on Disabilities, Handicaps and State of Health, 1999-INE, ONCE Foundation and IMSERSO)*

63% of all those with high or severe support needs are women with disabilities, compared to 37% who are men. (*Source: Survey on Disabilities, Handicaps and State of Health, 1999-INE, ONCE Foundation and IMSERSO)*

Women with disabilities barely take part in the spheres of power in society, despite their being a majority of women with disabilities in associations. This is the case even in organisations of people with disabilities, whose governing bodies are dominated by males. For example, less than half of all organisations have a female president, while the figure for associations of people with a sensorial disability is 20%. *(Women with disabilities and the disability movement, QRM, 2004)*

This overview leads us to the conclusion that many women with disabilities form a significant group of people that finds itself on the poverty line and demonstrates, along with other groups, the phenomenon of the feminisation of poverty in our country.

The double discrimination faced by women with disabilities is not the result of adding together their needs as people with disabilities and women; as both variables combine, a different and special status arises that must be understood and recognised. Given that it is a structural status, it requires a specific, innovative and long-term approach such as the present Plan of Action, which enables us to respond to the needs involved in this specific status and promote access to equal opportunities and full enjoyment of rights for this group of women.

Although women with disabilities legally enjoy the same civil and political constitutional rights, liberties and duties, and these can only be withdrawn in cases of impairment by means of a legal judgement and in the terms and to the extent set out in the judgement, their vulnerability makes it difficult to truly exercise these rights. This has been demonstrated in various studies and reports on cases of mistreatment, abuse and extortion they have had to endure. This especially vulnerable group, therefore, needs to have its rights made a reality —especially as beneficiaries and users of services and provisions— and requires specific protective measures to ensure it is truly able to exercise its rights and responsibilities.

Our constitution sets out clear and specific responsibilities with respect to promoting equality and non-discrimination. Article 9.2 of the constitution states that "*it is the responsibility of public powers to promote the conditions needed for liberty and equality to be real and effective*", while article 14 states, *"Spaniards are equal before the law and there shall be no discrimination on the grounds of birth, gender, religion, beliefs or any other condition of personal or social circumstance.*" Both articles, therefore, confirm the principles of positive action and non-discrimination on the grounds of disability.

The *Equal opportunities, non-discrimination and universal accessibility for people with disabilities act* (Act 51/2003) is the most detailed expression in our country of the new guarantees and effective implementation of the right to equal opportunities and non-discrimination. Article 8.2 of the act states that, "*public powers shall adopt additional positive action measures for those people who objectively suffer from a higher degree of discrimination or enjoy less equal opportunities, such as women with disabilities."*

However, it was after 1995 and the *4th UN World Conference on Women for the Social Advancement of Women* when public social policies began to include the demands and needs of those affected and associations of women with disabilities began to be set up. In 2000, the Spanish Committee of Representatives of People with Disabilities (CERMI in Spanish) set up its Women's Commission and initiated the process of establishing such commissions in all its regional committees. These initiatives have led to a wide-ranging debate on the needs and demands of women with disabilities in almost all regional governments and in many town and city councils.

The *1st International Congress on Women and Disability*, held in Valencia in 2003, the European Year of People with Disabilities, was a key event both because of the level of involvement by women with disabilities and the importance of the conclusions reached, especially those concerning the need to promote measures to boost autonomy among women with disabilities, allow them to participate in all aspects of social life and assume the social roles they wish without restrictions to impede them.

As a result, the Socialist Party included a commitment to adopt an Action Plan on Women with Disabilities in its election manifesto. The plan was adopted by the Council of Ministers on December 1st 2006, thus complying with the statutory duty set out in article 8 of the *Equal Opportunities, Non-discrimination and Universal Accessibility for People with Disabilities Act.* To do this, the General Directorate for Co-ordination in Social Policy on Disability set up a working group made up of expert civil servants in the fields of disability and gender from the Directorate, the Women's Institute and women from the disability movement who were also experts in the field. The group worked together on a draft plan that was sent to CERMI, as the umbrella organisation for the vast majority of the disability movement, on several occasions for comments and feedback. It was also presented to the Social Dialogue Forum and was finally approved by the National Disability Council.

The aim of the Action Plan on Women with Disabilities is *"to remove obstacles that cause a major shortfall in citizenship among women with disabilities by means of measures to ensure they are able to exercise and enjoy their rights*".

The plan is composed of the paper setting out the principles, the action areas —including aims and actions to be undertaken— and an appendix that serves as the foundation for the plan, given the pedagogical nature all plans should contain, including statistics and a study of a hidden reality: the status of women with disabilities, the invisible among the invisible.

The plan is based on the following principles:

- *Non-discrimination and equal opportunities,* in relation to men with disabilities and women in general;
- *Positive action and cross-cutting measures* in all policies, as two complementary means to bring about equal opportunities;
- *Independent living,* promoting the capacity for self-determination;
- *Participation* in all spheres of life - economic, social or cultural;
- *Mainstreaming,* meaning women with disabilities must be able to lead a normal life and have access to the same places, areas, goods and services as any other person;
- *Universal accessibility*, a condition that must be met by environments, processes, goods, products and services to make them usable and practicable, based on design for all.

The plan includes eight action areas containing operational goals aimed at meeting the needs identified through specific measures and avoiding overlaps with those already included in other plans, whether these involve people with disabilities or women in general:

- I – *Images and prejudices.* Aimed at bringing the true status of women with disabilities to light and debunk stereotypes and prejudices limiting their expectations. It includes actions aimed at the media, women themselves and social awareness.
- II – *Family life, personal relations and motherhood.* Dealing with the family and personal relationships, key factors in the life choices made by women with disabilities and the attitudes and prejudices in which socialisation takes

place, and including measures aimed at increasing the autonomy women with disabilities enjoy in these fields.

- III – *Education.* Considering three quarters of all women with disabilities failed to complete basic education, and only a minority (4%) have some type of further qualifications, measures are included to encourage women with disabilities to remain in education and develop their potential and knowledge to the full in order to be able to take decisions freely. Independence and access to employment – or to any sphere of power – is very difficult for those who lack training.

- IV – *Employment.* Women with disabilities have less chance of finding a job due to their lack of education, their disability and the prejudices and stereotypes held by companies and potential workmates, which cause discriminatory behaviour. This action area includes measures to be taken in three fields: occupational training, working for a company and self-employment.

- V – *Power and participation*. Women with disabilities have almost never participated in any sphere of power or decision-making process. Their presence has gone unnoticed even in OPWD or the feminist movement, so their involvement will be strengthened in all areas.

- VI – *Violence*. Preventing violence against women and providing victims with assistance are complicated matters. To the violence that is present in the home and workplace we have to add institutional violence and the added difficulties women with disabilities face when reporting violence – people do not believe them, they are unable to express themselves, and in some cases the aggressor is the caregiver. To combat this and in line with the measures included in the Gender Violence Act, reporting procedures are made more flexible and suitable for this group of women.

- VII – *Health.* The document has consciously avoided a health-based approach to disability, although logically people with disabilities are heavier users of health services. The proposals are aimed at ensuring health systems respond to women's needs.

- VIII – *Social and legal protection*. In this area social services, personal independence and general independence systems have been modified to introduce more flexibility, where needed, in order to enable women with disabilities, and especially the most vulnerable, to enjoy equal opportunities when using them.

The plan, as outlined schematically above, includes action areas for the General Administration of the State and others which are clearly recommendations for the various bodies and organs with responsibilities in these fields, both in the public sphere —Regional Governments and Local Corporations— and the social sphere —the disability movement, trade unions— in an effort to involve all the sectors affected.

Finally, and bearing in mind that the *3rd Action Plan on People with Disabilities* concludes this year, in the future 4th plan the aims and actions will be included to ensure the document is drawn up with the gender perspective in mind and to introduce a culture that is consistent with the principle of equal opportunities for women and men with disabilities.

Advocacy for Girls and Women with Disabilities

PROACTIVE MEASURES IN DISABILITY ORGANISATIONS AT ALL LEVELS

ANA PELÁEZ
Chairwoman, CERMI Commission of Women with Disabilities

The low level of participation by women with disabilities in organisations of people with disabilities is an issue the disability movement must seriously consider and remedy. There is now no place for irrational explanations used in the past to justify this lack of participation: highlighting the lack of appropriate training, unsuitable backgrounds for the demands of a professional career, difficulties in balancing work and family, lack of adaptive skills for the demands of a job and a whole range of attributes that could also be applied to men.

Consequently, it is now imperative to ensure that those who hold greatest responsibility in all organisations of this type have a true political commitment to promoting specific measures that give women the status that ethically, socially and professionally we deserve.

At the same time, what is needed is a strong and committed movement of women with disabilities capable of pushing through measures and policies that ensure real equal opportunities and non-discrimination. This movement must focus on developing a strategy covering five general spheres: politics, communication, representation, co-ordination and harnessing resources, and include a number of action areas at different levels and specific tasks at each level.

Based on the Spanish experience, we will now outline a framework that may help to guide those who are seeking advice and guidance.

1. Action Line on Political Participation

a) Within the framework of the National Council of People with Disabilities or European Organisations of People with Disabilities

1. Awareness raising about the need to develop specific measures that guarantee the participation of women under equal opportunities, taking into account the risk of dual discrimination and exclusion from participation in the association movement because of gender and disability reasons.
2. Development of specific rules on participation quotas whose introduction into all the working structure and associate organisations is directed and strongly recommended by the umbrella organisation.
3. Revision of the umbrella organisation statutes in order to guarantee non-discrimination and equal opportunities of its members.
4. Introduction of specific training on gender and equal opportunities in its annual assemblies and seminars.
5. Introduction of information on the situation of women and girls with disabilities in all research and studies.
6. Elaboration of specific studies on social and political participation of women with disabilities in the umbrella organisation and its member organisations.
7. Impulse to create women's commissions within the regional structure of the umbrella organisation and its member organisations, in order to strengthen continuous dialogue on priority subjects related to girls and women with disabilities and carers of people with general support needs
8. Strengthening of an Expert Women Network on Gender and Disability
9. Organisation of periodic meeting of women with disabilities

b) Within the framework of Public Institutions

10. Active monitoring of all policies regarding gender and disability that could be developed at Public Authorities level, in order to guarantee non-discrimination and equal opportunities of women with disabilities in the field of social policies.

11. Proposal of all necessary interventions and reports to guarantee non discrimination and equal opportunities of women with disabilities in the field of social policy.

c) Within the framework of the European Disability Forum

12. Lobby EDF and MEPs for the holding of a specific meeting of the European Parliament's Disability Intergroup on gender and disability, that would include a presentation of the general situation of women in the European environment, policies carried out for them by European institutions, possibility of innovative models being implemented in some of the member countries…

13. Active follow-up on all policies that may be carried out by European Institutions in the field of gender or disability to guarantee non discrimination and equal treatment of women with disabilities, putting forward, where necessary, some measures of positive action to narrow the initial gap for these women as a specially vulnerable group.

14. Production and publication of a Report on the Current Situation of Women with Disabilities within the European Union, from the viewpoint of women and girls with disabilities.

15. Organisation of European meetings of women with disabilities.

d) *Within the framework of the United Nations*

16. Active follow up and participation in the Follow Up of the Convention on the Rights of Persons with Disabilities.

17. Coordination with other organised groups of women with disabilities at international level.

2. Action Line on Communication

18. Elaboration and spreading of specific material on the rights of women with disabilities in universally accessible formats.

19. Elaboration of electronic bulletins about gender and disability that would inform of the main relevant issues.

20. Creation of a space in the EDF web page in order to spread specific information about women.

21. Design of a specific logo of women with disabilities that would help to give identity to the association movement of women with disabilities.

3. Action Line on Representation

22. Incorporation of women with disabilities in the observatories and specific working groups, within the context of the Public Institutions, dealing with women issues or specific areas that have a direct impact on them.

4. Action Line on Co-Ordination

23. Motivate the creation of Committees of women with disabilities in the EDF national and regional structures to strengthen the continuous dialogue about matters related to girls and women with disabilities and mothers of boys and girls with disabilities that are priority.

24. Strengthening of the European network of women with disabilities.

5. Action Line on Fundraising

Identification of funds to finance workshops as well as national and European seminars devoted to strengthen the leadership of women.

MAIN CONCLUSIONS

MARIA NYMAN
Policy Oficer, European Disability Forum

1. Participation

- EDF and its members only reflect the situation within their membership: as long as women are underrepresented at local and regional level they will, as a consequence, be underrepresented at national and European level. Therefore, there is an urgent need for awareness-raising on the need for gender mainstreaming at all levels of the disability movement and on the importance of equal representation of women and men in decision-making bodies.
- In order to be able to ensure the effectiveness of a quota of women in decision-making bodies, there is also a need, as a first step, for self-esteem training for women with disabilities.

2. Communication

- The media is an important tool for awareness-raising. There is a need to be pro-active towards the media, writing articles and proposing subjects for television programmes etc, as there is currently a severe lack of visibility of women with disabilities in the media. However, there is also a need to be vigilant in order to avoid women with disabilities becoming exposed to "sensationalist journalism."
- There is a need to provide awareness-raising material that everybody can understand (including in easy-to-read versions, etc.).
- It could be useful to take advantage of existing campaigns (relating to, for example, gender equality or disability equality) to promote the urgent need for mainstreaming of women and/or disability.

3. Fundraising

- EDF should explore funding possibilities through European programmes and other possible European sources.
- At national, regional and local level it could be possible to organize fund-raising activities (everything from a larger scale, such as concerts, auctions, etc., to a smaller scale such as selling chocolate, etc.) in cooperation with an industry partner, thus creating a "win-win situation" (for the disability organization it facilitates its work and is economically interesting, for the industry it gives them a better "social profile" and more people might be willing to buy their products if they know that they support an important cause).

DEVELOPING TOOLS TO INCLUDE GIRLS AND WOMEN'S PERSPECTIVE IN POLICY WORK

BRIGITTE TRIEMS
Vice-President, European Women's Lobby

Founded in 1990 the European Women's Lobby (EWL) brings together some 4000 women's organisations working to achieve equality between women and men. EWL represents the concerns, needs and interests of women in dialogue with national, European and international institutions.

The mission of EWL is to promote the empowerment of women in all their diversity; to advance gender equality; to combat all forms of discrimination and violence against women and to ensure full access for all women to their human rights through their active involvement in society and in policy development and implementation.

EWL recognises the diversity of women's lives and experiences and aims to include in its work the interests of the many women who face multiple discrimination, like women with disabilities.

Before going into details and describing some concrete examples on how the EWL is trying to influence European Policy, I would like to underline that policy is the result of interactions among different organisations —with particular interests and ideas— about what course of action should be taken. The sum of these interactions constitutes the policy process. And the policy process —the interactions among organisations— is part of a wider environment, or context.

Understanding context is vital to understanding and engaging more effectively in policy processes.

Political context shapes the ways in which policy processes work. To engage effectively in policy processes, non-governmental and civil society organisations need to understand political context. In some contexts, policymakers are keen to receive evidence and ideas from NGOs: there are established channels through which NGOs can make their inputs. In other contexts, NGOs are excluded from formal policy processes. To be effective, NGOs need to take different approaches in different contexts.

For NGOs seeking to influence policy and practice, context shapes the effectiveness of particular strategies. The influence of NGOs on policy is sometime quite limited. If NGOs can better understand the contexts for their actions, then they will be in a better position to devise more effective strategies, which may allow them to have more influence on policy.

Comprehensive knowledge and understanding of the concrete political situation are necessary for a successful inclusion of girl's and women's perspective in policy work. That's why an analysis of the relevant political fields as an important tool is indispensable before taking actions. Three questions must be answered:

1. What do we need to know?
2. What do we need to do?
3. How we can do it?

There is a need to see who are the policymakers, is there a demand for new ideas, what are the opportunities and timing for input into formal processes, what is on the agenda of policy-makers and what are their constraints. Potential supporters and opponents are to be identified, proposals for practical solutions to problems must be provided and clear policy options should be presented.

External factors: Partners, donors, other external agencies; networks; national and global factors

Organisational contexts: Strategic alignment, management behaviours, institutional pressures, funding cycles, historical evolution etc.

Relationships and collaborations: within and across organisation – via networks, ICTs, communications plans; core functions; support functions, etc.

Organisational knowledge: Forms and locations; creation, sharing, storage, use; key activities and tools.

Tools and techniques alone are not enough: a number of other factors need consideration. Findings have indicated in particular that where knowledge tools and processes, relationships and collaborations, organisational contextual factors and external factors are dealt with in an integrated and coherent manner, resulting strategies may prove more effective.

Now I would like to mention some examples of the European Women's Lobby's activities, to show how the EWL is working for equality between women and men, for equal opportunities for all and for the inclusion of girl's and women's perspective into policy work.

Roadmap for Equality between Women and Men

For the European Union 2006 and 2007 were and are years of commitments in the area of equality between women and men. Although there was no really groundbreaking step, decision makers in the different institutions adopted strategies and documents, which will potentially make a difference to the life of European women. The first of these is the *Roadmap for Equality between Women and Men* adopted by the European Commission in March 2006. We welcome this text which shares a common vision with the Roadmap, which was developed by EWL in 2005 as a model for the Commission's own Roadmap.

The official Roadmap recognises that gender inequalities persist and that access to re-sources, rights and power are unequally distributed between women and men. It also acknowledges the role played by the unequal sharing of care and domestic work between women and men combined with unbalanced tax and benefit systems in disadvantaging women. Another positive aspect of the roadmap is that is sees gender equality as a necessary condition for the achievement of the EU objectives of growth, employment and social cohesion and that it recognises the necessity of a dual approach combining both gender mainstreaming and specific measures. EWL was particularly pleased to see that a number of initiatives were included in the Roadmap: *A Communication on the Gender Pay Gap in 2007*; Support for the achievement of the Barcelona targets for the provision of childcare through the European Social Funds and a Communication on Gender and Development Co-operation.

The EWL membership really hopes that this Roadmap will be both a real motor for change and an effective way of strengthening equality between women and men and gender main-streaming in existing Commission policies. One of the EWL future priorities is the monitoring of the implementation of the Roadmap, in particular by the European Commission.

European Year of Equal Opportunities for All

EWL and its member organisations were actively involved in the preparations for the European Year of Equal Opportunities for All. The Year, launched at the Berlin Equality Summit of January 2007, concerns the six grounds of discrimination contained in Article 13 of the *European Treaty*: sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation with a strong recommendation to integrate a gender perspective in all activities. Actions during the Year are organised around the four themes of Rights, Representation, Recognition and Respect. These themes are all extremely relevant to those working for equality between women and men.

European Pact for Gender Equality

Another commitment made during 2006 was the adoption by all European governments of the *European Pact for Gender Equality* in March 2006. EWL lobbied all EU governments to make sure that they endorsed this text. This document highlights issues that need to be addressed by all Member States in relation to equality between women and men, in particular: Measures to close gender gaps and to combat gender stereotypes in the labour market; The promotion of a better worklife balance in particular the implementation of the existing European childcare targets and the creation of care facilities for other dependants; Better governance and better implementation and monitoring of gender mainstreaming. The Gender Pact actually does not foresee specific measures but it does give a higher profile to gender equality and it is a political commitment made by all European countries, which will be closely monitored by EWL and women's NGOs.

European Gender Institute

Finally, in 2006, important steps were taken towards creating a European Gender Institute. EWL worked closely with the European Parliament Committee on Women's Rights, as well as with the European Commission, to ensure a stronger political role for the future Institute, for instance in relation to supporting gender mainstreaming in EU policies and securing a role for civil society within the structure of the Institute. Although the rather limited budget of the Institute (€ 52.5 million for the period 2007 to 2013, the proposed budget of the future Fundamental Rights Agency being € 163 million for the same period) will not allow for in-depth action, EWL hopes that it will really be the champion of women's rights within EU bodies. In October this year the Management Board elected Germany as President and Belgium as Vice-President. The Gender Institute is based in Vilnius, Lithuania and should start its work during the second half of 2007.

EWL "Who Cares?" Campaign

The lack of affordable, accessible and high quality care services in the EU is a serious problem and is a major obstacle to women's full participation in all aspects of economic, social, cultural and political life. This gap results in a lack of real choice for women to reconcile work, family and private life. It also reveals the persistence of gender stereotypes that continue to underpin and reinforce the division of reproductive responsibilities and labour between women and men, both domestically and within society at large.

At the EWL Board of Administration meeting in May 2006, the European Women's Lobby officially launched its "Who Cares?" Campaign, which focuses on the provision of affordable, accessible and high quality care services for all dependants and people with additional support needs, available to all women and men whatever their financial situation. With this Campaign EWL highlighted the responsibility of the State to provide publicly funded care services, in particular at a time when Europe is facing important demographic and economic challenges. EWL also makes recommendations in relation to labour market issues and policies for the reconciliation of private and working life. During the EWL Care Campaign an e-petition was launched on the EWL website and the EWL General Assembly Seminar of October 2006 was dedicated to this issue; the Manifesto on Care adopted by EWL General Assembly outlines the main demands and recommendations of European women to the EU, national governments, local administrations and social and civil partners.

Women, Immigration and Asylum

2006 and 2007 saw a shift in EWL's agenda, with immigration as one of the political priorities following a decision by its member organisations. The rapid development of a common immigration policy at European Union level requires a keen level of gender monitoring so that women, for once, are not left out at the end of the process. But, as it stands for the moment, migrant women tend to remain invisible and therefore inexistent in European Union Justice and Home Affairs.

In March 2006, EWL published its position paper on the integration of third-country nationals in the European Union. It condemned the persistent discriminatory practices experienced by migrant women, the dependent legal status under family reunification schemes, the application of personal status law of the country of origin which can expose some immigrant women to serious violation of their fundamental rights, gender based violence, unemployment and discrimination in the workplace and their invisibility in decision-making positions.

EWL continued to monitor European asylum policies in 2006 and paid particular attention to the transposition into national law of the Qualification Directive. A fact sheet, entitled "*Asylum in the EU – What is the Qualification Directive and why is it important to women?*" was produced as well as a letter addressed to the Interior Ministers of the Member States seeking information on the type of measures that will be put in place at national level to ensure full implementation of this Directive with regard to specific provisions for women.

In January 2007 EWL organized the Seminar "*Equal rights, equal voices – Migrant women in the European Union"* that was followed by a follow-up seminar in October before the annual General Assembly. The aim is to strengthen the cooperation with migrant women and to provide a starting point from which migrant women living in the EU begin to voice their own experiences and to advocate their rights to European decision-makers.

Violence against women

Violence against women continues to be the most fundamental and widespread violation of women's human rights in the world. When we include all forms of violence against women, 45% of all women in Europe have been subjected to and suffered from men's violence. Every fifth woman in Europe has been subjected to violence from an (ex)partner, having her fundamental human rights violated by a man in her closest and most intimate social environment – her own home. At the core of the EWL work in this area was its European Observatory on Violence against Women (VAW) which has been working since 1997 as a network of independent experts in the field of violence against women from across Europe to monitor emerging trends in legislation and policy. In 2007a n EWL new branch was set up: The European Policy Action Centre on Violence against women allowing getting core funding to support and develop the Observatory.

The most pressing issue emerging from the past work of the Observatory experts is the need for coherent and uniform national policies on violence against women, as well as the urgent need to fill the existing void in EU legislation regarding violence against women.

Preventing trafficking for sexual exploitation and support to victims

In 2006, EWL was involved in 2 transnational projects on preventing trafficking and providing assistance to victims. The *project Promoting Measures to prevent Trafficking for Sexual Exploitation*, jointly coordinated with the Coalition Against Trafficking in Women (CATW), has supported women's NGOs working in 14 countries to campaign and raise awareness on trafficking and sexual exploitation. The second project is the 3 year pilot project, *Setting Standards and Developing Assistance for Victims of Trafficking*, which aims to strengthen victim support in and between the Nordic and Baltic countries.

EWL Strategic Review – Taking a look forward

In 2006, the European Women's Lobby decided to undertake a review of its work to reflect on EWL's goals, policy priorities and working methods. This step was taken for two reasons: the recent increase in membership from 15 to 28 National Co-ordinations with more new national Co-ordinations likely to join in the future; the changing political climate in the EU which may result in EWL changing its priorities both within the EU and globally. For us a strategic review process means taking time to review and reflect, after 15 years of operation, so that we can look ahead and plan the future of the organisation with a clear understanding of our goals, priorities, working methods, human and financial resources in light of the new and emerging challenges and opportunities. This new strategy represents the European Women's Lobby's renewed commitment to achieving equality between women and men.

In accordance with the new Strategic Plan 2007-2010 adopted in January 2007, the European Women's Lobby through its member organizations, aims:

- To support the active involvement of women in working to achieve equality between women and men ensuring the representation of women from different parts of the European region.
- To support national members through information /lobbying resources and training to actively engage with EU policy shaping and implementation of legislation at national level.
- Through analysis, evaluation and monitoring to provide regular input on all areas of EU policy development and implementation that have an impact on women's lives and on the promotion of equality between women and men with specific reference to the Roadmap for equality between women and men, the *United Nations Beijing Platform for Action and Convention on the Elimination of All Forms of Discrimination against Women*.
- To monitor and raise awareness about the development and implementation of gender mainstreaming in order to ensure the full integration of women's rights, interests and perspective in all areas of EU policy.
- To take into account the needs and perspectives of different groups of women, and the diverse experiences of women at all stages of their life cycle. These actions take place both in its internal policy and organisational development as well as in developing partnerships and joint working relationships with organisations that represent the many women that face multiple-discrimination in the European Union and globally.

EWL works towards a Vision of a peaceful and democratic European Union built on a culture of respect for human rights, in Europe and globally, where women and men have equal access to and responsibility for their personal integrity and choice, social, cultural and economic resources, political decision making and caring and family roles. Women's employment remains key to their economic autonomy and to greater equality between women and men in society as a whole. In the European labour markets, women face gender segregation, lower pay and poorer opportunities for advancement. That's why EWL is very active in the *Lisbon Strategy* refocusing process.

Women and men should be equally represented whenever decisions are made that affect their lives. Parity democracy or quotas represent a shift to equality of results and real democracy. Mandatory measures are an effective way to compensate for the exclusion and discrimination mechanisms against women that are inherent to political systems and social structures in Europe.

HOW TO ACTIVELY INVOLVE GIRLS AND WOMEN WITH DISABILITIES IN POLICY FORMULATION AND IMPLEMENTATION IN ORDER TO IMPROVE THEIR QUALITY OF LIFE

GORDANA RAJKOV
Member of Serbian Parliament

The facts

- Participation of women in political life in general is not enough;
- In 2006 it was 17% the highest in last decade (in 1996 11%);
- Out of 262 countries in the world, women are in leading position in parliament in 35 countries;
- Equality is perceived for 2077;
- In countries with quota system 23%, without it less than 12%.

Double discrimination

- Women with disabilities have particularly lower employment and income levels and greater social isolation;
- lower self-evaluations of civic skills and internal political efficacy;
- Their overall political participation is lower than that of men and women without disabilities.

In spite of that women with disabilities are

- equally likely to take action on disability issues;
- more likely to participate in protests and take action against perceived discrimination;
- more likely to be grass roots members of disability organizations rather than amongst the leadership.

Access to decision-making

- A vitally important area in gender equality generally;
- Women with disabilities are considerably more disadvantaged in this respect than men with disabilities and women generally;
- The problem starts at the most basic level: no means of making their voice heard and it is other people who speak on their behalf;
- Women are just as entitled as men to be present and involved in the life of society at all levels;
- It is both the right to participate and the opportunity to influence the destiny of communities;
- If a group is absent from the decision-making arena, its specific interests and needs and its particular perspective will not be given their due weight in the society as a whole.

Why is it so?

- Low self-esteem, fear or shame, isolation, being in institutions;
- Need for the assistance of another person even with essential everyday actions, mobility, and any form of participation;

- Prejudices and perceived social role of women as follower;
- Poor visibility of participation by women with disabilities in public life - either victim or exceptional individual;
- entrenched opposition of males who feel marginalized by society.

What can we do?

Empowerment

- Taking hold of personal strengths and using them to develop personal power and directing that force to attain personal goals;
- Sharing what works for me with other women with disabilities so they can develop their own strengths;
- If enough women want to share knowledge and power over their own circumstances, then a women's group is born.

My experience

- Taking hold of personal power is a huge challenge;
- The power of knowledge and experience - difficult to exercise due to the dominant leadership by males in organizations of PWD, NGOs, political parties;
- I had males colleagues who supported me and;
- I had a friend who as a women was already in leadership position when I started.

When one woman gains an opportunity then I feel she has an obligation to bring another woman through the door with her.

Networks of women with disabilities and support groups have already played a key role in defending their interests and helping them to participate and express their needs.

Development of women's groups and organizations needs to be carefully done so that we empower women at every level to participate in decision-making.

How?

- Long and slow process;
- Should start with identification of girls and women with disabilities;
- Family support and environment is very important, particularly for girls in adolescence period to build up self-confidence.

Few stages

- Get them together
- Motivate them
- Educate them
- Find aliases

Get them together

- Include disabled women in existing DPOs, other NGOs, women groups, political parties;
- Organize small events to build up a trust and experience exchange like voluntary work, leisure cultural, sporting activities, computer training, etc.

- Organize advice and counseling centers good start to get out from isolation;
- Include them in working groups, debates, round table discussions on disability issues reflecting women perspective of them;
- Inclusion in different local activities and campaigns for disabled peoples rights.

Motivate them

- Small projects, including income generations -achievements and success in a short time;
- Participation at local, national or European-level meetings;
- Find good role models and mentoring through special mentor programes;
- Provide additional resources (such as transport, PA or childcare);
- Organize meetings and discussion with disabled and non disabled women who are already recognized and active in political life;
- Promote the examples of good practice where women with disabilities could identify with other women and being encouraged to try this as well.

Educate them

- Organize job training programes for income-generating activities to increase disabled women's awareness of their own situation at grass-roots level and to stimulate their active participation;
- Training courses and education on different topics and level to enable sharing of knowledge and raise awareness;

- Leadership training seminars, educational programs to assist disabled girls and women to attain self-esteem, encourage them to take leadership positions and become trainers.

Find alianses

- Develop new alliances with other women groups. We often share the same issues as women in poverty, women in public housing, so let us combine resources on specific campaigns, so women show their combined strength;
- Negotiate the principles of gender equality in our own organization, representations in governing bodies, at different events and discussions;
- Disseminate information and awareness-raising material to existing DPOs, NGOs and decision makers to make them aware of the fact that multiple discrimination towards disabled women can exist;
- Stresses the need to raise the profile and improve the image of women with disabilities in the media, making the general public more aware of their daily lives.

Instead of conclusion...

- Women with disabilities have been empowered by lots of role models and lots of shared knowledge;
- If we can effectively connect with other women and women's groups around the nation or around the world there'll be no stopping for us!;
- We will stay and become more.

Local group

1. accessibility – barriers
    a. information
    b. law
    c. participation in the accessibility solving association issue
2. information / education
    a. diffusion – sensibilization – visualization
3. motivation, self esteem, union-sharing experiences for motivating the women with disabilities
    a. diffusion of capacities
    b. life experiences
4. resources
    a. positive models – good practices
    b. self esteem, self awareness
    c. showing positive models —presenting— to be present in decision making bodies
    d. financial resources —fundraising, raising awareness local position— not charity but more simpler to reach or realize

LOUD, PROUD AND PASIONATE

CONCLUSIONS

KARINA CHUPINA

At this workshop there were three groups working about this topic at local, national and international level and they concluded it was necessary to work on the following:

International Group

1. State – issues to be covered/solved
    a. Women with disabilities living in institutions
    b. Employment
    c. Education from childhood
    d. Creation of the web site as European forum of women with disabilities
    e. Official associations of the women
    f. Law on women with disabilities
2. Accessibility of employment /work
3. Work in together with association of women in Europe AND different disability organizations
4. Ratification of national conventions
5. Pressure of EU on local government to create conditions for changes in legislation and procedures

Q: not mentioned specific issue on health of women with disabilities – maybe to reinforce on this, create services as support for family planning, motherhood service, privet life (children, sex, work…) etc.

Q: integration of girls with disability to be more included into society into organizations in order to support lifelong, education, study, job, family, etc…

C: Paying attention, because the discrimination starts from school (mainstream or special also) / because special schools are considered as kindergarten and not the education institution.

The lack of individual education plan —basic of inclusive education. Other problem is within family— because the family is not well educated as well about those issues and possible solutions.

National group

For Disabled women organizations it is crucial to get involved and be visible at the policy making levels and this process should start from the disability movement itself ("starting from ourselves" otherwise we will not be treated seriously outside of the movement) and spread into other spheres of public spheres and decision making bodies.

Steps to achieve that:

1. Strong leadership
    a. enhancing leadership within organizations and organisations capacity building through trainings, seminars and workshops
    b. transnational networks, committees, conferences) creating a strong European body of European disabled women
    c. Active search for new leaders
    d. More visibility of organizations
2. Resources
    a. people – enhance disabled women motivation in taking part in policy making activities "the long slow process will bring lasting benefits in the end"
    b. money: look for transactional cooperation (other NGOs, academia, government agencies) –creating European partnerships
3. Sustainability of organizations—planning in a long perspective, being encourage to identify problems locally (micro perspective) and work on polices in a national (macro perspective)
4. Quotas: 50/50 women/man strong tools to execute that –working and installing within national and transnational appropriate laws and resolutions
5. Community of disabled women—
    a. enhancing better self –identification of problems

b. motivating them to take part in policy making activities
c. working on self-awareness & better education (also including the family of disabled women)
d. networking between different disability organizations

HOW CAN I, AS AN INDIVIDUAL, WORK AT LOCAL LEVEL TO SUPPORT AND IMPROVE THE SITUATION OF GIRLS AND WOMEN WITH DISABILITIES

ANNELI JONEKEN
Co-chair, EDF Women's Committee

What do we mean with local level? What does it mean to all of us? Do we think in the same way?…

How to promote the situation of girls and women with disabilities.

Involvement in local groups of different types I think we first could identify what types of groups it can be

We all have different experiences and we can learn from each other.

We might have a small family, live as a single person, or maybe in a big family.

We might have a small network of friends or maybe very many relatives and friends.

We maybe have colleagues at work and are involved in different social activities together with them, maybe we are students and belong to different groups studying the same subject.

We also might get to know other people in our everyday life and they become part of our social networks.

We belong to the local association of one or several disability organisations.

We maybe are a member in the local association of a mainstream political organisation or a mainstream local women´s organisation or some other NGO at local level.

Also we might be more actively involved in such associations and be a member of the board or a committee in such associations or involved in local issues as a representative for a smaller group.

What can I do as an individual? How each one of us can think and do and act at the local level where we live

Be active – you can start `thinking loud` with yourself and gradually in groups.

Identify issues of importance to you as a woman with a disability.

Gather knowledge, learn and listen. Think about how you get information about your important issues – through magazines or books you read or websites that you visit.

Identify and develop your individual networks, identify friends at the local level. Communicate actively with people in your networks -your ideas are important for them and their ideas for you.

Identify existing local organisations working with issues of importance to you.

You are probably member of one or more local disability organisations. Think about what this organisations has done to the important issues that you have identified for women with disability. Discuss the issue with other women and men in the organisation and find ways of promoting the issue. Make an action plan together to suggest for the decision making bodies in the local organisation. The issue might then develop into something that the local organisation wants to send also for decision and action at regional and national level, or maybe also at international level. Maybe it is an issue that should be decided on in the local municipality or city council. Your idea can start a snowball that grows bigger.

Think about what your local disability organisation of which you are a member has asked from its members that has a women´s perspective. How about maternity services for example or other issues in health care that are specific to women. Does your organisation work for all its members in practice?

You can want to become a member in other local organisations that you consider important if you are not yet a member. You can have an active or a passive membership. Active through accepting to be a board member and willing to do other tasks. You can make proposals, work with specific projects that you know are important for women and girls in this organisation. You can also be prepared to represent the organisation outside the organisation informing about the important issue in other for a. You can be a passive member, support the ideas of the organisation through your membership and at the same time learn by reading the organisations information and taking part in occasional events.

You can want to find likeminded people to join in establishing an organisation that does not exist yet if you are very keen on things to start happening and feel that nobody is doing anything – maybe it could be you who will start doing this chain of happenings that will lead to changes. It is enough with two people together at local level it does not need to be a big group to start with. You discuss and find out what it is that you together want to accomplish and gradually you will develop an action plan.

If you think you can promote an issue because you are a member in a mainstream organisation, or maybe you are on the board of such NGO organisation, do not be afraid to raise the issue that you have identified to be important for women with disabilities, find ways to get it on the agenda and into the action plan. First you might need to find out more of how the organisation works and how your idea best can fit into ongoing the processes of decision making.

Follow the current debate in your disability organisation about an issue where you have identified a missing women´s perspective. Contribute with your knowledge about this perspective, take part in the debate, discuss with other women to make your thinking stronger.

You can contribute with a disability perspective into an ongoing debate in a local women´s organisation where you see that they are missing to include women with disabilities in their thinking.

You can contact media representatives and suggest articles. You can consider getting training so that you can be prepared to give interviews to media representatives. Do not forget the magazines and websites of the organisations where you are a member.

Reflect on media reporting on new studies where there is no gender awareness in the study. You only get information of the situation for persons, not for how the situation is for women and men, or for girls and boys. Ask questions why there is no figures and facts and findings how women with disabilities are experiencing the situation.

Be alert of mainstream events of interest that are planned to take place at the local level, register as participant, study the program and prepare yourself to put specific questions when opportunity arises. Ask about accessibility at the location where the event is held and if they can provide the information in an accessible format for you. If you would need extra funding to take part, find out if you can get support.

Make suggestions of action that can lead an important issue for women with disabilities that you have identified forward. Do not be afraid of saying loud what you think if you are convinced it is an important issue. And if you have the possibility to take a leadership role and make a decision that you know is important, then do take the decision.

Find ways to channel local level ideas to your contact people at regional national and international level.

Find ways to inform at local level of action and developments at regional national international levels – like informing about this European conference to your networks at home.

Develop individual strategies, make individual goals and simple personal commitments to work for certain priorities with an individual timetable.

Recommendations to the Declaration of the Conference

A number of recommendations and action points to an action plan need to be developed in the small group discussions and the joint workshop discussions.

We need maybe also to group the recommendations in some logistic way and maybe put priorities too.

Reports from European National Disability Councils

AUSTRIA

AUSTRIAN NATIONAL COUNCIL OF DISABLED PERSONS (ÖAR)
DELEGATE: MARIA ROSINA GRUNDNER

The present situation of woman with disability in Austria is very difficult to evaluate, since only very few research results are generally present regarding the specific needs and problem situations for disabled persons. In particular those women who live in institutions or at home remain unconsidered. This invisible group makes it more difficult to analyse the life situation of young girls who disappear into their home after special schooling.

Such a lack of knowledge can lead, for example, to disabled girls missing out on a chance to take part in working life. Clearing agencies, interfaces between school and occupation, one tries, to work actively against. As regards health, it can be said likewise that the needs of disabled women have only recently been noticed. Relevant projects and scientific studies on the topic are welcome and should be supported also by public funding agencies.

This report is based on the Austrian women's health report published by the Ministry for Health and Women for the years 2005/2006.

Women with disability in working life

In the field of employment, it is well-known that women in Austria earn approximately a third less than men. For disabled women it can be deemed acceptable that their income —a combination of different allowances— is lower than that of non-disabled women and non-disabled men. This circumstance finds its effect in the rates of unemployment benefit and allowances in cases of emergency.

For the year 2000, unemployment benefit and/or emergency allowances amounted, on average, to 532 € for non-disabled women and for disabled women 483 €. In contrast, non-disabled men did receive on average 641 € per month and disabled men 617 €. The difference between men and women results also from the higher rate of part-time jobs among women and the smaller content. Furthermore, it is determined that disabled (and non-disabled) women having a longer subscription period than men have, and women over 45 years old are excluded from it. Here it is interpreted that this might have to do with the lower pension starting age. Job market services in Austria state further that switching jobs is difficult for disabled people in view of the weakening relating to market conditions.

Disability is not a clearly understandable category since there are many different views as to what is to be understood by the term. It remains unclear when we can speak of disability. Also, disabled women do not represent a uniform group. Depending upon support possibilities and social surroundings, they find their own resources, education, income etc. based on their differing possibilities. For all disabled women, however, that meet the criteria, it can be said that an independent life is more difficult or impossible. Overcoming these difficulties requires individual solutions and a high personal financial and organizational outlay.

Historical process of the discrimination of disabled women

Disabled women were categorised historically as women and due to their handicap. Two laws, which are still significant as regards the reproductive health of disabled persons, are responsible for non-disabled and disabled women being treated differently: on the one hand the sterilization law (see ABGB §146d, §282 Abs 3, StGB §90 Abs 2) and the eugenic indications for abortion (StGB § 97).

As a consequence of a broad public debate in 2001 on children's rights, sterilization was set within close and clearly defined borders, i.e. no young people may be sterilized. The agreement for sterilization is defined as a personal right; there is no substitute for consent. A solicitor may agree to sterilization only if a serious risk to life or severe health problems for the disabled person exists. In addition, a judicial permission is necessary.

The eugenic indication, however, permits abortion in cases of (allegedly) disabled children up to the ninth month of pregnancy. The extent to which this is used remains unknown, but the fact is that disabled women must still argue, if they are limited children to want and thus in their life draft. A decision of general principle made by the OGH —the highest Court of Justice— in 1999, which obliged a physician to pay compensation as a result of failure to inform a pregnant women about the disability of her unborn child, in addition asked the question about the medical adhesion.

In the discussion concerning the eugenic indication, it is also necessary to discuss the unequal position of (allegedly) disabled and (allegedly) non-disabled unborn children without infringing the woman's right to self-determination.

Experiences with physicians, particularly gynaecologists

Disabled women frequently report humiliating experiences with gynaecologists; contraceptive are regarded in principle as redundant; if a pregnant women is a disabled women, with pregnancy to abortion will turn out and a human-genetic consultation are put.

It is also the case that many medical instruments are not suitable, e.g. with an ophthalmologist, causing substantial difficulties time and time again. A diagnosis or a visible handicap leads to prognoses and/or exclusive measures from the beginning. With deaf women and mentally disabled women communication can be difficult, and this again leads to misunderstandings. Women with reduced mobility need female assistants, who are helpful for transfers and personal hygiene, while deaf women require a female interpreter and mentally handicapped women need to be accompanied by a solicitor or carer. The organizational and financial expenditure is high, in contrast to non-disabled women.

It becomes clear that it is on the one hand necessary to adapt medical instruments and train medical personnel. This should be implemented by disabled women since awareness-raising can take place more convincingly than if carried out by non-disabled women; disabled women are experts in their own affairs.

Considerations about prevention

The desire for sterilization is often justified on the grounds that it is regarded by women with disabilities as reasonable from a social point of view.

Treating disabled women is not yet included in training programmes for physicians. Also, for example, with gynaecologists the lack of time is problematic, given the circumstances and the fact that support and treatment of handicapped women requires more time. Women with disabilities are often considered by gynaecologist as sexless. Prevention, pregnancy and maternity are however important topics for consultation by handicapped women, and sexual abuse of disabled women is often ignored.

The results of a survey among Viennese gynaecologists showed that a third of the doctors consulted had regular contact with disabled female patients; the majority of their female patients with disabilities has a physical disability (64 per cent), learning disability (54 per cent), deaf (38 per cent) or visually impaired (ten per cent).

Barriers to mobility

Freedom to choose one’s doctor in often lacking because of barriers. Also the entrance to advisory boards becomes extremely laborious. Structural obstacles, brochures which are not available in Braille, lack of recognition for bearing languages, difficulties in handling psychologically ill women —to name but a few— make use of the health system by disabled women more complicated. A significant factor is also the circumstance that disabled women already took part in many programmes involving therapeutic methods such as logopaedics, stretching apparatuses and operations, etc., in recent years and experienced partially trespasses beyond the border, which shape the way they are treated by the health system.

Health services for women with disabilities

Disabled women judge their state of health as being clearly worse than non-disabled women. A good physical and mental condition is however of existential importance, since a degradation of the state of health can lead to a collapse of the daily support system and/or the strategies for overcoming the challenges of everyday life, which made an independent life possible with the respective disability up to then. The most frequent complaints are exhaustion, sleep disturbances and pain followed by general disruption of well-being and depressions. If the state of health allows, women with disability also have substantially more problems during menstruation. Also urinary tract infections can occur, because they are unable to go to the lavatory for hours. These are the effects of a substantial undersupply, while some health problems are caused by this undersupply.

Sexual abuse of women with learning difficulties

The project group Ninlil works against sexual abuse of women with learning difficulties and multiple disabilities. It offers empowerment, consultation services and support networks.

One in five women in Austria is affected by domestic force (Source: "*Stop the Force*", women's help line against male force).

According to a study from the year 1996, women with learning difficulties are clearly affected more frequently by sexual abuse than other women. Although no new research on this topic has taken place since then, experience shows from Ninlil that the data produced at that time are still present. As is the case for sexual force against women without “disability”, those responsible are mostly acquaintances. Possible abusers are therefore responsible persons and responsible people inside, relatives, co-inhabitants, physicians, partners of the friend... Approximately 23% of the people responsible are unknown who, however, in some cases belong to an institution e.g. assigned to the travel service.

There are some projects for women with disabilities in Austria. For example one can attend coaching and consultation in self-defence in Vienna given by mediators with the possibility of private advisers.

BELGIUM

BELGIAN DISABILITY FORUM (BDF)
DELEGATE: JACQUELINE TIRTIAT

About sources…

This subject is very important. Until now, we have to admit that the disability movement in Belgium didn't concentrate on this approach. Please, do consider this report as a first step in a process that should require a much deeper work. We will include this as a priority of the Belgian Disability Forum (BDF) and of the National High Council of Persons with a Disability during the coming years.

As a matter of fact, we have to admit that the topic of the situation of "women with a disability" in Belgium was not a main subject of studies until recently.

For a good part, we built this report on the result of two main documents reporting conferences:

1. *Femme et handicap, colloque international*, Université des femmes, 22 mai 2007.

2. Persephone vzw, *Jubileum conferentie Persephone*, 21/05/2005.

We did collect information from several other public conferences held by organisations that are members of the Belgian Disability Forum.

Two universal statements

For Belgium, as for all European countries, studies are giving as evidence that inequality between women and men is increased in the case of disability. In Belgium, this results in a very slow tempo in the process of reaching an adequate social integration of women and young women.

Aside from visible disabilities, it is important to keep in mind that some disabilities and some disease causing a situation of disability are invisible. Some of these do affect women with specific consequences, such as haemophilia, for instance[3].

Evidence of discrimination

In Belgium, disabled persons are clearly facing relatively important discrimination in their access to several domains of living in society.

We have to notice that some highly worrying situations are affecting women or young women to a higher degree or are even exclusively related to women's situations. We give here a non exhaustive list of these:

1) *Education*

It has been stated that according to several disability situations, some girls or women are more often confined to their own family environment than boys or men. As a result of this, supporting services and family help services are limited in their support to the development of these women or girls who could benefit from these actions[4].

2) *School*

Often, lessons and training in the so called "special education" are still marked by a differentiated logic according to sexes[5].

---

[3] A-Kadir (Rezan), *Journée belge de l'hémophilie*, Gosselies, 20/10/2007.

[4] Lief Vanbael, *Het uiteenzetting van KVG*, in *Persephone, Jubileum*, Op.cit., Loc. cit.

[5] *Femme et handicap* in *Colloque international*, Université des femmes, 22nd May 2007.

3) Emotional and sexual life

Using the protection of society as an argument does sometimes lead to the negation of all the needs related to emotional and sexual life in the case of a number of disabled persons in order to avoid risks of pregnancy. In several cases it leads to a complete ban of any kind of social contacts for several women or teenagers (at least with men). It is reported that the ban is less strict for men. Does it mean that their demands or expectations are more legitimate?[6]

4) Support for parenthood

The fact of a disability of the mother is often seen as a sufficient reason to separate the child from his (her) mother[7].

5) One parent family

The number of families with one parent only is relatively high within families with one disabled child. Among these, the number of single mother is much higher than the number of single fathers[8].

6) Caring mother

The number of mothers abandoning their professional life or career in order to care for a disabled child is significantly higher than the number of father doing so[9].

7) Violence inside the family

Cases of violence against women with a handicap inside of the family circle are reported. This reality is very difficult to quantify because of the social taboo. Nevertheless several cases are known and revealed how some women are kind of "jailed" in a complete dependence situation[10].

---

[6] *Ibid.*

[7] *Renard (Elisabeth),* in *Droit de vivre, droit de Mourir,* Colloque ASPH, Brussels, 16th-17th October 2006.

[8] *Ibid.*

[9] *Ibid.*

[10] Van der Buys (Ann), *Blij dat ik leef*, in *Persephone, Jubileum*, Op. cit., Loc. cit.

8) Living in autonomy

Disabled persons in general and women or girls in particular are often treated by the legislator and authorities as fragile persons that have to be protected. This kind of approach of realities of disability leads to a generalisation that tends to consider each and every person with a disability as to be protected. Deriving from this the easiest solution for authorities often consists of choosing a close control on the person which is in opposition to any development of the autonomy of persons with a disability[11]

9) Employment and earnings

We have to admit that in Belgium, like any other European country, persons with a disability is the social group which encounters the lowest rate of employment[12]

Situations of disability are also often related to poverty. That reality is even more crucial for women with a disability. On the other side it appears that the majority of the recruitment procedures end up in hiring a man with a handicap more often than a woman with a handicap

The law exists, but…

What explanation to this obviously negative situation of women with a handicap in comparison with the situation of men with a handicap? Are we to consider that there is a lack of legal instrument? Surely not!

Several supranational legal tools are coming as an asset to the Belgian laws, showing in which way it would be suitable to let it evolve. We will only refer to:

- *Convention on Elimination of Discrimination against women*, signed by Belgium;

---

[11] *Femme et handicap,…* Op. cit., Loc. cit.

[12] *Rapport sur la pauvreté et l'exclusion sociale.*

- *Convention on the Rights of Persons with Disabilities*, signed by Belgium on 31 March 2007. BDF is currently lobbying the Belgian governments in order to obtain a fast ratification of this convention[13];
- *Resolution of the European Parliament on the Situation of Women in the EU,* 26th April 2007;
- Council Directive 2000/78/EC of 27 November 2000 *Establishing a General Framework for Equal Treatment in Employment and Occupation*

Belgium is regularly quoted for the quality of its compulsory weight of laws with regard to equality between men and women in any domain[14].

Nevertheless, there is a gap between the law, politics and the concrete positive change in the day to day life of women with a disability. We have to notice that a real step forward within the politics regarding concrete integration of disabled persons in general and specifically of disabled women is slow to get started. We have to be honest: words are not sufficient to create. If the tool does exist, we still need the craftsman to use it and get down to work.

In Belgium disability policy is distinguished by:

- A strong regulation of principles: no discrimination based on disability in each and every field of live can be tolerated;
- No global mainstreaming of disability policy does exist concretely. On the contrary, series of politics are implemented within the specific field of sheltered employment, of support for the individual (financial and material support) and of accessibility to public places. Now, we have to notice that these regulations are not covering the entire field and are more shaped as puzzle pieces. There is still a lot of work to do for the Belgian disability movement;

---

[13] *The international Convention on the Rights of Persons with Disabilities. The commitment of the movement of Persons with a Disability*, National Conference, Brussels, 7th November 2007.

[14] The renewed law on equality between man and woman was published in Belgian Monitor of Laws on 30th May 2007. This law is known as going further then expected in the European Directive.

- No complete corpus of statistical data about the situation of disabilities has been available until now. At a Belgian level, collecting data based of disability has been taboo for a long time. Even if it now accepted as a useful tool for designing policy, it remains very difficult to be collected and aggregated due to the splitting of competencies between numerous levels of authorities (federal, regional, community). Existing statistical data cannot be simply added together to give a correct view of the Belgian situation;

- A vivid patchwork of organisations representing the various types of persons with a disability. These organisations are sometimes very small but each one is motivated by a real sense of service to their members. The political structuring of this mosaic of organisations on the basis of common topics is being undertaken. This is the aim of the Belgian Disability Forum asbl, bringing together 19 organisations.

The Belgian Disability Forum asbl, together with the National High Council of Persons with a disability and the Regional Advice Councils, are sensitizing social partners, policy makers and civil servants on the necessity to obtain a fast ratification of the *UN Convention on the Rights of Persons with Disabilities*. On this basis, they will concentrate their efforts on the following areas:

- Human based approach to disability: every one benefits from his/her own personality and own characteristics. Society has to recognise and integrate each of these and to suppress any social obstacles to this integration;

- Consensus on general approaches and collection of the positions within the BDF secretary;

- Awareness on legislation and mainstreaming policy of genders and mainstreaming of disability. Mainstreaming of genders and mainstreaming of disability cannot be antagonistic. They even have to be mainstreamed together at some level and about some topics, in due respect to their relative particularities. The general objective is to evolve towards development of the highest level of autonomy of persons and towards their reinforced integration in every domains of society;

- Systematic involvement of disabled people's organisations in all of the decision-making process.

Conclusion

BDF wants to stress that it is essential to think and act in favour of the situation of woman and girls with a disability, according to their specific characteristics. Nevertheless, it is of accurate importance to pay due attention to the coherence that must be kept in the implementing of concrete solutions within the general movement of integration of every person with a disability. The key must remain the removal of barriers.

If not, there is a risk of creating new discrimination: there is no worse exclusion politics than one that isolates one problem out of its general context. The solutions must be integrated in a global policy.

BULGARIA

NATIONAL COUNCIL OF PEOPLE WITH DISABILITIES IN BULGARIA (NCDPB)
DELEGATE: KRASIMIR KOCEV

The situation of women and girls with disabilities has always been on the agenda of Bulgarian disability organizations, and especially of the National Council from the very beginning and its creation.

However, there has always been a lack of statistics about the exact number of disabled women in Bulgaria. In 2005, however, the National Statistics Institute published the first statistics about disabled people, but the presented data were not precise/not given an exact number and totally insufficient. The main conclusions made were as follows:

- 49% of women with disabilities completed primary education, 42% completed secondary education and 10% studied higher education.
- 72% of people with disabilities rely on pensions; 8% are on family support.
- Only 13% of people with disabilities are employed. No breakdown between men and women with disabilities was presented.

The state policy on gender equality in Bulgaria falls under the responsibilities of the Ministry of Labour and Social Policy since 2000. The coordination and collaboration between the governmental bodies and the non-governmental sector regarding gender equality issues is achieved through the consultative National Council on Equality between Women and Men. It develops the state policy on gender equality and works for the promotion of gender equality as a part of state policy by putting special emphasis on the implementation of gender mainstreaming in policy making in all sectors. State policy should guarantee prevention and elimination of gender-based discrimination, equal access to the labour market and economic activities and appropriate measures for reconciliation of work and family life. Education and health care, especially reproductive health, are areas of special concern, as well as combating domestic violence and trafficking in human beings.

The activities, which focus on updating the ministries' priorities, according to the main priorities of the government, are set out in the annual National Action Plans for Promotion of Gender Equality (since 2005). They are directed towards the whole of society and encourage equality in decision making, awareness raising and elimination of gender stereotypes for the roles of women and men.

The measures of the state addressing gender equality in the labour market are included in the National Action Plans on Employment (since 2001), developed by the Ministry of Labour and Social Policy and adopted by the Council of Ministers. They include a separate section on promotion of equal opportunities for women and men. In this aspect, the *National Action Plan for Employment* for the last four years expresses the state policy, which introduces several consistent and special measures for encouraging the participation of women in the labour market, reconciliation of work and family life etc. The Consultative Commission on Equal Opportunities to the Minister of Labour and Social Policy, established in 2003, provides guidance to the ministry in the development of these policies. Legislation concerning people with disabilities includes: an *Integration of People with Disabilities Act* (in force since 2004), *National Strategy for People with Disabilities, Action Employment Plan for People with Disabilities* and the *Protection against Discrimination Act.* However, there is no legislation concerning especially women with disabilities.

Women without disabilities participate actively in decision making bodies, but also there are two women with disabilities who are engaged in such bodies at national level. One of them is a member of the Bulgarian Parliament.

At national level there is a great number of women organizations dealing with issues concerning women's situation in Bulgaria.

There is no women's committee in our organisation. However, our National Council, like many other disability organizations, works on projects concerning the situation of disabled people, including women with disabilities.

In general, Bulgarian women face everyday discrimination based on various grounds, such as gender, age, etc, and especially in the labour market, where for many years they have been not on an equal basis with men. For women with disabilities the situation is even worse, because they are compared not only to women without disabilities, but even to men with disabilities, so they suffer even greater discrimination. According to research by disability organizations and other interested NGOs, women with disabilities are employed less than men with disabilities, i.e. they face discrimination in the labour market, although a law for protection against discrimination has been on the statutes since 2005 and a Commission for Protection against Discrimination was set up in 2006.

Only a negligible percentage of people with disabilities is employed in Bulgaria. This means that 90% of disabled people are not in employment, among whom women with disabilities represent more than 50%. If employed, women with disabilities are employed in sheltered workshops doing low quality work and paid very low salaries. A professional career for them is very rare. Only a few women with disabilities can meet the expectation of society due to a failure to provide them with equal opportunities, therefore they are considered to be helpless and reliant on social benefits.

The main barrier girls and women with disabilities face nowadays —besides architectural barriers— is the lack of access to education and employment. Although Bulgarian legislation has been harmonized with European legislation and the *European Employment Directive* has been implemented, there are still barriers Bulgarian girls and women with disabilities meet in everyday life. Under the pressure of disability organizations and non-discrimination legislation, most universities have eliminated the barriers that existed before for disabled students. The number of accessible schools, colleges and universities increases, but is still far from satisfactory.

Other barriers are the lack of programmes for qualification and re-qualification, accessible transport, lack of accessible and sufficient social services and an under-developed market in such services and companies for cleaning, cooking, etc.

While women in Bulgaria nowadays have undertaken more and more social responsibilities —going to work and raising children while participating in social life at the same time— women with disabilities could not meet these requirements and are partially isolated from social life.

Women with disabilities are in a more difficult situation compared to women without disabilities because they cannot meet the expectations of society for full employment. They can either take a job or raise children, all due to the lack of a barrier-free environment and social services. The existing barriers prevente them from going to work and taking part in any field of social life. They play the "sole" role of a mother, which turns to be a big challenge for most women with severe disabilities.

Women and girls with disabilities enjoy the same status as the other members in our organizations. Around 50% of our members are women with various disabilities. They participate actively in the activities of the national disability movement.

Disability organizations —and the National Council on its part— have developed projects on social inclusion, awareness raising and training for disabled people, and especially youngsters with disabilities, about their rights, the new anti- discrimination legislation and so on. Many disabled women have participated in projects for temporary employment and to set up their own business.

Although there are legislative documents concerning gender equality and the integration of people with disabilities in social life, in practice they still do not work satisfactorily. The Bulgarian National Council has put on its agenda the following activities:

— Awareness raising of women with disabilities about their rights and the new anti-discrimination legislation;

- Advisory and consultative services and representation of women with disabilities in cases where they believe they have been discriminated against;
- Active partnership and cooperation with state, municipal and local bodies for combating discrimination at national and local level;
- Dealing with issues of girls and women with disabilities in cooperation with other NGOs at all levels;
- Implementing programmes, seminars and conferences for training women with disabilities, etc.

CYPRUS

CYPRUS CONFEDERATION OF ORGANISATIONS OF THE DISABLED (CCOD)
DELEGATE: MICHAEL LOUCA

Introduction

Trying to identify the status of girls and women with disabilities in Cyprus. I couldn’t separate it from the status of boys and men with disabilities.

The following Constitutional provisions were obtained from the book by Mr. Mikis Florentzos entitled “*The Legal and Social Position of Persons with Disability in the New Legal Order of the Republic of Cyprus as a Member State of the European Union. Equal Treatment-Social Policy*”. Mr. Mikis Florentzos was, until recently, Attorney of the Republic, and he is the President of the Cyprus Confederation of Organisations of the Disabled (CCOD).

A. Constitutional provisions

Articles 9, 28 and 35 of the *Constitution of the Republic of Cyprus*, to an extent are related to persons with disability, and are included in Part II of the Constitution. They establish the fundamental human right to a decent existence and social security (Article 9), equal treatment and equality (Article 28) and the demand, vis-à-vis the State, to secure the efficient application of these provisions and the exercise of the respective human rights of the preceding articles.

(a) Article 9 of the Constitution

Article 9 of the Constitution was formulated and came into force upon the establishment of the Republic of Cyprus in 1960. It establishes a very important human right of individual, the right to a decent existence and social security, which is of marked signification to persons with disability. It provides as follows:

“Every person has the right to a decent existence and to social security. A Law shall provide for the protection of the workers, assistance to the poor and for a system of social insurance”.

From the early stages of the Republic, by virtue of the provisions of the above article, laws were passed by parliament providing for the protection of the workers, assistance to the poor and for a system of social insurance. Neither the government and parliament nor the organizations of persons with disability had made use of, propounded or invoked the wider sense of the human right to the decent existence and social security of Article 9 of the Constitution specifically for persons with disability and the parents of person with intellectual disability until 1981, the International Year of the Disabled declared by the United Nations. The *European Social Charter*, which became part of domestic law by ratifying Law 64/1967, had also remained forgotten and the obligation of the state imposed by its Article 15 were not materialized and implemented by taking concrete legislative or other measures concerning the vocational and social integration of person with disability.

What constitutes a decent existence is not defined in Article 9 of the Constitution. As to the construction of this provision of the Constitution, the trend in the case law of the Supreme Court is that the prerequisite is the existence of a particular provision in the Law, to which cases may be compared and judged as to whether it is sufficient and efficient to ensure a decent existence in each particular case. (See Tasoula Pelidi and others vs. the Republic, through the Social Insurance Department, Recourse No. 1650/1999, dated June 15, 2001). Individuals, according to the case law in question, are not entitled to demand from the government (the Council of Ministers) the preparation and introduction to parliament of any bill for legislative provisions promoting, for example, decent existence. The reasoning for this is that the preparation of bills is closely connected with the exercise of legislative power. This is recognized in all states having a Constitution based on the principle of the separation of the powers of the State. (See Georgios S. Papaphilippou V. the Republic 1 R.S.C.C. 62.)

It seems that it has never been put before the Supreme Court that a specific legislative provision, relating directly or indirectly to persons with disability, contravenes the human right to a decent existence and social security enshrined in Article 9 of the Constitution. This could be done in the sense that such legislative provision is not sufficient to ensure such existence invoking Article 35, which imposes on the State the obligation to secure the efficient application of the provisions of Part II of the Constitution which safeguards the fundamental rights, including the right to a decent existence. This view has now been reinforced since 1981, when certain special legislative measures were taken, which will be discussed later, and two ratifying Laws were passed, Laws 42/1987 and 27(III)/2000, ratifying respectively *Convention 159 for the Vocational Rehabilitation and Occupation of Persons with Disability* and the revised *European Social Charter*, in addition to the *Persons with Disabilities Law 127(I)/2000*. The two ratifying Laws and the Conventions they ratified recognize certain rights of persons with disability and impose the respective obligations on the State to take legislative and other measures in general as well as certain specific, positive measures in the areas of employment and occupation, training, social rehabilitation and integration into the life of the community. *The Persons with Disabilities Law of 2000* declares certain rights of persons with disability embodying, in a half-finished and general way, as has been explained earlier, certain of the provisions of the Standard Rules. In addition, the recent case law of the Supreme Court has clearly established the direct civil right of individuals who have been affected by a violation of any human right, safeguarded in Part II of the Constitution, to be compensated for such violation. Moreover, it must not be overlooked that now, after the 1st of May 2004, the provision of Part II of the Constitution of the Republic safeguarding human rights are, to some extent, enriched by the provisions of the European Acquis and particularly by the provision of the Communities Treaties and the Directives that have already been set out, referring directly or implicitly to persons with disability. The human rights safeguarded by the *Constitution of* *the Republic of Cyprus*, and especially Article 9 for a decent existence, may be further influenced and enriched by the *Convention on Human Rights and Dignity of Persons with Disabilities of the United Nations*, which is being prepared, in the event that it becomes, in any way, part of the EU hard Acquis, as the European Union itself participated in the preparation of the Convention.

To conclude:

(I) The provisions of Article 9 of the Constitution for a decent existence and social security, so far as they concern persons with disability, as well as the provisions of Article 15 of the Europe Social Charter, as ratified by Law 64/1967, were not invoked or propounded by persons with disability or their organizations or organizations for them until 1981, the International Year for the Disabled declared by the United Nations, when the existing organizations of persons with disability cooperated and established unofficially a Coordinating Commission, which functioned and worked within the framework of the International Year. The final report of the Legislation Subcommittee of the National Commission of the International Year for the Disabled, which I drew up in my capacity as President of that Legislation Subcommittee, invoked and propounded the aforesaid constitutional and legal provisions for the first time. The aforementioned provisions formed a significant part of the basis and legal reasoning of the demands included in the final report of the Legislation Subcommittee, to which a reference will be made later. This report was delivered by me on the 3rd of February, 1982 to the late President of the Republic, Spyros Kyprianou, at the closing ceremony of the International Year for the Disabled. Reading this report now, one might conclude that it outlined beforehand, to a great degree, the development of legislation of Cyprus and the positive measures concerning persons with disability taken in the ensuing years up to the present; a development which began and is still proceeding with great delay.

(II) The amending Law, which amended the *Public Subsidy and Services Law*, as it was consolidated as *Law No. 8/1991* and particularly Article 8 (g), by virtue of which persons with disability are entitled to receive an additional amount of 50% of the basic amount of the public assistance granted to them plus home care, has its roots in and may be socially and legally reasoned on the basis of Article 9 of the Constitution safeguarding the right of every person to a decent existence and social security, according to the circumstances and needs of each particular case.

Particularly, Article 8 (g) of the aforementioned Law, as it was consolidated, reads as follows:

> *"In addition to any amount granted for special needs, in the case of person with disability, a special assistance will be granted for personal needs, amounting to 50% of the public assistance granted to the same person with disability for basic needs".*

(b) Constitution provisions on equality (Article 28 of the Constitution)

The provisions in Article 28 of the *Constitution of the Republic of Cyprus* safeguard the fundamental rights of individual for equal treatment before the law, the administration and justice. Article 28 prohibits any discrimination against anybody. From this point of view it recognizes, at least, the principle of non-discrimination against persons with disability. This, of course, as has been set out earlier, constitutes only the prohibitive aspect of the general principle of equality. These is no express reference in the provisions of Article 28 promoting or concerning the positive aspect of equality and the possibility of taking positive measures promoting the protection or status of any group of citizens. Ultimately, the interpretation and application of the provisions of article 28 is a matter of their construction and the concept of equality.

The relevant provisions of Article 28 of the Constitution read as follows:

> *1. All persons are equal before the law, the administration and justice and are entitled to equal protection thereof and treatment thereby.*
>
> *3. Every person shall enjoy all the rights and liberties provided for in this Constitution without any direct or indirect discrimination*

> *against any person on the grounds of his community, race, religion, language, sex, political or other conviction, national or social descent, birth, colour, wealth, social class, or on any ground whatsoever, unless there is express provision to the contrary in this Constitution.*

The Supreme Court of the Republic, which exercises the jurisdiction of the Supreme Constitutional Court as well, construed and applied the provisions of Article 28 of the *Constitution in Revisional Appeal No. 3385*, (the Republic through the Public Service Commission vs. Eleni Constantinou, 26th September 2002), in relation to the positive, legislative measure of the priority in employment, on a quota system basis, of a group of person among which were the war disabled. As has already been set out earlier, in this decision of the Supreme Court it was considered by the majority that the priority on a quota system basis of Article 3 of *Law No. 55(I)/1997*, which provided the above priority in the filling of vacant posts in the public sector, was unconstitutional on the grounds that it contravened the principle of equal treatment under Article 28 of the Constitution. It is true that the provision of Article 28 do not provide any exception, giving unconditional power to the legislator to establish positive legislative measures in employment based on priority or otherwise.

Nevertheless, these is the established case law of the Supreme Court, which accepts and applies Aristotle‘s concept of equality in both its aspects, i.e. its prohibitive and positive aspect, indicatively (Sergides vs. the Republic (1991) 1 C.L.R. 119, at p. 129), where the Supreme Court adopts Aristotle’s conception of equality. Various special legislative measures were considered in this case law to be constitutional and in agreement with the provisions of Article 28, as such legislative provisions refer to different situations or relationships. According to the aforementioned case law of the Supreme Court, discrimination-different treatment is prohibited only where there is sameness or analogous similarity. The Supreme Court in its above decision did not consider, in its majority, that there existed a difference or diversity between the group of person that benefited from priority in employment, provided for them by the above mentioned Law, and the other candidates for any post in the public sector, which could justify different legislative treatment.

It should be indicated that the above decision of the Supreme Court was based and formed on the basis of the specific provisions of Article 3 *of Law 55(I)/1977*, which provided the particular priority for persons not having any disability (children of war victims, children of persons missing since the Turkish invasion of Cyprus in 1974, etc.) and among them to those disabled due to war; that is to say to persons with disability whose disability was caused by and was due to a particular cause. Such priority was not based, therefore, on the social reasoning and special difficulties of and consequences to persons with disability so as to be employed and retained in work, being “an individual whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognized physical or mental impairment”, as the definition of the disabled, for the purposes of taking special legislative and other measures for their employment, is formulated in Article I of *Convention 159 for the Vocational Rehabilitation and Occupation of the Disabled*. It would be interesting to know what the judgment of the full bench of the Supreme Court would be in the case of a legislative provision providing such priority, based on a quota system, solely for persons with disability.

In any case, after the 1st of May, 2004, when Cyprus entered the European Union, the provisions in Article 7 of *EU Directive 2000/78/EC*, permitting member states to take positive measures for the employment and work integration of persons with disability, became, the least, supplementary provisions and part of Article 28 of the *Constitution of the Republic*, which safeguards the principle of equality. The effect of this is the establishment of an express exception to the provisions of Article 28.1.2 of the Constitution, permitting and promoting special positive measures for the employment of persons with disability. Such exception cannot be considered as being prohibited by the provisions of Article 28 of the Constitution. Moreover, the provisions of the aforesaid EU Directive have superior force to any other provision of the domestic legislation and the Constitution itself.

Conclusion

It can be seen that the Cyprus Constitution and legislation do not separate the status of girls and women with disability from boys and men with disability. However, it is obvious in everyday life that it is more difficult for girls and women with disabilities to exercise their rights and avoid discrimination in many aspects of life including job finding, social relations and family creation.

DENMARK

DISABLED PEOPLES ORGANISATIONS DENMARK (DPOD)
SIF HOLST (DSI)

In Denmark men and woman are officially considered equal and most of the time no special efforts are made to empower women or to ensure equal representation or equal rights. March 8th (International Women's Day) is celebrated by some Danish women and a number of reports showing the existing inequality is published or are commented upon on that day. The reports mainly point to the lack of women leaders at the topmost level of the business, public and the political sectors.

Across most of the Danish disability movement there is a feeling of equality and only recently a gender policy was established within DSI. DSI, the Danish umbrella organisation, has 32 member organisations and only 9 (28%) of these have women as chairpersons/presidents. DSI has a male chairperson and only 2 (28%) out of the 7 executive committee (board) members are women, only 1 (20%) out of DSI's 5 political committees have a woman as a chairperson, though all in all 39% of the members of the political committees are women. Out of DSI's 97 local branches, 29 (30%) of the branches have a woman as the chairperson.

Among youth women leaders are a majority, DSI-Youth's chairperson is a woman, 3 out of 5 (60%) in the board are women, 10 out of the 13 member organisations (77%) have women as chairpersons and 2 (50%) of DSI-Youth's political committees have a woman as a chairperson; all in all 61% of the members of the political committees are women. There are no local DSI-Youth districts.

It is important to note that besides the gender difference between DSI and DSI-Youth there is also an age difference. An estimate would be that a good deal of the key figures in the Danish disability movement are between 55 – 65 years of age, whereas in DSI-Youth the most active are between 25 – 35 years of age.

Very few disabled women (or men for that matter) are represented in national organisations or in political parties. In a few organisations one or more of the disability organisations have a seat on the board or are member organisations.

An organisation for women with disabilities has been formed but only has around 100 paying members. None of the disability organisations have a women’s wing or committee.

No actual problem identification-process has been initiated as yet, but based on experience; we can say that women with a disability are subjected to a dual pressure when it comes to participation in interest groups. Traditionally women are burdened with the majority of work around the house and concerning children. The gender roles we believe have been undergoing a rapid change and the work in most families is more equally distributed nowadays. However, we still believe this is a factor in regards to women’s role in society. Secondly, in a marriage or in a similar relationship between a person with a disability and a person without a disability, a certain degree of dependency develops; coupled with the traditional barriers for women’s participation, this is definitely a challenge.

The board of representatives of DSI has proposed that it should be examined whether funds could be gathered to undertake a project which can support the work of including both genders actively in the professional and political work in DSI. The project must basically focus on the barriers to equal representation of genders, recruitment methods and education of persons of both genders, so an equal participation of all areas of DSI; including both genders undertaking functions at the leadership level. This must practically involve the member organisations since all positions are filled by persons who are nominated by the member organisations and the branches. Contents and activities in such a project have not yet been defined.

According to my experience the level of equality between men and women with disabilities (and without) is gradually increasing over time, and if you compare DSI (where most of the active members are between ages 55-65) with the youth branch DSI-Youth (where most of the active participants are between 25-35), you will find that in DSI the majority of the leaders are men and among the youth the majority of the leaders are women.

It is my experience that women are facing four main problems, especially among the older generation:

1. They are not part of the boys' club. Men of a certain age tend to consider what other men would qualify to fill a position, it might just be that when socialising men have earlier tended to seek out other men and women other women – and therefore a man often comes first to mind, when men have to decide on a candidate.

2. Both men and women tend to think that women need protection whereas men don't. If a man has been sick recently and is considered for a position in a committee, most people would tend to think nothing of the illness, maybe even thinking that the position would be good for him, as it would take his mind off of things and if he is not up to it, he will probably say no himself. If a woman has been sick and is considered for the same position in a committee, most people will tend to "protect" her by not asking her at all.

3. A women will often need to use more of her life taking care of the social needs of her family. If an elderly family member, a husband or a child is sick, lonely or just needs to be looked after, the task will often fall to the woman (she will often feel the need of taking on the task). I have not included household chores in this, since these actual chores for many or at least for some disabled women fall to someone else (assistants or family member).

A man will often not have the same social responsibility (his traditional role will be to supply the financial or practical support). Therefore women more often than men must refrain from attending important events (e.g. a conference abroad) or for a longer period (e.g. on maternity leave or tending to an elderly parent); this of course results in both lack of experience and others might choose someone else and more reliable for the next task. Since younger women might not (yet) have the same responsibilities, this might also be a reason that they enjoy much more equality that the elder generation.

4. Due to exclusion from the "boys' club", exclusion as a result of protection and the exclusion that is the result of the woman's social role within her family, at least some women will have gained less experience that some of the men – both in regards in factual knowledge and in regards to leadership. If a woman is then a less qualified candidate than a male colleague, the male candidate will often be chosen.

When comparing non-disabled women's position in the Danish society in general, it is similar to women with disabilities' situation within the disability sector. There is a lack of women leaders in the elder generations and in the most prestigious positions, but among the young there might even be a majority of women leaders.

When women with disabilities want to be accepted in Danish society in general, they more or less meet the same barriers as men with disabilities, but adding those barriers with the barriers of being a woman it results in a double marginalisation.

As mentioned above, DSI has now put together an equal rights policy and is examining the possibilities of getting funds for a project.

In the country in general very little is done specifically in regards to girls or women with disabilities. If anything at all it is mostly as a part of a more general strategy – e.g. in 2002 the government put forward an "*Action Plan on fighting Violence towards Women*". Women with disabilities are mentioned in this plan as a special target area: "*Distribute knowledge concerning women with a disability to crisis centre staff, police and other authorities who work with women and violence"* and *"Participating in the development of accessibility guides to the women crisis centres"*

As mentioned at the beginning, the problem in Denmark is that men and woman are officially considered equal and most of the time no special efforts are made to empower women or to ensure equal representation or equal rights.

A bit more effort is made in regards to people with disability, but it is in no way a special focus area.

One specific example of a problem where women with disabilities are doubly marginalised is during pregnancies: for women in general there is a lot of support during pregnancy, including free health care and training, while for people with disability, disability aids such as wheelchairs are free as long as it is a “lasting” disability. When a women with a disability is pregnant her body will often need extra support, e.g. a woman who can usually walk if only poorly might need a wheelchair during at least the final months of her pregnancy. But in this case she will get no support, since the need is not lasting.

In general it is very difficult to get the Danish authorities and the Danish system in general to accept people with disabilities as more than disabled, e.g. as a woman, as part of a family or as a worker.

ESTONIA

THE ESTONIAN CHAMBER OF DISABLED PEOPLE (EPIK)
DELEGATE: MARE ABNER

ESTONIAN UNION OF DISABLED WOMEN (EUDW)
MAARJA KAPLINKSI

The EUDW was founded in November 1999, as an expression of our understanding that for too long disability has been regarded as mainly a medical problem (disabled people have been, and quite often still are, viewed as walking, or rolling, diagnoses) and, among others, the gender issue has been overlooked. (One might say that, according to that kind of thinking, there are men, women and disabled persons...).

According to our understanding, it is high time to move on from a diagnosis-centered to a problem-centered approach. So we saw it, and see it, as our main aim to help disabled women themselves and society at large to better understand that a disabled woman has the same basic rights to choose the way of life she prefers, and to fulfill the consequent duties. In order to fulfil our aims, we have organised different projects under titles such as *"Disabled woman - her special needs and sexuality"*, "Who is a disabled person?", etc. In 2005, a project organised by EUDW took place called "*Improving the social coping of physically disabled parents and their children*", which we think was a success. At present a follow-up project is being planned, as we saw that there was a serious need to deal with disabled parents' problems, and we also plan to activate self-help groups for disabled parents and disabled youth eager to have a family of their own.

We have also cooperated with women's organisations from Sweden, Norway, etc. A couple of years ago there was a joint project between the ILO and disability organisations from Latvia, Lithuania and Estonia (project partner from Estonia being the EUDW), called *"Developing entrepreneurship among disabled women".* We think it was an important step towards improving the employment possibilities of disabled women in the Baltic countries, and also a good means to improve collaboration between different disability organisations. Hopefully there will be a follow-up to the project.

At present there are about 70 members in the organisation. It is divided into North Estonian and South Estonian regional branches. The chairwoman of the North Estonian regional branch is Ms. Mare Abner, and the chairwoman of the South Estonian regional branch is Ms. Maarja Kaplinski.

The disability movement in the ex-Soviet republics dates back only about 20 years, and so it seems that we have to make up for a period of 20 to 30 years, in comparison to the disabled people's achievements in the Western countries. (Speaking of the ex-Soviet republics at large, there seem to be substantial differences from country to country as regards disabled people's situation, but we are hardly experts to discuss them).The problem is that, in the Soviet Union, disabled people just "did not exist" - the Communism builders were supposed to be fit physically as well as mentally... (The rise of awareness about the existence of disabled people and their rights that took place in the West after the World War II had no equivalent in the Soviet Union, except that the war veterans [especially "war invalids"] became a privileged class).

So disabled people either lived in institutions (which were in a deplorable situation as regards the structures themselves as well as the underpaid personnel) or stayed at home without many possibilities to get out and to participate in the life of the society. However, due to the fact that their organisations dated back to the first Republic of Estonia, the visually impaired and hearing impaired people were better organised and better aware of their rights.

Technical aids were hard to find and of low quality. There were cases, for instance, where the clients' feet were actually bleeding due to the orthopedic boots she was supposed to wear, and still the representatives of the enterprise declared that they hadn’t done anything wrong. Another question was that, as a general rule, such boots were heavy and ugly, and when, on one occasion, a disabled lady complained about that, she was told that they were good enough for her!

Then there was the total lack of accessibility, because due to the general attitude accessibility was just not thought of. There were special schools for children suffering from this or that disease, but there was just one school specially designed for mobility impaired children – and you were not taken if you had incontinence or epilepsy. (The school exists up to this day, and we understand that these clauses have been removed). So many children, boys and girls alike, got very little education, if at all (plus, the children having hydrocephalus often were, and sometimes still are, qualified as “unteachable”, without taking any pains to evaluate their intellectual abilities) and the isolation resulted in underdeveloped social skills.

As regards employment possibilities, there was one vocational school for disabled people, but initially only two professions were taught – sewing for young girls and household machine repair for boys. However, towards the end of the Soviet period, new professions were added to the list.

Financial support from the State for disabled people did exist but, in order to make their life easier, the respective officials did their best to keep the disabled people uninformed about their rights.

Of course, there were brave men and women who, against all odds, decided to go to university and successfully completed their studies in order to engage in a profession of their choice.

So that’s more or less what the background was like, when, in mid-80’s, thanks to better communication possibilities with the Western countries, the disability movement started to emerge in Estonia. (During that period, one could hear people returning from abroad say that it was odd to move around in Estonian cities, because there were no non-European people and no wheelchairs on the streets). Sports clubs for disabled people became starting points for disability movement, notably volleyball became very popular.

If the sports clubs had become a meeting place for "experienced" disabled people who already, in one way or another, had found their place in life, it became more and more evident that something had to be done to help young disabled people to get out of their homes, to socialise, in short, to do things that "normal" young people like doing. So, in 1994, the "Händikäpp" youth club was founded for disabled as well as able-bodied youth, and has since actively contributed to improving the life quality of disabled youth. It took some more years for disabled women in Estonia to take the courage to step out and to assert their right to be women in every aspect of a woman's life.

One of our big problems is that there is still no plausible statistics concerning disabled people at large, let alone statistics broken down by gender, and even the criteria to establish what is and what is not a disability remain rather vague.

Although the Republic of Estonia has ratified the Standard Rules, there is still a lot to be done in terms of equalisation of opportunities for disabled people, and disabled women in particular, especially in terms of changing attitudes. As regards the employment possibilities for disabled women, for instance, we really can't comment on the validity in Estonia of the observation made in other countries that in the case of a disabled man the desire to find a job is viewed as an understandable wish for self-accomplishment, whereas in the case of a disabled woman the wish to work is often explained as "well, one does need something to fill one's time". But it may very well be the case.

One thing is certain – that whereas no one is likely to deny that financial independence is one of the most important prerequisites for independent living, and disability is quite an expensive luxury, the belief that disabled men as well as women are unable, and/or need not or even should not work, is still very widespread. Also, as in recent times the employment issues for disabled people have been intensely tackled in Estonia, among other things it has become evident that if there are employers genuinely interested in putting in use disabled people's skills and knowledge, on the other hand the wildest superstitions still persist. So, for instance, it has been said that "all disabled people are in wheelchairs"! Which, of course, means that there is a lot of work to be done by the disability organisations themselves, for it is up to us to make ourselves better understood if we want to be a part of society at large, and not live in a separate little world of our own, as is sometimes implied.

There is also the problem of disabled people of non-Estonian ascendance, concentrated mostly in the Northeastern Estonia, and also Tallinn. Again there are hardly any statistics available, but the main difficulty is that due to their weak knowledge of Estonian, and apparently also inadequacy of some officials, they are not actually involved in the disability movement, and their living conditions seem to be less satisfactory than elsewhere. So far attempts to create contacts have not been very fruitful, although here also there are some signs of improvement. We may well censor them for not having learnt Estonian, but it is hardly helpful in the case of, say, a 50 year old lady with only basic education, and we don’t think it is worthy of a democratic country to make the accessibility and quality of social services dependent on one’s knowing the official language.

One of the major opportunities that is opening itself to disabled people is the IT sphere. There are disabled young - and not so young - men and women currently in training to become computer specialists, and on an everyday level more and more disabled people have a computer of their own, although there are still problems with that. And E-mail, MSN and internet are excellent means for disabled people to get in touch with the wider world. So, for instance, a disabled young girl from Estonia can get in touch with a disabled young girl in Australia, although this, of course, means good command of English – but there also the situation is improving bit by bit. And MSN is a great means for communication for, say, people with speech impairment.

One of the problems is that the current system of evaluating one’s capacity for work (at least in our country) again is strongly concentrated on physical abilities or rather, lack of them. For instance, a young woman, a university graduate having severe CP, in these terms is seen as 100% unfit for work! The doctors may argue that this is the evaluation of her medical state. But still – is it not a logical contradiction that a person with a university diploma should be considered unfit for work?

It is our belief that some aspects here need re-evaluation. Among other things part of the still current attitude seems to be that the basic characteristic of a disabled person is that he/she is not able to do this or that – a motion impaired person "cannot" walk, a person with speech impairment "cannot" speak, etc. And if it were true, one really might think that a disabled person has no business to go to the university, or to the gynaecologist, or get married. The only little problem is that it is not true – that a disabled person is first of all a human being, then a woman or a man, and then he/she happens to have a disability (just as he/she happens to have grey eyes) – and not viceversa.

Another grave problem for disabled men as well as women is that, in order to get rid of the problem of there being too many people receiving disability benefit, the respective Estonian authorities have seen it fit to diminish the degree of loss of the capacity for work in the case of many severely disabled (e.g. visually impaired or mobility impaired) people, on the grounds that they have "got used to" their disability! Admitting that the problem is there, this is hardly the way to solve it.

Here again it may be said that the visually impaired have been very active in searching and finding employment opportunities. If during the Soviet period the main occupation for visually impaired people was making brushes, nowadays quite a few visually impaired people, among them several women, have been trained as masseurs and a good foundation has been laid for continuing to train visually impaired people into that profession, although, here as elsewhere, problems come up. For instance, there was a case of an occupational therapist, blind herself, who, after having been working as one for 5 years, was told at a training course that she was not able to assess her abilities adequately, and, due to her disability, was not fit for such kind of work.

To continue on the issue of employment, it was interesting to observe in the interviews related to ILO-coordinated project that there was quite a serious interest among disabled women in entrepreneurship, and on the other hand the ideas about what it should be like varied from rather foggy to very concrete. As an example about the latter – there was one lady who had been thinking about purchasing a sawmill, and already was very well informed about the respective prices, etc.

The prerequisite for finding a good job is a good education. Here also there are lots of problems affecting disabled boys as well as girls, and also disabled parents of able-bodied children. One of the most serious problems is the accessibility of educational establishments. A couple of years ago an ancient and popular school in Tartu, South Estonia, was re-built, so that it now is new, nice – and completely unaccessible... (A case "from life itself" - a lady in a wheelchair told a story about how her daughter's teacher had sent her an invitation to the party that was going to take place in the school, but had added: "Well, actually, your mother can't come, can she?" The problem was that the classroom was situated on the 3rd floor...).

We might say that here accessibility doesn't mean only the accessibility of buildings, but again we have to deal with the question about attitudes – the teachers prefer not to take risks they think having a disabled child in the class may imply. On the other hand, the service of school assistant so far is activated only in Tartu. And, as high school education is not compulsory, quite often, after the basic education is completed (in Estonia it means 9 years), either the school finds a way to get rid of the "nuisance" (as we know, most children are not exemplary, and the disability is hardly relevant here), or the parents just get tired of fighting... Another way out is to study at home, but, according to our personal experience and conviction, this is not the best one, except, perhaps, in some cases. Studying at home means being one to one with the teacher and having minimal contacts with youngsters of one's own age, which is in dire contradiction with the idea of a gender-specific approach to disability and constitutes a serious hindrance to the socialisation process and becoming aware of being a boy or a girl which, in view of disabled (as well as able-bodied) girls' greater vulnerability may have downright dangerous consequences.

Besides, as regards socialisation, studying at home and otherwise having little contact with the outside world may lead to the situation where, say, a 20 year old young girl finds herself in a situation where she will have to start acquiring skills that normally are learnt at the age of 7. We don't think that a good education on a purely intellectual level combined with complete, or nearly complete, lack of social skills can assure a disabled youth a good start in life. What we are getting at here is the idea that most, say, motion impaired youngsters initially have quite normal, in some occasions even over the average intellectual capacities. So we are deeply convinced that we must do our best to spare them from ending up being “socially retarded”. The problem here is that socialisation is not learning to speak that, in normal conditions, happens by itself sooner or later. It is our conviction that the importance of timely and adequate socialisation cannot be underestimated.

Returning to the specific problems of disabled women in our country – so far it has been extremely difficult for disabled women to assert themselves as mothers, because, as already stated above, according to the widespread bias - unfortunately quite often shared by disabled women themselves - they are “just not supposed to” have family, let alone children (which, of course, is also true for disabled men).

It is sad to say that doctors are anything but free of such a bias. So there have been cases where a young disabled woman had to be examined by several specialists, but the doctors saw the visit to the gynaecologist as unnecessary! Plus, the counselling centres, clinics and shelters for women as well as, for example, the law offices, are also often not accessible and, in addition to the above mentioned biased attitude of many doctors, so far there is no specialised professional counselling about sex, family planning, etc. for disabled women. Also, a disabled woman who wishes to turn to the police or a shelter is likely to encounter serious difficulties, because neither the shelters’ personnel nor the police is prepared to deal with a woman having, say, a learning disability or a speech impairment. Neither is there so far the possibility for a disabled mother to get a personal assistant for herself and one to take care of the child(ren), although this service as such has existed in Estonia since 1997. In Estonia there has been a “hot case” of a woman in a wheelchair who got married and had 3 children, but afterwards the husband turned out to be violent. Such a thing happens to many a healthy and pretty woman every day. But here it has been commented over and over again that “it was her own fault to marry and have children”, or “the poor thing just wanted to have sex.” And when the problem arose about with whom the children were going to live, it was considered evident that a violent father just released from the jail was a better candidate than a disabled mother. Besides, it seems that many a worried parent has chosen to take this concrete example as a threat and a cause why his/her disabled daughter should not marry and have children.

Another grave problem is that sex education should consist of the guidance got at home and at school, and awareness about being of this or that sex and about the appropriate behaviour which develops in communication with young people of one's own and opposite sex. However, whereas among others the HIV/ AIDS prevention campaigns have demonstrated, the awareness of able-bodied youngsters about sexual issues is anything but satisfactory (which means that there are still lots of taboos surrounding these topics), in the case of disabled youth, on the one hand these topics are hardly discussed at home at all, believing that a disabled youngster is anyway "never going to" have a boyfriend or a girlfriend, children or family. (Occasionally artificially raised moral questions may come up - "you have no right to...", "this is not for you", you are different", which, by extension, may lead a disabled youngster to such severe self-esteem problems that he or she ends up believing that he/she has no right to do most things in this life, lest he/she causes problems to other people). On the other hand, due to hindered contacts with other young people, normal development of awareness about one's gender, sexuality and appropriate behaviour is complicated.

Speaking of the education disabled youngsters, and girls in particular, receive at home, we may say that in Estonia as elsewhere there are many good, brave and reasonable parents who do their best in order to help their children to become good men/women and good citizens. However, as until very recent times there was no counselling whatsoever available for family members of disabled children (or disabled adults for that matter), the parents were left alone for years with their problems, and had to work out techniques for coping with the situation on their own.

In some cases it has led to co-dependency and hence to serious problems in relating to the disabled child who is forced to live in sort of a "golden cage", i.e. on the one hand he or she is well (too well) taken care of, on the other hand all the decisions concerning him or her are made by the parents, as they think they know best what is good for the child. The situation can take an extremely serious turn when the child grows up and decides to leave home, as the parents' worries and fears for him/her have taken the form of regarding him or her basically as their property, and so they can't accept the idea of him or her being an autonomous human being. (Another question is that if, say, a 35 year old lady, disabled or not, continues to live together with her parents, it is hardly possible to avoid conflicts). Such a situation may lead to very serious self-esteem problems and other personality disturbances which may take years to cure, if it is possible at all to do so.

Tackling all these and other problems affecting disabled men and women demands a joint effort. Sadly enough, this turns out to be a major problem in the disability movement. (Somehow, though, we don't tend to think that there is anything specifically Estonian about that problem). Again and again controversies appear between different disability groups and different age groups in disability organisations, controversies for instance about whether to stand for, say, disabled women's rights or just to come together now and then, to have some coffee and chat, or sing and sew and knit.

Controversies between people of different age is a very ancient, and not at all a disability-specific problem (the studies of ancient manuscripts have demonstrated that already in ancient Babylonia elderly people used to complain that young people were spoilt!). It is our belief, though, that here the situation is complicated by people having different backgrounds in terms of their experience of life (here also I am referring mostly to women, as I think I am less well aware about the men's situation). The elderly and the older-middle-age disabled people have grown up in the conditions where such terms and ideas as independent living, equal opportunities, accessibility, etc. were not even dreamt of, and rather than adapting one's environment to one's needs, one had to adapt oneself as well as one could, which meant a very hard fight deserving the deepest respect. So it may well be that when these elderly people see and hear the younger generation speaking about the right to demand taking into consideration one's special needs, and, as many of them have become bitter over the years, they take it as arrogance or a wish to make one's life too easy. But these are our ideas derived from certain observations, and they may well be not quite valid. However, one point about getting adapted is renunciation ("this is not for me anyway"), and so there have been cases where young disabled women have discussed party dresses, and an elderly disabled lady has got mad at them!

Be that as it may, one thing is clear – improving the life quality of disabled people at large, and tackling the special issues of disabled women needs joint effort of disabled and able-bodied people, men and women, young and old, and wisdom and tolerance to move from misunderstandings, wherever there are any, to mutual understanding and cooperation, in other words, improving the world starts from oneself.

FINLAND

FINNISH DISABILITY FORUM (FDF)
KATRI KOSKINEN

Disabled women are nowadays included in CEDAW-reports in Finland. Finland's latest CEDAW-report has just been published. For that report the following issues were highlighted concerning disabled women:

— **Violence.** Disabled women face violence more often than non-disabled women. However, it is still a kind of taboo and most of the refugee homes and services for women who have confronted violence are still not accessible for disabled women. We have started discussions on these themes with professionals working in this field and done some education to raise awareness of those professionals. Also trafficking may concern disabled women; examples of such practices have emerged. So we should also be alert to the topic of disabled women and trafficking.

— **Personal assistance.** The population is aging and more and more the same services have been planned for elderly and disabled. Home services have become more rigid and disabled women usually do not get the assistance they need in a way that suits their age and life-situation. We have still not received the legislation in Finland that personal assistants would be guaranteed for disabled persons who need them.

— **Education and employment.** Many disabled women still have to live in poverty if they live all their adult life on pension. According to one recent study, only 17% of severely disabled people in Finland was employed.

— **Accessibility.** Generally speaking, accessibility is on rather good level in Finland but there still are places that are not suitable or accessible for disabled women, for example examining tables of gynaecologists, some maternal clinics, fitting rooms in shops, etc.

Disabled women in the field of disability organizations

Co-operation of disabled women in different disability organizations: Network of disabled women

Here in Finland we are celebrating next year the 5th year of the disabled women's network. In this network disabled women from different disability organizations (14 organizations at the moment) have produced together an action plan for disabled women (http://www.invalidiliitto.fi/attachments/action_plan_by_women_with_disabilities.pdf) and organized seminars on disabled women.

Quotas of women in decision-making bodies

In the Finnish Association of People with Mobility Disabilities (http://www.invalidiliitto.fi/portal/en/) women are represented in decision-making bodies at the moment as follows:

In the executive council (2006-2009) of the Finnish Association of People with Mobility Disabilities there are 3 chairpersons, 2 of whom are women. Otherwise there are 10 members, 4 of whom are women.

In the executive committee (2006-2009) of the Finnish Association of People with Mobility Disabilities there is a total number of 56 places. Of these, eighteen representatives are female.

FRANCE

FRENCH COUNCIL OF DISABLED PEOPLE FOR EUROPEAN AFFAIRS (CFPH)
FEMMES POUR LE DIRE, FEMMES POUR AGIR (FDFA)
MAUDY PIOT
PRESIDENT

A brief history of the Association

The driving force behind the creation of our association was the wish to fight against double discrimination faced by women with disabilities.

For some years, we were aware that women with visual impairment found it very difficult to get out of their homes. It is true that this was due to accessibility problems, but it was above all the consequence of a lack of self-confidence and fear of the tremendous effort needed to pluck up the courage to make themselves seen. As women with disabilities, they felt the full weight of double discrimination. It was thought it would be good to organise one-day gatherings for these women to address different subjects such as femininity, motherhood, women's sport, personal image, violence, employment and so on.

In 2003, declared European Year of People with Disabilities, We wanted to open up these fora for visually impaired women to women with different disabilities. A group made up of six women with and without disabilities was started, who began to reflect on this project.

At the time we had no resources in terms of finance or logistics. The project, however, led to the "*Women with disabilities and citizens"* forum, sponsored by

Lucie Aubrac, which brought together almost one thousand people in Paris City Hall on November 25th 2003 (we had to turn people down as we were fully booked!). At the time there were six people involved as volunteers, but approximately forty women joined us to make the project a success and, among other things, help us secure sponsors and donors. At the same time, we felt the need to set up a support structure, so in April 2003 we set up the “Femmes pour le dire, Femmes pour agir” association.

We wanted women with disabilities to take the floor and their place as citizens with full rights. The forum was a success, and this showed us there was real expectation and a pressing need. Since then the association has not stopped growing, and we now have 200 members, of which 30% are volunteers.

Our association aims, through respect and listening, to promote the expression and mainstreaming of all women with disabilities regardless of their disability. Naturally, most of our members are women, but our male friends are not excluded either as volunteers or as members. The Board of Directors has 18 members, both men and women and people with and without disabilities from different ethnic backgrounds and from different social settings; and, of course, with a wide range of disabilities: sensory (partial sight, hearing loss, deaf and blind), motor disability, people with third degree burns, people with epilepsy, polyartritis, people with physical or mental disabilities, diabetics, people with genetic or acquired illnesses, with rare diseases and so on. This social, physical, professional and generational diversity is what enriches and FDFA and makes it so strong; our differences lead each and every one of us to “look at things from a different point of view”.

We wish to be recognised and work actively in the life of our cities. The association organises different activities aimed at bringing our members out from solitude, sharing and exchanging experiences and, above all, combating the double discrimination faced by women with disabilities.

To this end, five commissions have been set up:

— “Discussion Group” commission;

— Aesthetics and make-up commission;

— Leisure time commission;

— Social life and meetings commission;

— Research on disability commission.

To this list we should add a sixth commission; the commission that seeks subsidies and funds, because we need money to respond as best we can to the needs of women and men and organise activities and gatherings such as the 2005 national forum under the slogan "*Women with disabilities and life ahead of them"*, sponsored by Simone Veil, or the 2007 forum with the slogan "*Femme Création Handicap*", sponsored by Nicoletta.

Finally, we have a web site on Internet (www.femmespourledire.asso.fr) set up by volunteers and managed by one of our members. We receive a lot of E-mails asking for information and advice through our site, or simply thanking us for our activities. More and more institutions, associations, maternity hospitals, local organisations, media, etc., are showing interest in our work and appealing to us for assistance.

Women with disabilities: citizens in France

Women's status is France is undoubtedly evolving, as is that of women with disabilities. We are, however, still far from achieving equal opportunities for all.

Before I give an overview of the situation of women with disabilities, I would like to underline that the issue of femininity is something that affects each woman within her own body and flesh. Women and men are essentially different; their bodies are different in shape and qualities. This difference between the sexes (physical representation) is not the root cause of male oppression. The real cause is the imaginary, symbolic representation which endangers the male in relation to the female. Woman, who are you?

The reproductive woman, the woman who bears the small being for nine months, the woman who will give it shape and create it, is a danger to men. There is a need to subdue the woman, make her inferior and discomfit her to enable the male to enjoy his apparent superiority. The social body wishes to oppress the female body to avoid the anguish the female being creates in the male.

Women with disabilities in France do not have a special status; large organisations try to set up commissions where women may carve out a space for themselves.

Women are most active, but we have to point out that in most cases the chairman is still a man and males dominate boards and executives. There are few female or feminist associations of women with disabilities, and their demands are barely heard.

"Femmes pour le Dire, Femmes pour Agir" is one of the few associations to include individual women, regardless of their disability, in exchange, work, creation, etc., to combat the double discrimination faced by women with disabilities: being a woman and being a woman with disabilities.

Two per cent of women with disabilities find a job, and very often this employment is precarious. To date, there are no measures in place for women with disabilities who wish to have children, no adaptations in maternity hospitals, no accessible gynaecology services and so on. The fact that the pregnant woman is observed says a lot. It is the woman's fault – she should be ashamed of showing herself pregnant. Women with disabilities who give birth are still often considered incapable. Social services are prepared to remove custody of her children. Very little is done to accompany the woman/mother, and in fact they are soon singled out. Fathers are not normally questioned.

We are highlighting the "inferiority" of women —their inability— and this takes us once again to the male supremacy over the female. Among younger women and men there is a tendency towards equality. In literature, for example, books such as Catherine Vidal's "*Femme sexe et cerveau*" question the idea that men are mentally superior. Françoise Héritier's book "*Male, female. The thought is the difference"* takes a new approach to looking at differences between the genders. Young women with disabilities no longer stay at home – they are offered the same structures as young men. There is no specific decision on women with disabilities; they form part of the community of women.

I believe this is positive. We demand that women with disabilities are considered first and foremost citizens —in all aspects— rather than someone “with disabilities”.

Disability is not our identity; it is due to the circumstances of life. Our identity is as female citizens.

GERMANY

GERMAN DISABILITY COUNCIL (DBR)
GERMAN NETWORK OF WOMEN LESBIANS AND GIRLS WITH DISABILITIES
(ASSOCIATION “WEIBERNETZ”)
MARTINA PUSCHKE

Germany has more or less 4 million women with disabilities (WWD).

Networking in Germany

- A nationwide Network of WWD (“Weibernetz”);
- 10 federal Networks of WWD;
- various Women’s Groups in (social-) associations;
- Cooperation with the German Disability Council and the National council of women’s associations.

Employment

- Employment rates of Peoples with Disabilities has improved somewhat in 2007.

Health system

- The health system in Germany is not at all accessible;
- There are only a few barrier-free gynaecologists' surgeries;
- Health care policy does not take gender aspects into account.

Violence

- No data about (sexualised) violence against WWD (it is planned for 2008);
- Only 10% of women's shelters and information centres are not accessible;
- most German therapists are not willing to work with women with learning difficulties or with deaf women (2002 survey).

Important policy papers

The situation of WWD becomes more and more a topic in policy papers of the German government. Two examples:

- Action Plan to provide for violence against women: WWD are mentioned (issued in 2007);
- Campaign for participation in working life: WWD are mentioned (issued in 2004, renewed in 2007).

GREECE

NATIONAL CONFEDERATION OF DISABLED PEOPLE
DELEGATE: AGATHI KARRA

Unfortunately, in Greece there *is a lack of statistic data* about people with disabilities in general and women with disabilities in particular. Nevertheless, the National Confederation of Disabled People (NCDP), recognizing the fact that women with disabilities belong to one of the most vulnerable social groups —because they confront multiple discrimination conditions due to disability and gender— always tries to promote their rights with many different ways which will be presented later.

The NCDP policy concerning gender mainstreaming takes 2 forms:

a) a vertical gender mainstreaming and b) a horizontal gender mainstreaming.

In order to ensure vertical gender mainstreaming, the NCDP always includes both in its General Council and Board (Executive Secretariat), a number of women that are either disabled or mothers of disabled children. More specifically, 4 women participate in the General Council and 2 in the Board.

Women with disabilities are undoubtedly a highly vulnerable group, facing several barriers in many different areas of life. The main difficulties that they confront, excluding the obstacles opposed to every person with disability, could be summarized as follows:

Lack of equal opportunities in employment, causing severe financial problems and inevitably leading to a damaged or non-existent self esteem and social recognition.

Lack of counseling, in order to guarantee the right of women with disabilities to have a family, relationship, sexual contacts or to be a mother.

Lack of sufficient protection from violent behavior, sexual abuse and safety.

Lack of assistance and encouragemen,t in order to help women with disabilities attain self esteem and participate actively and prolifically in decision making.

Lack of sufficient provision of health and medical care, on the basis that like any other woman, they need regular medical examinations.

Lack of "an open mind" when it comes to women that are not able to give birth due to their disability, which in traditional Greece stigmatizes them, since the social status of a woman depends on her marital status.

Given the aforementioned barriers women with disabilities face, it is easy to export safe conclusions on the main differences between the situation of a woman with disability and a woman without. Women without disabilities are more independent, they have more opportunities to claim better jobs and inevitably a decent and satisfactory financial status. Furthermore, women with disabilities are more often victims of sexual violence than any other woman.

Women and men with disabilities, on the other hand, need to cope with the same obstacles and barriers while trying to be included in society (for example obstacles in education, in accessibility, in information society, in means of transport, in health care, employment, etc). The only exception is once again the fact that women with disabilities are more often victims of abusive behavior.

Finally, we should also mention that there's also a difference in the way women with disabilities and women in general are treated in urban and rural Greece. In rural Greece people are more "narrow-minded" in terms of accepting and including diversity in their everyday life. Therefore, especially women or men with disabilities are not easily accepted in the local society and, most of the time, this leads to confinement.

Conclusions

There is no specific legislation concerning women with disabilities at national level. However, the equality of men and women is protected by the Greek Constitution. The most frequent measures taken are unfortunately fragmentary and abstract. The existence of a holistic approach is absent.

The NCDP has concluded that the dimension of disability is not incorporated in the policies of the public bodies that are responsible for the specification of measures that promote gender equality at national level, a fact that consequently leads to a disregarding behavior towards the special needs of women with disabilities.

NCDP Action

In order to counter discrimination against women with disabilities at our level, the NCDP proceeds in the following actions:

In all its policy documents and proposals to the Greek State, the special conditions and situations that women with disabilities or mothers of disabled children experience, are always not only included, but also clearly highlighted.

In all its proposals for more targeted actions in favor of people with disabilities, e.g. the ones submitted in the framework of the implementation for the programmatic period of *EU Structural Funds for 2007-2013*, the NCDP always refers to the (targeted) actions required for the wellbeing of women with disabilities.

In all projects and programs coordinated by the NCDP at national level, e.g. the projects in the framework of the *Community Initiative EQUAL*, not only women with disabilities but also mothers of disabled children are included in the target groups.

NCDP Proposals

The NCDP strongly believes that in order to counter multiple discrimination due to gender both at European and national level, we should proceed to the following actions:

a) The dimension of disability should be taken into account by all European and national bodies that define the strategy and policies concerning gender equality.

b) The gender dimension should be incorporated in all national and European disability organizations.

c) European and national legislation is absolutely necessary in order to counter multiple discrimination.

d) New, targeted actions should be taken in favor of women with disabilities.

e) Women with disabilities should be included as a separate target group in all European projects implemented at national level.

f) New studies should be conducted in order to collect sufficient statistical data.

HUNGARY

HUNGARIAN NATIONAL COUNCIL OF FEDERATIONS OF PEOPLE WITH DISABILITIES (FESZT)
MARGIT NÁSZ

People with disabilities belong to the most disadvantaged population in Hungary. For many of them not only their disability or health, but also the difficult social circumstances or insufficient services make their lives even more difficult and almost impossible to lead a normal life like other people in society.

Some data related to people with disabilities, according to the census

The number of persons with disability increased from 369 000 (1990) to 577 000 (2001), their rate within the society increasing from 3.5 % to 5.7%. According to Hungarian legislation, people with disability are: people with physical, mental disability, visual and hearing impairments and people with autism.

The composition of the disabled population, based on gender, has changed as well; in 1990 there was a male majority, but in 2001 there was a female majority – just like in society.

Population according to disability and gender in 1990 and 2001

Gender	*1990*		*2001*	
	Disabled (%)	*Non-Disabled (%)*	*Disabled (%)*	*Non-Disabled (%)*
Male	53.6	47.8	49.0	47.5
Female	46.4	52.2	51.0	52.2
Total	100%	100%	100%	100 %

Within the Roma population living in Hungary as the largest ethnic minority —but also in other groups living with disadvantages— women have to face multiple barriers and discrimination. One reason is the pervading disadvantageous situation of all women generally.

Qualifications based on disability, ethnic group and gender, and highest finished school

Qualification	*Non-disabled people (%)*	*All disabled people (%)*	*Romas with disability (%)*		
			all	*male*	*female*
Lower than 8th class in elementary school	19.3	31.6	64.6	58.8	72.2
8th class elementary school	30.2	38.8	30.08	35.2	25.2
Secondary school with professional certificate only	17.1	10.3	3.0	4.1	1.6
Secondary school with final exam	23.3	14.3	1.2	1.5	0.9
High school, University	10.2	5.0	0.3	0.4	0.1
Total	100	100	100	100	100

Education and employment rates among disabled Roma people are even lower than among disabled people in general. Educational opportunities for Romas are even fewer than for the non-Roma disabled population: Almost two thirds of them, and three quarters of Roma women, did not even finish the 8th class of elementary school, while only 4.5% had the opportunity to continue their studies.

It is well known that the Roma population in Hungary is the most disadvantaged in society in respect of demography, education and labour opportunities. These disadvantages are growing and have become socially unacceptable in the case of Roma disabled people, and especially of Roma disabled women.

There are only 61 employed people in 100 households of people with disabilities, while in the case of non-disabled people this amount is 99. Regarding economic activities, there was a significant difference even in 1990 between disabled and non-disabled people; the employment rate among the disabled was close to 17% while that of non-disabled people was more than 44%. Basic changes in the labour market in the nineties resulted in a decrease in the employment rate of disabled people to 9% in 2001. This number has not changed in the present time.

Employment opportunities are worse in the case of people with disability than in the rest of society. In the labour market they often face prejudice and hidden discrimination while searching for a job, on the one hand, but on the other hand sheltered employment offers far fewer opportunities then in the 90s. Labour offices only recently began to offer training, retraining and job opportunities to people with disabilities within very limited possibilities. At present, nearly 100 thousand women of active age with disability do not work.

Within the NGOs of people with disabilities the rate of women and men is different. One reason for this may be the fact that most members and officials work voluntarily for the NGO – in the interest of all people with disabilities. In many cases men with disability are working for the NGO in the board or in other sections, while women with disabilities take care of the household, especially in the country side.

As regards FESZT, the umbrella organisation of people with disabilities in Hungary, women and men are in parity on the Board. Within the NGO there is a women's working group, however it has not been working for the last few years.

The reason is the lack of a national network of disabled women, therefore no financial means can be allocated. We will submit our proposal to the Board in order to create a national network, for which we will try to raise funds.

We have carried out activities in order to promote equal opportunities and full participation in society for all disadvantaged groups in society. In the Jász-Nagykun-Szolnok county, at the Social Service Center in Szolnok, we have carried out many training courses, services and programmes first of all for women with disabilities and Roma women with and without disabilities. These include principally training in computer skills on different levels, training to prepare for the labour market, training to become a social assistant, training in peer counselling, sign language interpreter's training, field practice for social workers and many more. Among trainers there were also disabled women.

As part of a PHARE ACCESS project in 2004, we carried out a sociological study regarding the situation and possibilities of disabled people, especially women with disability, by means of asking the disabled themselves questions and surveying also the rest of society (inhabitants) and politicians. The aim was also to inform the public about the rights and special needs of disabled people. We wanted NGOs of people with disabilities to get to know each other's activities and work together for their rights. Beyond real numbers and facts the everyday life of women with disabilities are still influenced by:

- Prejudice;
- Lack of knowledge and information about them and their difficulties;
- Discrimination in education, training and the labour market;
- Lack of possibility to participate in decision-making processes regarding their life;
- Lack of social inclusion, institutional segregation;
- Insufficient provision and share of information, insufficient advocacy;
- Lack of knowledge on their rights and possibilities;
- Lack of skills for self support, lack of self respect and self defence;

- Lack of suitable training and employment facilities.

There are two points in the survey results which should also be mentioned:

- Concerning barriers, many participants wrote about stigmatization (denouncing), loneliness, lack of understanding, marginalization, mockery, loneliness, defencelessness, locking into oneself, problems with self esteem, lack of employment opportunities, dificulties in transportation, in getting information and in communication.
- Several participants explained, that society finds it strange when a person with disability has a desire for love and sexuality. In this case people treat them in a paternalistic way, they treat them as children. This situation can become Citical especially in certain families and institutions.

During our work in the field of advocacy we very often come across violence within families against women —and also women with disabilities— discrimination and violence against people in vulnerable situations. Today we are working together with NGOs and experts who are in direct contact with groups of victims of violence, and can provide them with help.

In the last few years several good and up-to-date laws, regulations and services have provided support to people with disabilities towards bringing about equal opportunities (if most of them were implemented). Among others, there is a network of so called “Houses of Opportunities” which can be found in many towns throughout the country. Their task is to support social groups facing discrimination, like women, people with disabilities, Romas (including Roma children), the elderly and people living in remote areas. Often they support the work of self help groups of disabled women.

The League of Hungarian Women for Career Development, together with mayoresses belonging to the National Confederation of Local Governments, initiated activities in order to concentrate on the difficulties of women with disabilities. The name of the project is “March Belongs to Women with Disabilities”. It aims to draw the attention of society to the special situation of one of the groups that is most at risk of social isolation, and to start a dialogue as well as an exchange of experiences in order to support women with disabilities to create balance between family, work and self-realization. Further aims are to motivate dialogue between stakeholders to achieve inclusion in the labour market, and to point out that only a dialogue “for and with them” can reduce discrimination and violations disabled women face every day. Also good examples should be demonstrated of how a woman with disability is able to live a full and dignified life. These aims are in line with European Union objectives in terms of equal opportunities.

Miracles do not exist! We have to create them with common will and work!

It is important people understand that success at work and in privacy is also very important for us, but it is much more difficult for us to achieve. Even if we are women with disabilities, we have to be beautiful and strong just like any other woman!

ICELAND

THE ORGANISATION OF DISABLED IN ICELAND (ÖBI)
DELEGATE: STEINUNN PORA ARNADOTTIR

In the year 2004, 4.7% of Icelandic males, 16-66 years old, were on disability benefits. The figure for women in the same age group is 7.7%, that is: 4 709 men and 7 302 women. The general trend over the last few years has been a slightly higher growth in disability among women.

The main causes of disability among women in 2004 were:

- 37% rheumatic disorders
- 29% mental disorders
- 8% neurological disorders
- 7.5% cancer

The legal status of disabled men and women in Iceland is the same, yet studies indicate that disabled women in many ways have weaker social and economic standing than their male counterparts.

In the year 2006 the PM's office appointed a committee to review the legislation on disability evaluation. The committee had 10 members, all of whom were men. Later the committee was reappointed, this time including one woman.

The Organization of Handicapped in Iceland (abbreviated as OHI) has not established a special gender-equality policy nor taken any direct steps to improve the status of disabled women. However, the law of the organization includes a friendly request that the member associations nominate representatives of both sexes for its general meeting.

On the OHI board of 2007-8, two out of seven members are women and two out of three stand-ins are women.

Few, if any, disabled women count as public figures in Icelandic society, while disabled men —albeit severely underrepresented— have a few such role-models, e.g. in politics.

The OHI Women's Movement was founded on March the 8th 2005, on International Women's Day. It is meant to be a platform for discussion and a strategic tool for handicapped women and women who face long-term illnesses, aiming at creating one society for all with equal opportunities – a society where disabled women have the chance to flourish and develop their abilities.

The OHI Women's Movement aims to:

- Utilize the strength and experience of disabled women in order to benefit all women and fight prejudice;
- Work for improved job opportunities for handicapped women and women with long-term illnesses;
- Act as a platform for disabled women to get their voices heard and create conditions for discussion and expression among them;
- Encourage broad-based and visible solidarity among disabled women to improve their economic, educational and social status;
- Remain informed about latest studies and research of interest to disabled women and to serve as intermediary between researchers and the OHI.

A few issues of importance:

- Violence against disabled women;
- Worse services for women in health institutions;

- Foetal screening;
- Financial dependence of disabled women on their spouses;
- Worse financial situation of women, e.g. because of inferior insurances/ pension funds;
- Prejudices against disabled mothers;
- Empowerment of disabled women.

ITALY

DPI AND THE NATIONAL COUNCIL ON DISABILITY (CND)
RITA BABUTO AND EMILIA NAPOLITANO

Introduction

Gender and disability are two dimensions that are hardly ever connected in today's reality. Gender, which represents, in one way or another, the fundamental element of cultures and societies, is hidden in the world of disability. Beyond all doubt, its concealment is at the base of the violations of the human rights of the individual who is female and has a disability.

The double discrimination suffered by disabled women, being female and disabled, is evident but difficult to reveal because these women don't have the right words to express themselves or to denounce the fact. By and large in today's society every woman, due to her culture and tradition, is immobilised in a marginalised and discriminated role. Women with disabilities, in particular, live in a more difficult condition because frequently this role isn't even recognised: they aren't human beings; they aren't citizens but beings without rights, without gender, body, intelligence, desires, and emotions.

In her relationship with the world, a woman with disabilities is constantly exposed to attitudes and glances that reveal fear, compassion, pity and intolerance; these are reactions that are deeply humiliating for her as a human being and person. This means that she is not recognised, not visible in a world where the female image is conditioned by abstract standards of beauty and charm that induce us to see disabled women as "flawed women".

According to public opinion, the disabled woman has an asexual body without any femininity. Her body, precisely because it is impersonal and undesirable, often suffers abuse (physical, sexual, psychological, etc).

Being invisible or transparent means not being recognised as a person among others in a mutual relationship, in the most intimate and deepest dimension of one's physical and emotional identity. The family, school, social and professional contexts in which they live do not allow women with disability to create relationships in which they can live fully what they are: namely women!

In fact, it is difficult for a woman with disabilities to find affirmation in the individuals she interacts with, or even worse, she is often excluded and cast out of her living environment. All this leads to a low self esteem that will condition her thoughts and actions throughout her life, strongly limiting her possibilities to have new experiences and to measure herself not only against others but also with herself.

The disabled woman's search for identity is already undermined during the first years of her life, when, in the family setting, instinctively, nobody recognises her femininity. In fact, when a baby girl is born, her parents and especially her mother have already made a life project for her, even unconsciously. This project is a script that has repeated itself throughout the ages: a girl grows up, goes to school, has friends, becomes a woman, gets engaged, gets married, has children, etc. When a disabled baby girl is born there is no such plan and while growing up she will develop a strong relationship of dependence with her mother. This exclusive limitation to the mother figure risks generating a "return-to-the-womb" behaviour and the disabled girl will always remain a "mama's girl"; consequently, as a grown up she will lack any form of sexuality.

The sexual dimension, basically a taboo in disability, is not recognised at all, the maternal language doesn't even name it! The disabled girl, once she has become a woman, can't identify with her mother's body that denies her daughter's sexuality, but at the same time lives her own sexuality through its generative ability. All this strongly hinders the disabled woman in developing her female gender identity.

Normally others identify a woman as a woman, first her mother, then her father and later her partner, and in this way she is able to define her gender identity. This process is more difficult for a woman with disabilities because her gender is hardly ever recognised.

All women, including women with disabilities, discover their body and sexuality during adolescence. Adolescence is a very delicate phase in the life of a person. There are morphological and physiological transformations of the body together with an explosion of physical sensations never experienced before, and each individual can react differently on these, putting in action inter-psychic and interpersonal dynamics that show the passage from childhood to womanhood. However, the woman with disabilities is never fully aware of what is happening to her because she is conditioned by her family and living environment that tend to repress her typical feminine emotions: she is a disabled woman who will never be a wife, mother or lover!

Women with disabilities are the victims of social exclusion, which is not determined by their condition of disability but by a strong prejudice which considers the disabled woman as unable to contribute actively to a full social life and is therefore unproductive. She is a person who has to be fed and washed, sometimes educated and placed in the job market, always in separate places in order not to disturb the harmony of a society that cannot face its real ghosts.

Social exclusion is a phenomenon that keeps disabled people separated in different times and places from other citizens. We could say that, on an objective level, it re-proposes an experience of alienation, which takes place inside every individual every time he/she encounters a new situation or every time he/she meets someone or something unknown or different from him/herself. Getting in contact with something new frightens people and may lead to an alienation of oneself. Dealing with people that use a simple, less intellectual language or other means of communication, people that use a wheelchair, or in general dealing with situations that represent a new reality is very difficult, it is easier to isolate them on a psychic level or separate oneself from them on an objective level.

The disabled woman is the most excluded among the excluded. She doesn’t have the same equal opportunities as other women or as disabled men.

"Inside the movement of people with disability, gender has been regarded as something irrelevant, the same has happened to the social dimension, the class dimension, the ethnic dimension and the dimension of sexual orientation. Disability is considered as a unitary concept that overshadows all the other dimensions. The current approach shows a tendency to hide the gender factor when examining the lives of people with disabilities and overlooks the influence gender has on them. In short, the movement of people with disabilities still hasn't recognised the multiple discrimination of disabled women, determined by the combination of gender and disability and this has led to a lack of interest in designing activities and programmes, actions and policies aimed to fulfil the specific needs of the latter. It seems as if women with disabilities were not involved or regarded when women radically brought into discussion the age-old predominance of men over women, which turned the symbolic order of non equality between men and women upside down and which rightly condemned abuses and violations inflicted on women.

The feminist philosophy continues to ignore and exclude women with disabilities. Women joined men, with or without disability, banishing women with disability to a level inferior to their intellectual and political capability. The keenness to diffuse an image of strong, powerful, capable and attractive women is one of the reasons why disabled women have been excluded from the feminist movement; in fact, their depiction as defenceless, sexless, dependent, needy and passive beings only reinforces the traditional stereotypical image of women. The disabled woman has always been regarded as inappropriate for the traditional roles of mother, wife, housewife and lover and at the same time as unsuitable for the new roles of society where the myth of productivity and appearance dominate."[15]

Disabled women are denied the right to fulfil themselves as women, mothers, companions and professionals due to prejudices and preconceived opinions that limit their choices. For example, when a disabled woman wants a child others —and in the first place doctors— are alarmed because they judge it as impossible

---

[15] Peer Counselling Handbook "From Victims of history to protagonists of life", by Rita Barbuto, Vincenza Ferrarese, Giampiero Griffo, Emilia Napolitano, Gianna Spinuso, Comunità Ed., p. 37.

because, due to prejudices, maternity is a privilege of completely “healthy” women. Healthy according to mental standards that consider disabled women as ill people, someone to take care of, people that cannot take care of others, in this case of their child, which according to these standards will probably lead an unhappy life. Being convinced of this nobody will ever build a delivery room that answers the special needs of disabled women or even worse these women are so conditioned in their way of thinking that they wouldn’t dare discuss the way others see them nor the denial of their procreation, and this is so deeply rooted that they aren’t even aware of their maternal desires!

Or, should disabled women succeed in realising their dream of becoming a mother, many cannot live this role completely. Accessibility barriers obstruct a simple walk with the children and makes it impossible to walk them to school or take them to the doctor’s, to share those moments that form the affective relationship between a mother and her child.

Even the disabled women’s right to life is constantly an issue of discussion. They risk more than others to undergo forced eugenic practices —sterilisation, forced abortion and medical experimentations— for fear they might give birth to disabled children. Baby girls were and still are left to die because they are unproductive; they ask for euthanasia because their economic situation doesn’t allow them to live a dignified life.

Furthermore, let’s not forget the gratuitous violence in institutions, especially against women who are unable to represent themselves; or think about what happens in the medical field where the body of a woman with disability usually isn’t treated with respect but is considered purely as an object to examine and is very often exposed on video, in medical magazines etc. frequently without their consent.

Over and over again when these girls and women have to face physical female problems they collide with the violent practices of medical personnel, unable to take care of their bodies in the right way. In fact, many disabled women have spent most of their lives naked, exposed to the icy and curious glances of those who should have taken care of them and of their deepest intimacy.

Therefore is it very important for a woman with disabilities to defend her right to live a dignified life! It is high time that women with disabilities fully recognise their possibilities and their humanity, through which they can develop an ever growing self esteem, also to protect those women who are never listened to because they are deprived of their rights and because they are victims of segregation, in a culture that gives no space to differences.

It is exactly in these contexts that the woman with disabilities must take up her responsibilities and react in order to obtain a cultural, social and political change which guarantees everyone, without any exception, the universal ethical values that recognise the dignity of the essential diversity of the human race.

Gender and the Convention on Human Rights of People with Disabilities

An enormous step forward was *the Convention of Human Rights of People with Disabilities***,** the first treaty of the 21st century, approved on 25th August 2006 and adopted definitively on the 13th December 2006 by the General Assembly of the United Nations.

The Convention represents a historic finishing line for the movement of people with disability all over the world. In fact it brings together, in brief times, positions and requests of the Governments and organisations of people with disabilities all over the world.

The goal of the Convention is to promote, protect and guarantee the full and equal enjoyment of all human rights and of all fundamental freedoms by people with disabilities, and to promote respect for their dignity.

Women with disabilities offered a very important and significant contribution to the drafting of the Convention. In fact, if for the movement of people with disabilities this UN Document represents a milestone for the recognition of their human rights, for women with disabilities it represents the first opportunity to be recognised as persons. In fact, their multiple discrimination and their condition of invisibility have been highlighted for the first time. To insert the gender issue in the Convention wasn't simple. The representatives of the Governments and organisations that drafted and consequently approved the convention came from different cultures and societies which didn't make the work of the disabled women involved in the whole process easy.

But disabled women have made it, starting from the awareness that:

- Gender neutral documents don't give enough space and attention to women, including those with disabilities;
- Disabled women, beside facing double discrimination, must also face the problem of a double invisibility: as women and as disabled people;
- Fully adopting the principle of mainstreaming also means guaranteeing that the gender point of view will be adopted explicitly in every country in the development and the implementation of laws, actions and programmes that regard disability;
- Affirming equality between men and women is necessary but not sufficient;
- Writing explicitly about the specific problems of women with disabilities increases the possibility that Governments will take adequate measures to solve them.

In fact, for the first time in such an important document, not only is there a specific article on women and girls with disabilities but what is more, the gender issue is underlined and highlighted in the most significant articles of the entire treaty.

Here are some parts of these articles to explain better and to let you know more.

Article	*Text*
Preamble	*q) Recognising that women and girls with disabilities are often at GREATER RISKS, both within and outside their homes, of VIOLENCE, injury or abuse, neglect or negligent treatment, maltreatment or exploitation.* *s) Emphasising the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities.*

Article 3 General principles	*The principles of this Convention are: • Respect for inherent dignity, individual autonomy —including the freedom to make one's own choices— and the independence of persons; • The non-discrimination; • The full and effective participation and inclusion in society; • Respect for difference and acceptance of people with disabilities as part of human diversity and of humanity; • Equality of opportunity; • Accessibility; • Equality between men and women; • Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.*
Article 6 Women with disability	*1. States Parties recognise 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 of all human rights and of the fundamental freedoms by these women and girls with disabilities. 2. The States Parties shall take all appropriate measure to ensure the full development, advancement and empowerment of women for the purpose of guaranteeing them the exercise and the enjoyment of the human rights and fundamental freedoms set out in the present Convention.*
Article 8 Increase of awareness	*States Parties undertake to adopt immediate, effective and appropriate measures: b) To combat stereotypes, prejudices and harmful practices regarding people with disabilities, including those based on gender and age, in all areas of life.*
Article 16 The right of not being the victim of exploitation, violence and ill treatment	*1. The States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect people with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects. 2. The Member States shall also take appropriate measures to prevent all forms of exploitation, violence and abuse, by ensuring moreover, appropriate forms of gender- and age- sensitive assistance and support for persons with disabilities and their families and caregivers, through the provision of information and education on how to avoid, recognise and report instances of exploitation, violence and abuse. The States Parties shall ensure that the protection services are age-, gender- and disability sensitive.*

	4. The States Parties shall take all the 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 integration 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.
Article 28 Adequate Living Standard and social protection	*2. The States Parties recognise the disabled people's right to social protection and the enjoyment of this right without discrimination based on disability, and shall take appropriate measures to protect and promote the exercise of this right including measures to:* *(b) Ensure people with disabilities, in particular women and girls with disabilities and elderly people access to social security programmes and programmes for the reduction of poverty.*

The Situation in Italy: Statistical Data[16]

As said before, in a world built and run by men, being a woman and disabled means a life of multiple discrimination. Women with disabilities are, at all times and no matter how, women, but they are never recognised as such. Erroneously people think that the situation in Italy is different, that the situation of women with disabilities is definitely better here than in other countries, that the economic and cultural poverty in which women with disabilities are segregated is typical for the developing countries and is therefore not the condition of one million seven hundred and twenty-one thousand Italian citizens.

The latest estimate talks about 2 million 824 thousand people with disabilities living in Italy, of whom about 60 thousand men and 1 million 864 thousand women. We need to specify that these numbers refer to people defined as civil invalids by the Law of the 30th March 1971, n.118 and in the Legislative Decree 23rd November 1988, n.509.

The number of people with disabilities, from the age of six onwards, that live with their families is about 2 million 615 thousand, meaning 4.85% of the

---

[16] The statistic data were taken from the website www.disabilitaincifre.it

Italian population. Of this percentage, 33% —894 thousand people, i.e. 3.4% of our population is represented by the male gender and the remaining 67%— 1 million 721 thousand, i.e. 6.2% of the population by the female.

Disability regards mainly people over 60 years old: 17% of people over 60 are disabled —2 million 57 thousand individuals— and 37.7% are over 75 years old. People with disabilities under 60 years old are 620 thousand; 188 thousand of them are younger than 14.

Education

"Access to education will always be and remain a serious problem for people with disabilities. Traditionally children with disabilities were put in special and segregated schools or in separate classes inside ordinary schools and their education was largely inferior compared to that of other children. In this context of segregation, girls and women with disabilities receive less schooling due to the stereotypical opinion that considers both women and disabled people as dependent, emotionally unstable and needy of care and therefore it is not only difficult to educate them but it is also a waste of time. Even if women have conquered a significant place in this field and, today, they can easily attend university courses that prepare them to be as professional as men in every field of knowledge, this is not the case for disabled women, who are still directed towards certain training choices that lead to subordinate positions and inferior roles on the labour market and consequently to less paid jobs."[17]

In the youngest age group (between 15 and 44), the qualification obtained is mainly influenced by the condition of disability but not by gender differences. In fact, the percentage of people with disabilities, male and female, without qualification is more or less the same: 17.7% and 15.3%. There are no gender differences among people without disability, even though their numbers are a

---

[17] Peer Counselling Handbook "From Victims of History to protagonists of life", by Rita Barbuto, Vincenza Ferrarese, Giampiero Griffo, Emilia Napolitano, Gianna Spinuso, Comunità Ed., p. 39.

great deal smaller compared to those of people with disabilities, namely 0.4% of men and 0.6 % of women.

In the intermediate age group (between 45 and 64), besides the presence of the disability factor there is also the gender factor: among people with disabilities, 22.5% are women without any qualification in comparison with 12.6% of men; the percentages decrease enormously when we regard people without disabilities but they are always in favour of men; in fact, 5.7% are women without disability and without qualification against 2.6% of men.

Access to education is not only influenced by the presence of disability and the gender difference but also by age. The elder generation have only a limited number of school integration initiatives at their disposal should they want to obtain a qualification or higher qualifications (secondary school diploma and university degree). They have fewer opportunities than when they were younger. People with disabilities between the age of 15 and 44 with a secondary school diploma or a university degree are 35.6% against 16.8% between the age of 45 and 64; the percentages for people without disabilities are 53.4% and 31.7%.

Without qualification:

Age	*Women with disability*	*Men with disability*	*Women without disability*	*Men without disability*
15 - 44 years old	15.3%	17.7%	0.6%	0.4%
45 - 64 years old	22.5%	12.6%	5.7%	2.6%

In the eldest age group (over 65), besides the presence of disability, the gender factor plays a significant role, always to women's disadvantage, especially regarding secondary school diplomas and university degrees. In fact, only half as many women with disabilities obtain higher qualifications compared to men with disabilities, in fact the percentages are 4.9% for the former against 9.9% for the latter.

The elderly have more problems because they can't benefit from mainstreaming education policies: 35.6% of disabled people between the age of 15 and 44 have a secondary school diploma or university degree, in comparison with 6.4% of those over 65. Looking at persons without disability of the same age groups the percentages are 53.4% and 13.1%.

In the last few years there has been a significant increase in university attendance. In fact in the academic year 2000/2001 there were 4 813 students with disabilities matriculated, while in 2004/2005 there were 9134. During these five years there has been an increase of 90%.

None of the consulted sources refers to gender; actually, we don't know how many female students with disabilities are matriculated at university in Italy. It would be nice to suppose that the same phenomenon that happened to the non-disabled girls in Italy also happened to the girls with disability. In Italy throughout the years, the female investment in education has grown more that the male one. The percentage of girls that get their qualification is increasing more than that of boys of the same age group and it surpasses it for high school education and university. In 2001-2002, 77% of nineteen year old girls got their high school diploma against 67% of boys. The percentage of twenty-five year old female graduates is 23%, compared to 17% of male graduates. Unfortunately, there is no information available that sustains the hypothesis that also girls with disabilities have increasingly more opportunities to obtain their high school diploma or university degree.

Employment

"In Italy, job inclusion regulated by Law n.68 of 12th March 1999, still implies serious problems for women with disabilities, who, when starting a job, lack the necessary competences due to their discriminatory education; not forgetting the prejudice of the labour world towards people with disabilities and women in general, considered as failures, as passive and dependent individuals. The lack of job opportunities and financial possibilities is typical for women with disabilities, exposed to higher risks of economic poverty and lack of social relationships.

As we said before, people with disabilities and women must face a lot of obstacles in their fight for equal opportunities and they continue to endure *serious discrimination. But the double discrimination (due to gender and disability) experienced by women with disabilities show they have been ignored both by the movement of people with disabilities and by the feminist movement.*

Only in the last decade have there been serious efforts to identify and understand the forces that mould their lives. These attempts mainly concentrated on how the condition of being a woman and having a disability can interact, and on how women with disabilities see and live their experiences. But today they still belong to the most vulnerable, the most isolated and the most discriminated groups of society. Therefore it is necessary to develop a major understanding of their lives to remove the remaining obstacles in order to obtain their complete inclusion and participation and to guarantee their equal opportunities, total freedom and the right to self-determination."[18]

Among people with disabilities only 2% of women are employed cf. 7.7% of the men, an analogous situation can be found among people without disability, 33% are employed women and 58.2% are men.

Age is a differentiating factor: among persons with disability between 15 and 44 years old, 15.5% are employed women and 29.4% are men. When we take into consideration the age group between 45 and 64, 6.6% are employed women and 20.8% are men. The generations of young people with disabilities and most of all women seem to benefit more from employment integration policies than the elderly.

Gender difference seems to be irrelevant as regards the search for a job, if one refers to the age group that ranges from 15 to 44 years old: in fact, 13% of disabled women and 13.1% of men are looking for a job.

The presence of a disability doesn't seem to affect the choice of being a housewife: 33.1% of women with disabilities claim to be housewives, in comparison to 30% of women without disability.

---

[18] Peer Counselling Handbook "From victims of history to protagonists of life", by Rita Barbuto, Vincenza Ferrarese, Giampiero Griffo, Emilia Napolitano, Gianna Spinuso, Comunità Ed., p. 40.

Access to the labour market for persons with disability is very difficult; 82% of them only have their pension as a source of income, compared to 25% of people without disability. 82% of women with disability receive a pension and 83% of men. The gender factor considerably affects economic independence; in fact, only 2% of women with disabilities has income from employment compared to 6.4% of men with disabilities.

To shed light on the job situation in Italy of women with disabilities, we will give you a table taken from the *III Report to Parliament on the state of the implementation of Law n. 68 of 12th March 1999 "Rules for the right to employment of the disabled"* of the year 2004-2005.

Italian population in active (productive) age and disabled people between 15 and 64 years of age, classified according to geographical area. Absolute values in thousands - Year 2005[19]

	Population in active age			*Population in active age with disability*		
Geographical areas	*Persons*	*%*	*% women*	*Persons*	*%*	*% women*
North –West	9 324	26.8	46.8	144	27.4	38.8
North-East	6 655	19.1	46.7	88	16.7	42.4
Centre	6 585	18.9	47.5	101	19.3	53.5
South and Isles	12 215	35.1	48.4	193	36.6	44
Italy	34 779	100	47.5	526	100	44.1

The breakdown by gender shows some interesting differences between the whole population and the population with disabilities; while the percentage of women in their productive age is 47.5% (more or less the same for all geographical areas), the percentage of women with disabilities in their productive age is 44.1% on a national level, but in Central Italy we notice a different trend with a percentage of 53.5%, higher than the male percentage.

As regards the registration on single lists, in 2004 there were about 15 000 more men with disabilities registered than women with disabilities. In 2005 there

---

[19] Indagine ISFOL-PLUS 2005.

were about 10 000 more women registered on the special lists than men. This phenomenon can be connected to a general increase in registration for both sexes. In short, in 2005, in all, 645 220 persons were registered on the special lists, 91.4% were people with disabilities, almost equally divided between men (49.6%) and women (50.4%).

From the interpretation of the available information another delicate question emerges, namely the so-called “double discrimination”. Disabled women, victims of this double discrimination, are extremely penalised when talking about job introduction: in none of the Italian regions the percentage of women with disabilities introduced on the job market is higher than that of men. In short, even if we notice a general upward trend, in this case gender differences are more obvious compared to the general phenomenon of the registrations.

Both in 2004 and 2005, the number of men with disabilities introduced on the job market, by numerical or nominative employment or by convention, is much higher than that of women with disabilities. This difference is more or less repeated in the next year, in spite of the general increase of the job introduction phenomenon.

We will show you the situation according to gender on a regional level regarding the registration and job introduction problems in the year 2005. In twelve Italian Regions (Abruzzi, the autonomous Province of Bolzano, Calabria, Emilia Romagna, Friuli Venetia Julia, Lazio, Molise, Piedmont, Tuscany, Umbria and Valle d’Aosta) there are more women with disabilities registered than men with disabilities. The largest discrepancy between men and women can be found in Lazio, where there are 8 000 more female registrations than male ones, and in Calabria, where there are 5 000 more women registered than men. In the other regions there are only minor differences.

Despite this picture, in no Region, except for Emilia Romagna and Lombardy, is the number of women introduced on the job market higher than that of men. The introduction of women normally happens in companies that are compelled by law to employ people with disabilities. Those that are not obliged continue to employ mostly men with a wide difference in Calabria and Lombardy. Tuscany is an exception; it is the only region where the female introduction on the labour market outnumbers the male, even if only by seven cases.

Comparing the information at our disposal regarding the period from 2004 to 2005, we notice that the female enrolment on the single lists is increasing, even if there is a slight drop in Lazio, Marche, Molise and Sicily. In any case, for this two years' period, Sicily is confirmed as the region that has the highest number of women with disabilities enrolled. In the same period, the biggest increase was registered in Puglia with about 5 000 more enrolments.

To conclude, in 50% of the Italian Regions women with disabilities are the largest group enrolled on the single lists. There is, however, a discrepancy between the huge number of women with disabilities willing to work and their actual introduction to the job market. The introduction of women in companies that have no obligation is largely inferior to that of men, even though there is a slight increase. This gender disparity introduces further suggestions to reflect on and evaluate the existence and consistency of the double discrimination theme.

Social Life

To understand the social life of women with disabilities in Italy better, we need to start from the paradigm that there is a close link between people, their autonomy and independence, the need for self determination, and society, inside of which, in theory, everyone can be independent in a network of relationships. This possible link contains a lot of obstacles and limitations for people with disabilities since, despite a paradoxically avant-garde legislation, cultural and social attitude still give them only separate answers that violate their rights of citizenship as well as their Human Rights.

Living in conditions of equal opportunities is only possible in a society where everyone lives together with other citizens. Only an inter-independent life, only the inter-relationship between persons with different disabilities and abilities, only a society that allows a person with disabilities to compete on the same level as the other citizens in order to create solutions for a collective life, can guarantee that people with disabilities are born, grow up, procreate and live together with others. This means overcoming the standardisation and the normalisation imposed on the citizens by the industrialised and post-industrialised societies and introducing a diverse normality and allow it to subsist: a society where normality is diversity and diversity is normality.

Today, Italy, except for some happy places in the northern and central Regions, is characterised by an insufficient attention and lack of specific services for independent living for people with disabilities and for the inadequate accessibility of our cities, public transport and all cultural contexts. As results from the data at our disposal, the insufficient attention paid by Public Institutions to the needs of people with disability is compensated by their family and friends. There is not a big difference between people with disabilities (49.9%) and people without disabilities (56.8%) as regards their contact with relatives and friends. But these data change if you take in consideration the gender and age factors. To elucidate it, please observe the following tables:

Age	*Women with disability*	*Men with disability*
15 - 44 years old	34.7%	28.4%
Over 65	47.7%	54.9%.

From the data at our disposal we have the following numbers regarding the degree of satisfaction that people with disabilities receive from their family relationships:

	Women with disability	*Men with disability*
Satisfaction from family relationships	30.3%	30.5%

	Persons with disability	*Persons without disability*
Satisfaction from family relationships	30.4%	34.6%

Regarding the degree of satisfaction from friendships the following table shows:

	Persons with disability	*Persons without disability*
Satisfaction from friendship relations	15.6%	25.6%

Participating in social life means being able to participate in cultural and sports activities in the same way as any other citizen. If we refer to the participation of people with disabilities in sports activities the data at our disposal show us that the disability factor affects more than the gender factor. If we consider the age group from 6 to 44 years the situation is the following: 55.9% of men with disabilities and 47.4% of women with disability practice sport activities. These numbers increase when we consider people without disabilities: 80.6% of men and 76.7% of women.

Marital Status

To evaluate the family condition of people correctly we need to consider alongside the presence of disability also age and gender.

It is more difficult for men with disability to modify their marital status than it is for women, especially when they are young: 82% of men with disability between 15 and 44 are single as opposed to 75.5% of single women with disability. These percentages diminish growing older, in the age group of 45 to 64, 23.9% of disabled men are unmarried whereas 18.8% of women with disability are single. Over 65 there is a reversal; 7.5% of men are unmarried against 9.5% of women.

Separation and divorce are slightly more diffused among women with disabilities compared to men that live in the same condition. If we consider, for example, the age group from 45 to 64, 3.4% of women separate or get a divorce compared to 3.1% of men; looking at people without disabilities, these figures are 3.7% for women and 3.1% for men.

Even if there are more widows than widowers, the difference becomes bigger if we consider the presence of disability. 14.5% of women with disabilities between 45 and 64 years old are widows against 1.8% of widowers. If we consider the over 65 age group the differences become even greater: 65% of women with disabilities are widows whereas there are only 21% of widowers with disabilities.

We must also add to this the fact that 36.9% of women with disability live alone compared to 13.2% of men.

Health

The medical model sees disability as a problem of the person, directly caused by illness, trauma or other health conditions that need medical assistance under the form of individual treatments carried out by experts. The intervention aims to cure disability and, when this is not possible, to change the individual's behaviour so that he/she adapts him/herself to the environment as it is. Medical assistance is a priority and on a political level the main solution is to modify or reform the policies of health assistance instead of creating services that answer the social and cultural needs of the persons.

The bio-psycho-social model makes it clear to almost everyone that society produces handicap and therefore we must consider human health in its diverse dimensions: biological, psychological and social. But despite all this, the disabled person's image of his own state of health is still very much influenced by the medical model. In fact, only 8.6% of people with disabilities say they feel well or very well, against 61.3% of people without disability. There are no significant differences between the sexes: 7.3% of women with disability feel well or very well against 10, and 7% of men.

The increase of this negative perception of one's state of health is linked, besides being related to the presence of disability, to the ageing process: 26.4% of people with disabilities between 6 and 44 years old say they feel bad or very bad; between 45 and 64 this augments to 56.9%; over 65 years old 61.7% of people with disabilities have a negative perception of their state of health associable to subjective factors (more vulnerability, solitude, etc.) and to objective factors (ageing, emergence of chronic pathologies, etc.).

Even the differences recorded regarding the degree of satisfaction about one's state of health seem mostly to be linked to the condition of disability rather than to gender. People with disabilities, both men and women, have more or less the same degree of satisfaction about their state of health; 30.6% of men and 24.9% of women declare themselves satisfied.

Often people with disability don't have access to health services because investing the already scarce resources for them is regarded as useless.

From the data we have consulted, it seems that in Italy in this sector as well there is no relevance given to gender. If in the world women with disabilities are the most disadvantaged as regards access to treatment, especially in developing countries, when a girl or a woman is ill it happens that they are not given the right cures, an untreated earache for example can lead to deafness. Despite the lack of specific information that might support this affirmation, the same happens in Italy; in fact, direct contacts and exchanges tell us that women and girls with disabilities must face many barriers when they need medical care. Very often their needs and specific problems, as for example maternity and gynaecology, are not included in ordinary care programmes. Moreover, we have no information whatsoever about informative campaigns on sexuality, birth control, prevention of sexually transmitted diseases, breast cancer or cancer of the womb organised for them. Nor do we have any information, except for some informative campaigns organised by associations of people with disabilities, on whether official health campaigns have given special attention to other forms of communication as sign language, Braille, etc, or information campaigns that use a language suitable for women with learning difficulties or mental disabilities.

Another painful topic in Italy is the inadequateness of diagnostic instruments, of accessibility to health institutions and incompetence of the medical staff when treating the specific needs of women with disabilities.

Going deeper into the ethical and bioethical issues, we know that women with disabilities are widely discriminated in the world; in fact, they undergo sterilisation, hysterectomy and abortions often without their consent. It is true that in Italy practices such as sterilisation, hysterectomy and euthanasia are illegal and culturally unacceptable, but we have no information that rules out whether they are not actually carried out.

Surely we can say that in Italy there is no specific economic, social and technological support in favour of women with disabilities. We know for sure that today in Italy there are no environmental conditions, environment in the broad sense of the word, that guarantee women with disabilities a good quality of life. We are aware that the quality of life, of everyone and in particular of women with disabilities, doesn't depend solely on a subjective and individual condition but on a network of relationships and support that society offers them. In this situation women with disability are often disheartened by a complete lack of relationships and affections which may lead to a loss of motivation to live. Is this perhaps the condition of the Italian women with disabilities? We can't verify this because as we already wrote before we don't have information.

Violence and Abuse

The risk of physical and sexual violence is very high for women with disabilities, the risk percentage doubles compared to those that don't have this condition. They are seen as an "easy target". Studies carried out in industrialised countries show that between 39% and 68% of girls and 16% to 30% of girls with a mental retardation are sexually abused before their eighteenth birthday[20].Women with psychiatric disabilities or those that live in institutes are also at risk of violence or abuse. Even if a woman succeeds in escaping from a violent situation there are only a few accessible anti-violence centres.

In Italy none of the laws in favour of women refers to women with disabilities. Despite the fact that women with disabilities are more exposed to violence of a sexual, physical and psychological nature there is no reference to them in the *Law n° 66* of 15th February 1996 "*Rules against sexual violence*". We can hypothesise that the lack of legislative reference forms the basis for a complete absence of information regarding violence and abuses suffered by women with disabilities in Italy. Even in the last report "*Violence and maltreatment against women*" commissioned by the Ministry for Rights and Equal Opportunities and

---

[20] Sobsey, 1994, as reported in Reynolds, 1997 cited in Rousso 2000.

carried out by Istat, based on the results of research on the safety of women, carried out from January till October 2007, there is no information regarding women with disabilities.

The non-existence of data doesn't mean that the phenomenon doesn't exist. On the contrary, it means that it is an extensive and complex phenomenon that should be examined, because knowing more about it is essential for the development, institutionally, of the policies and services needed to address the problem. In fact we believe that the lack of policies and services in favour of women with disabilities is at the base of the countless episodes of violence they have to endure without reporting them. How can they accuse their tormenter if they depend on him for their survival? How can a woman with disabilities who suffers sexual, physical and psychological violence accuse the relative she depends on to eat, get up, wash and go to the toilet if she has no economic independence to have her own house? How can she react if she doesn't understand that the denigrations, the control over her behaviour, the isolation strategies, the intimidations, the economic limitations inflicted on her by her relative violate her Human Rights? How can she report the assistant she depends on to satisfy her primary needs, if she is not aware of the violence he is imposing on her, meaning if she doesn't understand that being jerked, pushed or hit is a violence? How can she denounce an institute/home she turned to in the hope of finding protection and a welcome?

Reflections and Proposals

Thanks to the recent approval of the "*International Convention on the Rights of People with Disabilities*", by the UN, August 2006, women with disabilities can, in one way or another, start to feel a bit more protected on a legislative level.

The Convention represents the finish line of a growing process, which started some decades ago, of people with disabilities and societies that have become aware of what the condition of disability implies, experienced personally or by institutions that offer services.

Contemporarily, however, the Convention also represents the starting point for a growing process that is still to happen, because even though every day we fight to remove discrimination against us, in many contexts a lot of primary services for our daily life, such as for example personal assistance, aren't yet guaranteed. As regards women with disabilities, the preamble and articles 3, 6, 8, 16 and 28 show the increase of their awareness of the double discrimination they suffer daily, as women and as disabled persons, their awareness of the lack of visibility and equal opportunities compared to women in general and men with disabilities in such a way as to emancipate and claim their rights.

At present, women with disabilities are trying to conquer their space inside the different social contexts analysed in the previous paragraph, but much is still to be done.

The States that have signed the convention recognise the fact that women and girls with disabilities are the subject of multiple discrimination and they will implement measures aimed at their empowerment and sensitive to the gender issue, to ensure the full and equal enjoyment of all human rights and fundamental freedoms by women and girls with disabilities.

Following a suggestion from DPI Italy, a working group was created "disability from the gender point of view" inside the Italian Federation to overcome Handicap (FISH), political spokesman of the Italian government. The group is also supported by the Italian National Council on disability (CND). At the moment the group is composed of 19 women coming from different associations belonging to FISH and coordinated by (DPI Italia) and Anna Petrone (FISH). They intend to work on two types of actions:

Empowerment of women with disabilities

The group of women wants to dwell on the question of gender linked to disability, reflect on their rights and emancipate from their disadvantageous condition of double discrimination. Through empowerment processes the woman with disabilities learns to evaluate herself for what she really is and to realise that disability doesn't cancel her right to a happy life of quality. However, she has to work on important themes for her psychological growth, such as for example her relationship with her body, her self respect, being proud of being a woman, accepting her sexuality, the right to motherhood, to employment, to a wider social participation, to receive personal assistance as an essential condition to be able to plan an autonomous, independent and self determined life.

This means activating a process that is not easy or pleasant, both for women with disabilities that have to conquer their place in society and for society that has to redefine its standards and recognise those that have always been given in a passive role as productive people. The group will also work for those women that cannot represent themselves alone.

A good practice for empowerment: Peer counselling

In promoting the culture of disability DPI Italy starts from the paradigm that non discrimination and equal opportunities are at the base of the respect for the Human Rights of people with disabilities. Every non justified special treatment, every social and/or material disadvantage a person with disability has to face due to the lack of inclusion of his specific needs in policies and in ordinary services, represents a violation of his Human Rights.

In its job of cultural promotion, DPI Italy Onlus tends to enhance the value of disability as an ordinary human diversity, and favour the relationship of inter-independence and reciprocity of the growing processes of every person on various levels: natural, human, civil, cultural and environmental. It gives special attention to people with disability as persons and to their empowerment process through which they are “empowered” and they can strengthen their capacity and possibility to regain their personal resources and take control over their lives.

After having verified the need to develop empowerment processes, DPI Italy has structured a methodology and created a new practice, namely individual and/or group Peer Counselling. This methodology is based on a help relationship between two or more persons with disabilities that allows those that want to start or strengthen an emancipation process away from disadvantage, to face fears and personal limits as well as objective problems, identifying the most adequate solutions and attitudes to realise personal life projects.

When DPI Italy started with the activity of Peer Counselling, we found ourselves surrounded by women, even though this was not what we had intended. Afterwards we verified the same situation elsewhere, in Italy and abroad, where the experience started and developed in an exclusively female universe. Surely, this is not just a single case. The main elements of Peer Counselling belong to women, for example: putting the inter-personal relationship central, sharing experiences, listening, taking care of the person, paying attention to the dimensions of the body and imagination. There is a strong link between Peer Counselling and the female world.

DPI Italia strongly believes in Peer Counselling as a methodology and human experience because it recognises it as an efficient instrument for people with disabilities, and more specifically for women, that allows them to break down the wall of silence around them and to destroy the label of “transparent visibility” given to them by those that surround them.

Mediation with the Government on the theme of female disability

FISH, being the political spokesman of the Italian government regarding the theme of disability, represents the needs of the working group of women with disabilities to participate actively in equal opportunities policies and in national, regional and provincial programmes in order to activate inclusive actions.

The group sets the following objectives:

- Promote training activities (peer counselling seminars, self-help groups, etc) and information addressed to women with disabilities from the network of associations belonging to FISH and others, to make them become aware of their abilities and possibilities to play an active role inside the Federation, following the equal opportunity philosophy;

- Implement awareness raising processes, innovative policies and services to favour equal opportunities for women with disabilities and respect for their Human Rights, with special attention to the gender issues and the double discrimination of women and girls with disabilities, for the year 2007, proclaimed “the European Year for the Equal Opportunities of everyone” by the European Union;
- Gather information and follow the monitoring of the CEDAW, the *Convention on the Elimination of Discrimination against women (*UNO, 18th December 1979);
- Support the necessary lobby actions until national Governments and their delegates ratify the Convention;
- Take action to bring about a legal and legislative framework on a national, regional and local level to guarantee the measures needed to achieve the objective of full participation and equality for women and girls with disability. In particular, affirm the need to issue a law that protects the rights of women and girls with disabilities in case of abuse and sexual violence inside and outside their homes. Specific attention should be given to women with disabilities who can not represent themselves;
- Take action to guarantee adequate resources on a national, regional and local level for the diffusion of services aimed at overcoming multiple discrimination due to gender and disability. Services such as: personal assistance, mobility services, rehabilitation, health services, education, training and employment, independent living and social security;
- Guarantee that the Ministry of Equal Opportunities and all other bodies in charge of gender issues on a national, regional and local level, provide for the inclusion of women with disability and their increase in every field of political and social life;
- Ask the Government and other bodies in charge (Ministry of Equal opportunities, Department of Equal Opportunities, Councillors in charge of equality on a national, regional and provincial level, etc) for the creation of an Observatory of disabled women.

LATVIA

THE LATVIAN UMBRELLA BODY FOR DISABILITY ORGANISATIONS (SUSTENTO)
DELEGATES: ILZE LAINE AND GUNTA ANCA

General Situation in the Field of Gender Equality in Latvia

Legal framework on gender equality issues

The *Constitution of the Republic of Latvia* has no special provisions regarding gender equality; however, it is considered that article 91 of part 8 guarantees gender equality. The article prescribes that "*all people in Latvia shall be equal in front of the law and court*", and that "*human rights shall be exercised without any discrimination*". The Constitution provides for equal rights to vote and be elected. Latvia has had a woman as the country's president since 1999.

Latvia has ratified the majority of the international human rights agreements since the restoration of independence. The most important of these include the *Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Social and Economic Rights (ICSER), the International Convention on the Elimination of all Forms of Racial Discrimination (CERD), the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR*), and *the European Social Charter (ESC)*. Specifically in the field of women's rights, the *International Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)* was also ratified by Latvia in 1992; however, the *Optional Protocol* to CEDAW is yet to be ratified. Neither has Latvia yet ratified the Protocol 12 to ECHR, prohibiting discrimination, nor has it ratified the *Council of Europe's Framework Convention for the Protection of National Minorities*.

The *Law on Labour Protection* came into force on 1 January 2002 and the new *Labour Code* on 1 June 2002. The requirements of European Union Directives in the field of equal treatment are incorporated in these laws. It is necessary to raise awareness and understanding on equal treatment, which is essential for social partners. Although specific articles in the *Latvia Labour Code* focus on the gender aspect, measures should be undertaken to ensure that the above norms stimulate *de facto* equality in the economic as well as other areas of life.

Figures on Gender Equality in Latvia in general

Some basic indicators:

Life expectancy

Life expectancy in Latvia is marked by gender differences: the projected life expectancy in 2005 for females is 77.2 years, for males 67.1.

Female/Male economic activity rate

Economic activity of women in 2005 in the age group 15-64 was 65.0 % and of men 74.3%.

Salary gap

Over the period since 1995 the gender pay gap has decreased - with female salaries being 78.5% of male salaries and 84.4% in 2005.

Rate of employed persons and monthly average gross wages and salary by sex and kind of activity, 2005
Sex distribution by employment sector

Type of activity	*Rate of employed persons (annual average)*		*Monthly average gross and wages salary, LVL*		*Female salary as % of male salary*
	Females (%)	*Males (%)*	*Females (%)*	*Males (%)*	
Industry	42	58	180	234	77
Transport, storage and telecommunications	30	70	236	282	84
Financial intermediation	62	38	443	871	51
Education	81	19	222	242	92
Health and social work	85	15	203	231	88

Source: Central Statistical Bureau, Statistical yearbook of Latvia 2005.
Employed population aged 15 –74 years in main jobs by sex and by occupation, 2005.

The labour market in Latvia is not friendly for women. EU official information testifies that employment indicators compared between genders show different attitudes towards men and women, differences in working conditions, in salary and lower remuneration for the same job, although legislation prohibits gender-based discrimination.

	Women (%)	*Men (%)*
Legislators, senior officials and managers	42	58
Professionals	66	34
Technicians and associate professionals	64	36
Clerks	77	23
Service workers, shops and market workers	74	26
Skilled agriculture and fishery workers	44	56
Craft and related trade workers	17	73
Plant and machine operators and assemblers	18	82
Elementary occupations	48	52
Total	49	51

Source: Labour force survey: main indicators in 2005.

Statistical data from Latvia shows that women's remuneration is on average 19.5% lower than men's, women are more often employed in occupations with lower remuneration and more likely to work only part time, which means less social tax payment and a lower old age pension later in life.

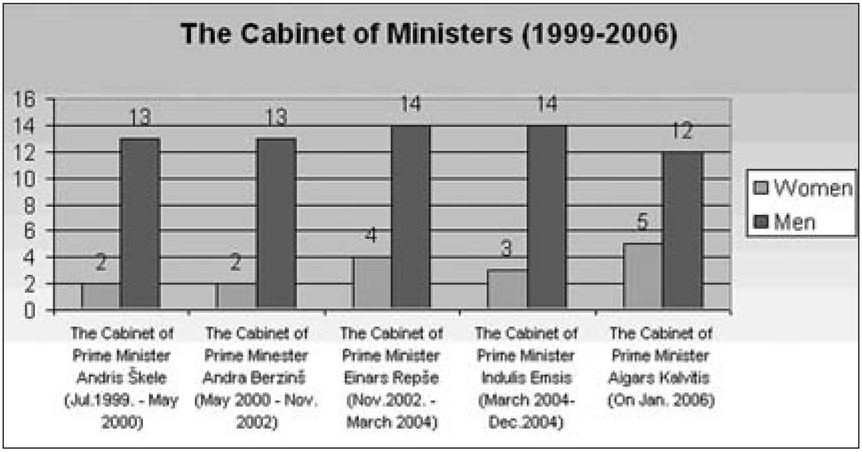
Graduates from universities by level:

2005/2006	*Women, %*	*Men, %*
Bachelor's Studies	65	35
Master's Studies	68	32
Doctoral Studies	59	41

Source: Source: Central Statistical Bureau of Latvia, 2006.

Political representation

The right of both genders to vote and be elected was recognized in Latvia back in 1918. However, politics is one of the areas where the gender equality principle is not honoured *de facto.* Since the restoration of independence among deputies of the Saeima (Parliament members) women compose approximately 8% - 20%. Likewise, in the Cabinet of Ministers there is a constant pronounced gender disproportion:



Representation in Local Government

Among those elected there were 42.3% women and 57.7% men in the local government elections on March 2005. At the same time women form only 18% of the elected members in city councils. Looked upon from a vertical power perspective, only 23% of mayors are female.

Representation in the Civil Service

While there are more women (71%) than men (29%), senior decision-making positions are most frequently held by men while women are more often delegated the role of deputies, substitutes and executors of decisions. The low participation of women in politics is related to the political culture and long traditions in Latvia, where politicians is perceived as a male field of action.

Women and men in the State administration		
Position	*Women (%)*	*Men (%)*
State Secretary, Director of State chancellery, director of Secretariat of the Special Assignments	56%	44%
Deputy State secretary, Deputy director of State chancellery, Deputy director of Secretariat of the Special Assignments	41%	59%
Director of department	71%	29%
Deputy director of department	68%	32%
Specialists	72%	28%
Total	71%	29%

Decision making

Significant gender disproportion can be observed also in other positions and levels where decisions are made (e.g. public agencies, executive positions in large enterprises) where the representation of women is low. The share of women among entrepreneurs/business people is still quite low - only 1.5% of the total number of employed women are employers (men – 4.8%). The number of women employers (owners) has increased to 2.3 % in 2005 (among men – 4.8%).

Maternity, paternity and child-care leave

Maternity leave

Maternity benefit is provided 56 days before and 56 days after expected childbirth. Maternity benefit shall be allocated in the amount of 100 % of the woman's average insurance contribution payment salary that is calculated from six month's income.

Paternity leave

Fathers are entitled to 10 days leave to be taken before the baby has reached the age of 3 months. Paternity leave benefit is 80% of the father's previous salary.

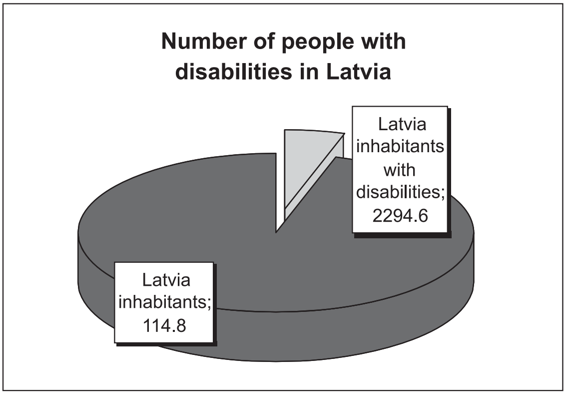
Child-care leave

Starting from 1 January 2005, a new policy has been introduced which entitles one of the parents up to the child's 1st birthday to receive a benefit amounting of 70% of that person's previous salary (meaning his/her former income after tax). For employees this means not less than 56 Lats and no more than 392 Lats per month, while for non-employees it is 50 Lats per month, and up to the child's 2nd birthday 30 Lats per month. People who choose to work during parental leave are entitled to receive 50% of the benefit.

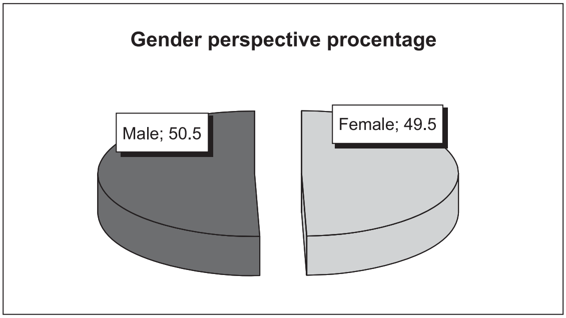
The Central Statistical Office provides information that in 29% of families (so called one-parent families) women are the only providers and carers for children. These are mostly women who provide care for sick, disabled and elderly family members, doing unpaid jobs at home.

Women with Disabilities in Latvia

With an area of 64 589 square kilometres, Latvia is approximately one and a half times the size of Denmark. As for population, Latvia has 2.5 million inhabitants, which gives the country a population density of 38.7 cap/km2. There are about 114 000 people with disabilities in Latvia.



The Latvian Umbrella Body for Disability organisations does not have a specific women's committee, but all issues concerning gender equality are raised in cooperation with our member organisation Latvia Association of Disabled Women "Aspazija" (LADW "Aspazija").



LADW “Aspazija” was founded in April 1998. The goal of the Association is to give support to women with disabilities to obtain an equal status in society as well as to protect their interests and rights.

To achieve this goal, the Association has decided to operate in several directions:

- To promote the protection of the social and legal interests of members;
- To provide information and education for disabled women;
- To supply disabled women with psychological and moral support;
- In case of emergency, to offer assistance to the family of a disabled women;
- To promote the improvement of legislation in the Republic of Latvia regarding the condition of disabled people in society;
- To organize cultural activities;
- To draw attention to the problem of disabled women through mass media;
- To organize its own information and education issues;
- To cooperate with the state, local municipalities and NGOs, as well as with other physical persons, both within the Republic of Latvia and abroad, that would contribute to a successful implementation of the objectives of the Association.

Our mission:

To absorb the light in you and then help it reach others – education, integration, peer support.

Aim:

To enable and support women with disabilities obtain an equal status in society and to protect their interests and rights.

Tasks:

- To provide information and education for women with disabilities;
- To provide psychological and moral support for women with disabilities;
- To co-operate with the State, local municipalities and NGOs, as well as with similar overseas organizations;
- To promote the protection of the social and legal interests of members.

LADW “Aspazija” has 10 branches in Latvia and a total of 500 members; the board of our organization has 5 members. The goal of the association is to unite women from all over Latvia for active cooperation to realize and solve their problems, to help them become equal members of society, as well as to protect their interests and rights and to encourage cooperation among its members.

The association has begun its activities in several regions of Latvia, setting up regional branches. We have organized many seminars for disabled women in Riga and the suburbs. We also try to involve disabled women in our organization as much as possible. We develop the work of our organization and try to make it wider. Working actively within the organization, disabled women will grasp what an NGO movement means, what possibilities it gives, and what should be known to join this movement.

“Aspazija” is a member of several umbrella organizations and coalitions in Latvia:

- Cooperation Council for Latvian Women’s Organizations.
- SUSTENTO – the Latvian Umbrella Body for Disability Organizations, where there is one representative from LADW “Aspazija”.

By joining together, women with disabilities also can make their voice louder and influence political development in their own country.

Disabled women in Latvia suffer triple discrimination – due to their disability, their gender and their economic status. It is the most fragile group in society, and it is very important to strengthen and empower women with disabilities.

There are environmental, psychological and a lot of other obstacles which make the process of integration of disabled women in society very hard. Mostly these are concerned with low level of awareness in our society about possible solutions. Our experience shows us that one of the most important things to promote inclusion in society is useful and available information. Disabled women have a lot of obstacles at the present time:

- Problems of local people and stereotypes regarding people with disabilities and disability;
- Low level of communication skills among disabled people;
- Low level of employment among disabled people;
- Low level of education.

The main obstacle if you become disabled is if the husband leaves the family and the disabled woman remains without income and alone with her children and her problems. To solve partially such problems LADW "Aspazija" has developed some EU, local and international projects:

Main projects:

- Support for more efficient management of the Association "Aspazija"- supported by NGO Centre;
- "Improving our Empowerment Tools" – PHARE TACIS support programme;
- "Support Centre for Women with Disabilities in Latvia" – Queen Juliana Foundation support programme;
- "Developing Entrepreneurship among Women with Disabilities in the Baltic States – exploratory survey in Latvia" – ILO Disability Programme, 2003;
- ESF project "Disabled Women on the Way to Business", 2005;
- ESF project "Disabled Women's Motivation for the Future", 2007.

We are working on specific legislation for our target group in close contact with our umbrella organizations – the Cooperation Council for Latvian Women's

Organizations and SUSTENTO – the Latvian Umbrella Body for Disability Organizations.

Every year LADW “Aspazija” organizes a two-day forum involving all the branches and addressing different and real problems for disabled women, where we invite national and local authorities to participate.

LITHUANIA

LITHUANIAN NATIONAL FORUM OF THE DISABLED (LNF)
DELEGATE: EVELINA GRICIUTE

The *Constitution of the Republic of Lithuania* guarantees a wide spectrum of civil, political, social, economic and cultural rights that protect human dignity and secure —for every Lithuanian— freedom, security and equal opportunities for personal development. Seeking to implement those constitutional goals, Lithuania became a party to various human rights treaties, adopted various legislative acts and created a number of institutions for this purpose. However, despite The Constitution, the Law on Equal Opportunities for Women and Men and other legislation measures, discrimination against disabled women still exists.

The exact number of disabled women is not monitored in Lithuania, so usually it is discussed like two different but close discriminations forms; discrimination of disabled and discrimination of women. The situation of disabled women in Lithuania is still affected by historical factor: for more than 50 years Lithuania was occupied by Soviet Union. In this ideology nobody was interested in disabled women and their problems. This approach appears nowadays too. During 17 years of independence, human (including women's) rights enhancement and protection were never a rational State policy, but rather a side result of more important political goals. Many concrete measures advancing protection of human rights (enactment of legislative acts, ratification of international agreements, and establishment of institutions) were often adopted due to pressure from international institutions to which membership was being sought.

In the last few years there have been some noticeable optimistic aspects in terms of achievements related to measures which are conditions for the equal treatment of men and women. First of all, these changes concern the formulation of equal opportunity legislation and new instutions fighting for women's rights (for example the Ombudsman for Equal Opportunities and women's committees in trade unions) in Lithuania.

National governments in Lithuania clearly manifest political preferences for the 'integrationist' approach to gender equality policies and gender mainstreaming. In the last months the Government approved the Fourth Report from the Ministry of Social Security and Labour on the implementation of the *UN Convention on the Elimination of All Forms of Discrimination against Women* in Lithuania. The Report provides information about the implementation of equal rights for women and men in the areas of employment, education and social security; the status of women in rural areas, their life and work conditions; opportunities for women to develop business; opportunities for women and men to participate in political, cultural and social activities; reduction of violence against women and support for women who are victims of violence; combating trafficking in women; elimination of traditional stereotypes, opportunities to combine family and work responsibilities and other issues of gender equality. The report also reviews the most recent legislation, programmes, tools, and projects of all ministries, the Office of Equal Opportunities Ombudsperson and other institutions and organisations implemented since the end of 2004 till the beginning of 2007, as well as examples of good practice in women's non-governmental organisations participating in the implementation of different programmes and tools.

Despite some positive changes in Lithuania, there are many aspects which should be modified. According to statistics from last year, women still experienced inadequate access to work and support programmes. Their economic leverage is weakened. Insufficient measures were undertaken to address sexual harassment problem, exploitation of women, human trafficking, domestic violence, discrimination based on marital status, and difficulties faced in combining work and family.

One of the areas where discrimination exists against women is the labour market. Women's right to work is not guaranteed adequately. Whilst the number of registered unemployed persons is declining, the ratio of women therein is growing. The number of women registered as unemployed grew from 57% in 2005 to 62% in 2007. Differences in the average wage of men and women in Lithuania are greater than in other Member States of the European Union. Men earn more than women; even in spheres predominated by women. Generally this difference is about 18%; in some sectors, such as financial services, women are paid 51% of men's wages.

Accordingly, women face a higher risk of discrimination in the labour market, despite a prohibition on gender discrimination by the *Law on Equal Opportunities for Women and Men*. Lithuania is not promoting a family model of two breadwinners, either. A study carried out by the Vytautas Magnus University indicated that women 'pay more' for the possibility to have a family. They also face more stress trying to combine private and professional lives. Discriminatory practices especially are targeted at young women who enter the labour market, and women of pre-retirement age are particularly vulnerable to recruitment into part-time jobs and to impoverishment. The main forms of discrimination against women in the labour market include discrimination by age, difference in salary (men's salaries are 1.4 times higher than women's), inequality in management positions, and discrimination against young women returning from maternity leave. Discrimination is especially common in the private sector where employers offer short-term contracts to young women as well as casual work to avoid maternity and childcare costs. On the other hand, employment of women has already exceeded the Lisbon Strategy goal for 2010 and was 62.2% in the second quarter of 2007. According to the difference between the level of employment of women and men (5.6%) Lithuania stands fourth in the EU.

Sexual harassment in Lithuania is regarded ambiguously. On the one hand, the majority of society opposes and condemns sexual harassment at work. On the other hand, women faced with the problem of sexual harassment are unwilling to take legal action due to fear of condemnation and humiliation. They often turn to psychologists for help; a small number decide to initiate legal proceedings, of which the outcome is largely ineffective.

The *State Strategy on Fighting Violence against Women for 2007–2009* is a positive development. The strategy envisions allocation of resources to NGOs assisting abused women, improvements in the legal framework, and introduction of effective penalties. It is important that the goals set forth in the strategy are implemented effectively in practice.

Lithuania is one of the leading European countries in human, essentially women, trafficking. Every year approximately 1 000 to 1 200 women leave the country for or are sold into sex slavery. Lithuania remains a country of transit and a destination for human trafficking. Women trapped in human trafficking express feelings of insecurity. They often refuse to testify in court, which inadvertently creates favourable conditions for the continuous development of human trafficking. It is essential, therefore, to create a safe environment for women to testify in human trafficking cases.

References:

http://www.socmin.lt/index.php?1857649008

http://www.hrmi.lt/images/img/Human_Rights_Overview_Lithuania_2006_20070724Pataisyta.pdf

http://www.gap.lt/gegm

LUXEMBOURG

LUXEMBOURG NATIONAL DISABILITY COUNCIL
INFO - HANDICAP ASBL
ANDRÉE BILTGEN AND EUGÉNIE ENSCH

The situation of disabled women in Luxembourg cannot be seen separately, but has to be considered through the following perception: in fact, Luxembourg is a small country and has a specific migration situation, therefore the necessity to opt for:

- A philosophy “for all”;
- The “mainstream”: namely to sensitize and associate all actors in the field; and
- The “gender-mainstream”: promote actively the elimination of interferences which may exist with regard to equality between women and men. The target of a better quality of life can only be realised by joint efforts and actions involving commitment and confrontation. These keynotes sit perfectly enter with the philosophy “for all” of Info-Handicap, namely the defence of interests of “the disabled person” in the sense of wide collaboration and of common interest.

At the present time we have two situations: on the one hand we have disabled women living independently, on the other hand, the disabled women living in a sheltered institution. Based on our experience, we notice a positive change in the mentality of society (participation/integration) towards disabled persons (women

& men) in general, which consequently generates their increasing presence in society. Nevertheless, we still are seeing a lack of awareness in society as far as the “gender” of a “disabled person” is concerned. No difference is made between the disabled woman and the disabled man; it’s just “a disabled person”. A latent double discrimination against disabled woman persists too (employment, participation in social life).

Statistics, Data

There is no official data in this respect in Luxembourg, due, on the one hand, to the legislation relative to the protection of personal data, and on the other hand to the fact that no studies or statistics were made so far.

Even refugee homes and services for women who have confronted violence don’t dispose of data relative to disabled women.

Quota of Women in Decision-making Bodies

Political Life

In fact, although women (disabled & non-disabled women) represent the majority of the population, there is a lack of women leaders on all levels in the decision-making policy. This situation is not in relation with the importance of the women in society (extremely low rate in Municipality Councils, only one woman out of 21 members of the Council of State). Although the participation of Luxembourgish women in political life is not much developed, the fact that a third of the members of the Government are women shows the will of the political parties to promote the participation of women on this level.

Economic & Associative Life

The same statement as for the political life stands for economic and associative life. Women are under-represented, particularly in most prestigious positions.

Conseil Supérieur des Personnes Handicapées (Higher Council of Disabled persons)

Mrs. Andrée Biltgen is the president of the Higher Council of Disabled Persons. This council is the Government's unique advisory organ for political matters in favour of disabled persons (women & men). The Higher Council's mission has been defined by the Law dated 12.09.2003 relative to disabled persons.

Mission. To assist and advise the minister competent for policies for disabled persons in his coordinating work; To bring together the partners involved; To advise all projects for law or regulations regarding the field of disability; To study all questions and subjects submitted by the minister.

Groupe de travail et de réflexion représentant les femmes ayant un handicap (Working and reflexion group representing women with a disability)

In 2003, the European Year of Disabled Persons, an "ad hoc" committee was created within our organisation Info-Handicap asbl, in order to widen the scope of sensitization and awareness in society, and particularly among non-disabled women, with regard to the problems faced by women with disabilities (cf.: Positive actions of Info-Handicap). This working group still exists and is responsible for specific activities.

The main obstacles disabled women face today (disabled men too) are located on several levels, and, in general, include all kinds of handicaps: physical handicap, blindness, hearing impairment, mental deficiency and psychic problems.

Accessibility

Public transport is hardly accessible: non-existent or difficult access for wheelchairs/announcement of the stopping places by acoustic signs (blindness), visual signs (hearing problems) and pictograms (mental deficiency) hardly exist.

Built environment: The situation is the same with regard to access and signage.

Improvements are going on here and there, but there is still a huge work to be done.

Education and vocational training: reforms are absolutely necessary.

On July 19th, 2007, the Ministry of National Education and Vocational Training submitted 3 draft laws which will, together, reform the 1912 Education Law; there is, furthermore, a project to reform vocational training.

In Luxembourg education for disabled children can be characterized by three important periods:

Law of 10.08.1912, excluding disabled children by discriminatory measures;

Law of 14.03.1973, introducing the educational obligation for all disabled children (special education);

Law of 28.06.1994, promoting the integration in education for disabled children: possibility of a complete integration and partial integration.

Communication and Information

A positive change in the attitude of the citizen towards a diversified society took place. Yet, we have the impression that people with a sensorial disability (new communication technologies should be put into practice more systematically) and a mental disability (approach by pictograms, also with knowledge of the facts that the problem of illiteracy seems progressing all over Europe) are neglected.

The situation of disabled women in everyday life is not much different compared to men with disabilities. The problems occurring are often communication problems and seldom based on bad intention, but more based on the fact of very little occasions, contacts or exchange. A disability is tied to a person's capacities and the context where those capacities should be used. Once this barrier is overcome, often the problems are cleared up.

According to the Higher Council of Disabled Persons, the types of violence a disabled person might face are not much different from the violence that all other person might face. However, a woman with a disability is distinctly more vulnerable, because her possibilities for defence as much as her possibilities of communication are limited. It seems, however, that very subtle forms of violence and aggressiveness are more and more prevalent.

Refugee homes for women in distress have not much experience so far concerning disabled women in general (as far as physical disability is concerned, partly due to the lack of accessible infrastructures - but, accessible rooms are foreseen in their future accommodation projects). Nevertheless, these services for women in distress welcome *all women* and look for mostly adapted solutions by a targeted orientation.

In professional life, there are still inequalities between women and men, as for example: difference in salary and the unemployment rate being higher for disabled women. Furthermore, a latent double discrimination, namely exclusion due to gender and disability.

The measures or solutions that have been taken to tackle the multiple discrimination that women with disabilities face are as follow:

A. Government level:

We want to mention the evolution in the ministry competent for women and for disabled persons: the Minister, one and the same person for all the ministries mentioned.

> 1994 - 1999: Ministre de la Famille + Ministre de la Promotion féminine (women) + Ministre aux Handicapés et Accidentés de la vie (disabled persons) = pronounced attention on specificities

1999 - 2004: Ministre de la Famille, de la Solidarité et de la Jeunesse (competence disabled persons) + Ministre de la Promotion féminine (women) = relation/link

2004 - 2009: Ministre de la Famille et de l'Intégration (competence disabled persons) + Ministre de l'Egalité des chances (women & men) = mainstream

Legislation (specific):

Security and health for working women

- Loi du 26 mai 2000 concernant la protection contre le harcèlement sexuel à l'occasion des relations de travail et portant modification de différentes autres lois (protection against sexual harassment at work)

Discrimination

- Loi du 15 mai 2003 portant approbation de l'amendement au paragraphe 1 de l'art. 20 de la Convention sur l'élimination de toutes les formes de discrimination à l'égard des femmes (additional clause in the convention concerning the elimination of all kinds of discriminations against women)

Violence

- Loi du 8 septembre 2003 sur la violence domestique (law concerning domestic violence)

Equality in treatment & *Centre for equality in treatment*

- *Loi du 28 novembre 2006 concernant la mise en œuvre du principe de l'égalité de traitement*. Le centre a pour mission de promouvoir, d'analyser et de surveiller l'égalité de traitement entre toutes les personnes sans discrimination fondée sur la religion ou les convictions, le handicap, l'âge, l'orientation sexuelle ou l'origine ethnique (the principle of equality in treatment - mission of the centre: promote, analyse and supervise equality in treatment without discrimination based upon religion, handicap, age, sexual orientation and ethnic orgin).

Revision of our Constitution

- Loi du 13 juillet 2006 portant révision de l'article 11, paragraphe 2 de la Constitution, libellé comme suit:

> "*Les femmes et les hommes sont égaux en droits et en devoirs. L'Etat veille à promouvoir activement 'élimination des entraves pouvant exister en matière d'égalité entre femmes et hommes (equality between women and men - rights and duties).*"

- Loi du 29 mars 2007 portant révision du paragraphe (5) la Constitution:

> *"(5) La loi règle quant à ses principes la sécurité sociale, la protection de la santé, les droits des travailleurs, la lutte contre la pauvreté et l'intégration sociale des citoyens atteints d'un handicap" (social security, health protection, rights of workers, fight against poverty and social integration of citizen with a handicap).*

UN Convention on the rights of disabled persons, adopted on 13.12.2006

The Convention on the rights of disabled persons was ratified by the Grand-Duchy of Luxembourg on March 30th, 2007. The aim of this Convention is to promote, to protect and to guarantee the complete and equal entitlement of all the human rights and all the fundamental liberties of disabled persons and to promote respect for their human dignity.

Positive actions by the Government:

- Media campaigns: information & awareness raising relative to equality between women and men;
- Fight against violence towards women & fight against domestic violence (information, awareness raising and detection of the specificity of domestic violence, thematic training modules, intervention network);
- Gendertraining;
- Agreements with employees' bodies attached to the Ministry of Family and Integration and the Ministry for Equal opportunities;
- Collaboration with the women's and disability movements (sponsorship, conferences, training etc.).

B. Positive actions by our organisation - Info-Handicap asbl

Positive actions specifically regarding women: *Empowerment*

In the framework of the Daphne Initiative 1998, financed by the European Commission, Mobility Inter- national organized an educational programme "self-assertiveness", in order to train sexual violence prevention trainers. The writers of this report were formed as specific trainers with the aim of offering similar training modules on a national level. On their return home they elaborated a concept focussed on the Luxembourgish specificities (based on the original Netherlands concept "Weerbarheid"). Since 1999 they have organised:

- Empowerment training courses for women with a physical disability (2) and for women with a mental deficiency (4);
- Continuous empowerment training for women with a physical disability & a mental deficiency;
- Action and awareness raising week "Images of women" on the occasion of the International Women's Day on the 8th of March and in the framework

of the European Year of Disabled Persons 2003, in close collaboration with the Departments for women from 3 local public authorities (municipalities): photo exhibition, film screenings, concerts, round table discussions and conferences, self-defence workshop, relaxation workshop, accessibility workshop, PC training course for women with a mental disability.

(www.bettembourg.lu/files/infos/Brochure%20Femmes%20et%20 Handicap2005.pdf)

- The project *"Images of women*" was one of 5 European projects selected by the European Commission and presented in Rome during the EYDP 2003 Closing Conference.

Selection criteria: joint approach to two kinds of discrimination: gender and disability/collaboration between different types of actors but in close relation to citizens: ONG and 3 local public authorities/differential approach showing as detailed as possible an image of the realities linked to different types of disabilities and trying to offer possibilities of expression and active participation to women affected by very different handicaps.

Follow up: since 2003, independent PC training workshops and self-defence training workshops for persons with a mental deficiency continue to be organized in partnership with local public authorities, high schools, associations.

- Dance performance in a wheelchair (by a trainer);
- Conference of the Assoc. of Curative Pedagogues in Ulm (Germany) "Women and disability".

Future specific actions regarding women:

- Empowerment training courses for girls and women with hearing problems;
- Concept and publishing of a "Leitfaden" which contains training modules aimed at women with a physical disability, mental deficiency and hearing problems.
- Positive actions general*: Awareness, Accessibility, Tourism, etc*.

The activities of Info-Handicap in favour of disabled persons in general also concern disabled women. As examples amongst others:

- Dossier pédagogique (Educational Leitfaden for schools, high schools, social workers, etc.);
- Training workshops in accessibility: C.F.L., Université du Luxembourg, Ministère de la Fonction Publique, car garages;
- Training/information workshop: Lycée technique pour professions éducatives (High school for educational professions);
- Training workshop for family assistant staff organized by the Ministry of Family and Integration;
- Project Travel accompanying guide (training of the volunteers and project coordinating);
- Different accessibility projects: Welcome, ECA, Build for All, Polis, Euregio for All;
- Rollitour (Tour of Luxembourg in wheelchairs);
- Participation in Salon des solutions pour tous, Salon Vacances, Bourse du Bénévolat;
- Seasion of conferences Université du Luxembourg + Pédagogues curatifs + ANCE: Handicap et Egalité des chances, mainly for university students;
- Campaign 1 million signatures (240.02 % for Luxembourg);
- EU Campaigns against discrimination & European Year of equal chances for all, organized by the Ministry of Family and Integration (truck, conferences, round-table discussions, etc.);
- Itinerant exhibition ASTI-Info-Handicap-Service RBS in the framework of the European Year of equal opportunities for all (21 portraits showing diversity in Luxembourg - aspects: age, disability, ethnic origin).

MALTA

MALTA FEDERATION OF ORGANISATIONS OF PERSONS WITH DISABILITIES (MFOPD)
IRENE SCHEMBRI

The latest statistics on the population of Malta gives the figure of 405,577. There are 199,836 males or approx. 49.25% as against 205,741 females which make up approx. 50.75% of the population.

As per census data, there are 2,560 disabled males in employment and 806 females.

Despite all the efforts made by the National Commission Persons with Disability (NCPD) to encourage all persons with Disability to register themselves, not everyone approaches the Commission. Thus there exists no proper data.

We do not have any female MPs who have a disability or who are mothers of children who cannot represent themselves. The National Commission Persons with Disability, which represents all persons with disability has, in its own structure, women with disability. The role of the NCPD is very influential and highly instrumental in decision making regarding all issues that concern persons with disability. However, unfortunately, within this structure there is nobody who represents persons with intellectual disability.

Despite the fact that there are many organisations working with and for various disabilities there are no specific groups for or of women and girls with disabilities.

The national organization, which is the Malta Federation of Organisations Persons with Disability (MFOPD), has an Executive Committee of ten members of which two are women. In my opinion this is a very unbalanced Committee.

Women who are members of MFOPD and who are very active had always shown interest to be on this Committee. One can feel that the feedback and/or input given by women at Committee level is not given the merited attention.

The absence of women with disability and or parents of persons who cannot represent themselves is also felt within the National Council of Women. The same applies within the National Council for the Promotion of Equality.

I wish to point out that the employment rate given for the second quarter for the year 2007 is 74.3% for male whilst that of female stood at 36.8%, leaving an employment gender gap of 37.5%. The employment of women who are gainfully employed is the lowest in Europe. The various stigmas that are still found in our country are the main barriers that any woman faces even more so for a woman with a disability and most particularly married women with disability.

The status of a woman with disability makes a difference even where social benefits are concerned in that a woman who is married and whose husband earns just more than the minimum wage loses all the benefits she enjoyed before getting married. She hardly finds any support from any agencies run by the government with the upbringing of her children. This can be particularly more serious when the mother is visually impaired.

In Malta a man has always enjoyed advantages for employment over women. In the past, women employed in the public sector were asked to resign on getting married. The National Council of Woman has worked very hard to change this mentality; however, it is still much easier for a woman without disability to be employed then for a woman with disability. The feedback we receive is that it is much easier for a man with a disability to be given a job then a woman with disability. A woman with disability refrains from applying for employment because of the obstacles as mentioned above.

Due to the fact that there are no particular organisations for and of women with disability, no other organisation or entity is working to tackle the many discriminations that Maltese women and girls with disabilities face.

There is a vacuum in Malta in this particular and sensitive issue. In my opinion the NCPD and MFOPD need to take this issue more seriously and place it as one of the major topics on their agenda.

THE NETHERLANDS

NATIONAL DISABILITY COUNCIL FROM THE NETHERLANDS (VGPN)
YVETTE DEN BROK

How to analyze and improve the situation of women with disabilities

A short description of the situation of women with disabilities in the Netherlands

In the Netherlands there are approximately 1.5 million disabled people and a comparable number of chronically ill people. In total, therefore, about 2.5 to 3 million people – 15 per cent of the Dutch population. Many of these people are elderly. A little more than 50% of disabled people in the Netherlands are woman. That is partly because of their age (women live longer then men and older people have more handicaps), but if you look at disabled people under 65, you'll see more women then men too.

Equal treatment of disabled people in the Netherlands still has a long way to go. Reports by the Social and Cultural Planning Office (SCP) show that it is still harder for disabled people in the Netherlands to find work or to participate in education or leisure activities. They often have lower incomes and frequently encounter obstacles in all sorts of places, which makes it difficult to participate.

In reports about the situation of disabled people such as this by the SCP, they don't differentiate between men and women. This is a strange situation because from the beginning of the eighties in the 20th century until a few years ago there were several groups of women with physical handicaps who made it very clear that it is important to pay attention to gender and handicap too.

Because of this, disabled women's groups carried out several projects and research programmes regarding the special situation of women with physical disabilities. All of these pointed out that gender of course has its influences on the lives of disabled people. Women with disabilities do not only have other feelings about their handicaps then disabled men, they have also another position in the community. Women with disabilities in the Netherlands, for example, do generally have better education then disabled men. But their position in the labour market is worse. To disabled women people often say: *'It is good for you to study a lot,'* but when a disabled woman asks for a paid job, she'll often hear something like '*You don't have to work. Stay at home and enjoy yourself.*' If a disabled man asks for a paid job, everyone understands him. Because paid work is far more important for men than for women, they still seem to think.

And when a disabled woman decides to stay at home and to have some children, she doesn't do well either. People will say to her: '*You can't raise children! You are disabled!'.*

If nothing you do is good, you choose your own way. And many disabled women in the Netherlands do so. Many of them create their own paid work, mostly with success! And there are disabled women who decide to have children, mostly with success too. Other disabled women lead their own lives without paid work or children and they are happy too. And —like other people— some women with disabilities are unhappy and lonely.

Research carried out in the year 2001 pointed out that disabled women have to do more to lead their own lives and to get what they need than men. This resource also pointed out that disabled women often do not only take responsibility for themselves but also for their children, their family, their neighbours and their friends. But the government doesn't look at this. A disabled woman gets a scooter mobile or an adapted bike to go outside, but when she has children or she is responsible for her old mother-in-law, she needs an adapted car to take them with her. The government doesn't listen to this kind of arguments.

At present research is being done in the Netherlands about the emancipation of disabled people —men and women. In this research they do pay attention to gender. Many disabled women in this research think that women are much stronger than men and that because of that women can better handle and organize their lives with handicaps. Some men in this research say that they think that women can't allow themselves to be very ill or very passive, because they have to do things in the house. For men it is easier, they say.

Both men and women in this research think that for disabled women it is more difficult to get a paid job than for disabled men. Also it is very clear that gender influences the lives of disabled people and that needs attention. But in the Netherlands they've never paid special attention to the position of women with mental or physical handicaps and the groups of women with physical handicaps have all finished their activities. Not because everything is okay now, but women lost their interest in asking for attention for gender. Probably you can state that there were two reasons for this. The first one is that disability organisations and the government did not really listen to what women had to say. The second reason was that the general position of men and women with disabilities became worse during the last years. Because of that women got the feeling that there was totally no interest anymore for their message and that they had to join 'the big group', to protect the general position of disabled people in the Netherlands.

Probably this last reason also explains why it has always been a very small group of disabled women who asked for attention for gender. Many disabled women are active in organizations, but they don't pay attention to their own specific situation. Apparently they think that the general position of disabled people is more important and maybe they don't recognize themselves as women. Many disabled people have namely been raised up as 'gender-less' beings. An organization of young people with a handicap in the Netherlands already has very concrete plans for research in this field, the effects of this and how to promote gender becoming a part of the raising of children and young people with handicaps. Maybe this will contribute to a future with disabled women who do think and talk about their special position in the organization and in the community.

But first of all there is a need for disabled women who think and speak about gender and their own situation. And in the Netherlands there are not enough of that kind of women. But we shouldn't forget that there are many disabled women who do very good work for the emancipation of women with handicap in their own environment by living their own life!

Validism and Gender

When disabled people and especially disabled women want to explain our situation to disability organizations, to women's organizations and to the government, it is important to theorize it. Of course we have the Disability Theory and nothing is wrong with that but I think it can also be good to look at it in another way. Because of that, I developed the concept called 'validism' a long time ago. Validism has the meaning of discrimination because of having a handicap, as nearly the same way sexism has the meaning of discrimination because of your gender. By giving something a name you make it exist and touchable and people can do things with it. That's why I gave discrimination because of having a handicap a name.

I am very glad that in 2005 I could write a book about it, commissioned by the Dutch Council of Disability and chronic illness. That book is called 'Validism and gender. About living with a handicap'. The reason why in my book I also talk about gender is that I think that the fact that disabled people often have been seen as sexless beings is the culmination of validism. In this fact you namely see that people think that disabled people are not normal people with the duties, roles and needs that normal people have. Because, whether we want or not, most of the things that we do and think have to do with being a man or being a woman (gender). In fact the whole society is based on gender. If you are not a man and not a woman, what do people expect from you? You are at least a very strange person and you would not easily be accepted in society.

And in my opinion is the fact that people generally don't consider disabled people as normal human beings the main reason of validism. People don't want to know that handicaps are a normal part of human life. They want to believe that health, beauty, unbelievable strength and a very sporty body are normal conditions and that in fact every human being has the right to have these conditions. Having handicaps doesn't fit in that picture and therefore they think disabled people are another kind of beings.

Four levels of validism

I split Validism in four levels. I did so to make it easier to analyze with what kind of discrimination we have to deal with at a certain moment.

The first one is the level of cultural validism; about how people consider disabled people. I already spoke about it, but it also depends on which culture you live in. In Africa they look at people with disabilities in a different way than in the west.

The second level is the level of institutional validism. This is about the possibilities in the community. Do people with disabilities get the same possibilities as other people? And are these possibilities as self-evident for them as for other people?

The third level is the level of interactional validism. This is about how people with disabilities and people without disabilities interact with each other. Very often the handicap influences the interaction, because people don't know how to handle it.

The fourth level is the level of the internalised validism. It's the validism of disabled people's self, how they consider themselves. Very often they do think they are less than others because of their handicap. And I think that if they can change that —if they can think of themselves as normal people who are as worthy as others, if they think they actually count and if they think that the world is theirs too— they can take their place in the community and show other people that they really are normal people. In that way they are able to destroy validism on all levels. Because if people know disabled people they'll consider them as normal people and they'll think disabled people should have the same possibilities as they have and they'll handle disabled people in normal way. So the key to getting rid of discrimination because of having a handicap is to get rid of self-discrimination.

Gender and the four levels of validism

As I said, the culmination of validism is that people suppose that gender does not exist for people with disabilities. In my book I explain that this is, of course, not real. Gender is everywhere where people are and you can't do anything without being confronted with gender. And above if you face the facts; disabled women do have a worse situation than disabled men. That's gender too.

But there is something strange with disabled women and gender. As I said, people often think that disabled women don't need to work (what they mostly surely do expect of not-disabled women these days!) and they also don't expect disabled women to stay at home and raise children (the traditional woman's role). In fact they don't fit in gender. Women with disabilities fall in a vacuum, however you want to name it!

Besides, it is important to say that gender is not only a thing for women. It is also important for the position of men to face the effects of gender. That will become clear when we look again to the four levels of validism. Gender has to do with all aspects of life, so it is self-evident that you can also see it in all the levels of validism. As we face cultural validism, we see that in the West your appearance is very important. People think it is normal to have a perfect body and because of this people with disabilities have been considered as not normal. But your appearance is also important in gender. Therefore you see that people think some handicaps are worse for men and other handicaps are worse for women. For men it would for example be worse to have a growth-related illness and stay little. For women it seems to be worse to have scars.

When we look at institutional validism we see gender too. For men it is for example easier to get a paid job and an adapted car than for women. But when a disabled man needs some adaptations to take care of his child, it will be more difficult to get these for him than for a disabled woman.

In the interactional validism we also see effects of gender. Some people say it is easier for a disabled man to have a relationship than for a disabled woman. For women it is mostly easier to take care of someone, so she'll have fewer difficulties to take care of her partner then men have.

Internalised validism has also to do with gender. In the research about emancipation of disabled people I'm working on at the moment many respondents say that women are much stronger than men and therefore they can easier handle their lives with a handicap. I think that's true and that disabled people do have no other choice than to be strong. The support they get is too bad to base their lives on!

Intersectionality as a tool

If it was not, it will be clear after reading this that for both disabled women and disabled men it is important that policymakers face the effects of handicap and gender.

The American jurist Kimberle Crenshaw once introduced a concept, called ''crossroadthinking" or "intersectionality". She did so on behalf of black women. Their specific situation gets no attention either. Organizations and policymakers think and speak about 'black people' and about 'women', but not about 'black women'. In the case of disabled women the same thing happens. Organisations and policymakers do think and speak about 'disabled people' or about 'women', but not about disabled women. That is why intersectionality can be interesting for us too.

With her concept 'intersectionality' or 'crossroadthinking', Crenshaw means that nobody ever has only one property or quality. Every person lives on the ''crossroad" of several properties or qualities. Policymakers have to recognize this and to look at this. When they think about new policy they also have to think about which special meaning that new policy will have for black women. Or, in our case, which special meaning the policy will have for disabled women. And of course for disabled, black women. Or which meaning it will have for disabled, black, lesbian woman, and so on.

Crenshaw also says that there are some qualities that make the chance to be discriminated larger than other qualities do. The quality of being a woman, for example, makes your chance to be discriminated much larger than the quality of being a man. And in my opinion having a handicap is such a quality too. If you do have many of such qualities your discrimination-risk is very large. Policy-makers have to face that and to look for ways to decrease that risk.

Your discrimination-risk depends also on your environment. If you are a woman you will have a greater chance of being discriminated when you are among men than when you are among women. That would for example be a reason to guarantee that both women and men are working in places where important decisions have to be taken, also in disability organizations. It would be an important reason too for having many disabled people in the community too, because the risk of being confronted with validism is much larger as long as there are only a few disabled people in the society.

Above all, disabled people can also use intersectionality as a tool to develop a stronger image of themselves. If you can consider your handicap as only one of your qualities, you will see that you are much more than your handicap. You will also see that you should not live apart from the community only because of that handicap. And you will see that you should have fewer chances in the community, because of being a disabled woman.

To sum it up in one sentence, we, disabled women and men, should work out intersectionality as a tool to improve our situation!

POLAND

WORKABILITY EUROPE
DELEGATE: MONIKA BARANIEWSKA

Poland has over 38 million inhabitants, of whom 5.5 million are people with disabilities. In comparison with 1988 this group grew by 50%.

There are 4.5 million people with a legally recognised disability.

Source: Central Statistical Office (CSO) National Census of 2002.

Institutions acting for the benefit of people with disabilities in Poland

Government Plenipotentiary for Disabled People (Department in the Ministry of Labour and Social Policy)
State Fund for Rehabilitation of People with Disabilities (PFRON)
Local government bodies
Institutions for disability assessment
Non-governmental organizations

State Fund for Rehabilitation of People with Disabilities (PFRON) is the state's targeted fund supporting activities aimed at the social and professional rehabilitation of people with disabilities.

Required employment index

Every entrepreneur doing business in Poland who employs over 25 people is required to employ 6% of people with disabilities.

For every vacancy he is obliged to pay PFRON 40.65% of an average remuneration, that is 40.65% x 717 euro = 291.46 euro.

Funds collected this way by PFRON are redistributed to people with disabilities through:

1. additional financing to remuneration of people with disabilities;
2. covering the increased employment costs of people with certified mental illness, mental handicap, epilepsy or blind workers;
3. co-financing group therapy workshops;
4. co-financing professional activity units;
5. adaptation of workplaces for people with disabilities;
6. loans for people with disabilities to start a business or agricultural activity;
7. partial funding of participation of people with disabilities in rehabilitation camps;
8. partial funding of rehabilitation and orthopaedic equipment and other forms of aid;
9. partial funding of elimination of architectural barriers.

Degrees of disability

1. Severe degree of disability means a person whose bodily fitness has been harmed, who is unable to work or able to work only in sheltered workshops

and —in order to function in society— requires constant care and help from other people connected with inability to live independently.

2. Moderate degree of disability means a person whose bodily fitness has been harmed, who is unable to work or able to work only in sheltered workshops and requires temporary or partial help from other people in order to function in society.
3. Minor degree of disability means a person whose bodily fitness has been harmed, reducing in an essential way his/her ability to work in comparison to a person with similar qualifications, but of full mental and physical ability, or has limitations in functioning in society which can be compensated by providing orthopaedic equipment, other forms of aid or technical means.

Government priorities concerning people with disabilities

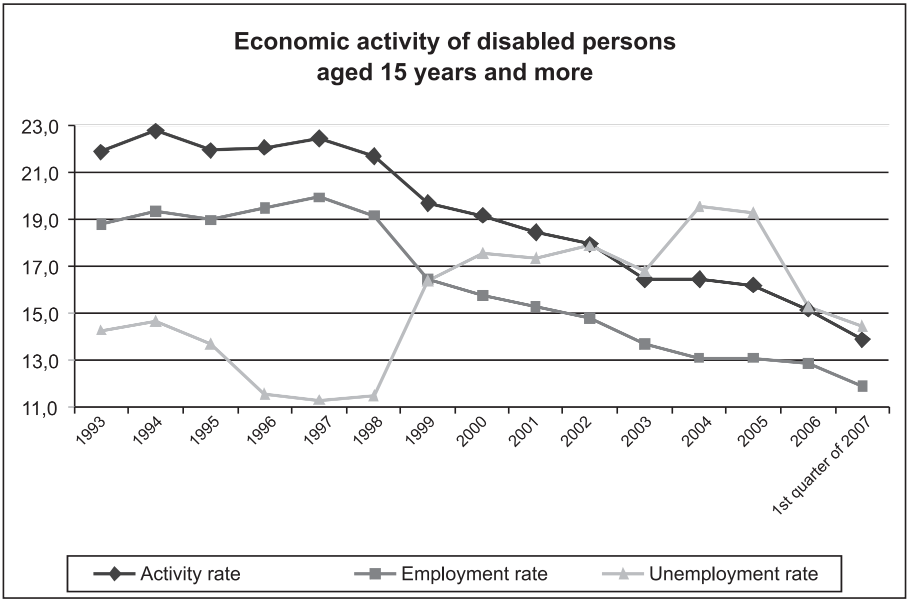
1. Propagating active participation of people with disabilities in professional and social life.
2. Finding employment for people with disabilities on the open labour market.

People with disabilities in the total population in %

Specification		*Total*	*Male*	*Female*
In total population	People with legal and/or biological disability constitute	14.3	13.9	14.7
	People with legal disability constitute	11.6	11.8	11.5
Among people aged 16 or over	People with legal and/or biological disability constitute	17.1	16.7	17.5
	People with legal disability constitute	14.1	14.4	13,8

Source: CSO National Census of 2002.

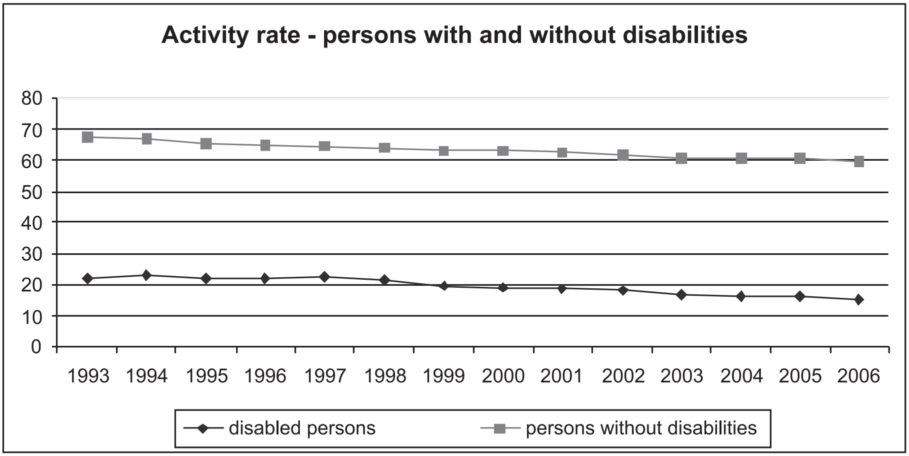
There is no great difference in the percentage of disabled men and women in the total population; what may be interesting is that more disabled women than men do not have legal documents proving that they are disabled.



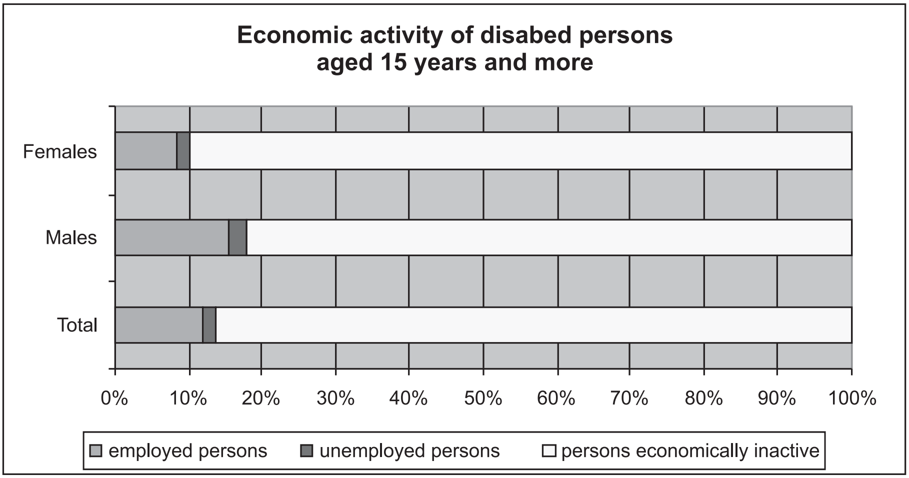
Graphic 1. Source: CSO BAEL.

The economic activity of disabled people in Poland has been decreasing since 1993. When we compare the trend for the activity rate between persons with and without disabilities (diagram below) there are no differences. However, there is a significant difference in activity of persons with and without disabilities. In the 1st quarter of 2007 the activity rate for persons without disabilities amounted to 56.3%, while this rate for persons with disabilities amounted to 13.9%.

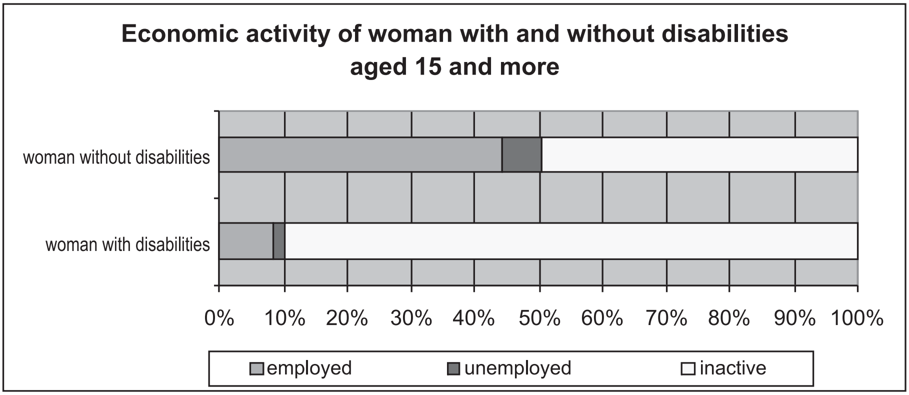
If we compare the economic activity rate between men and women with disabilities, we see that more women than men are inactive. Only 10.1% of disabled woman are active (employed or unemployed). Only 8.5% of disabled women have a job, while 17.8% of disabled men are active, and 15.3% are employed.



Graphic 2. Source: CSO BAEL.



Graphic 3. Source: CSO BAEL 1st quarter of 2007.



Graphic 4. Source: CSO BAEL 1st quarter of 2007.

When it comes to comparing the economic activity of women with and without disabilities the difference is shocking.

The reasons for inactivity among persons with disabilities are shown in the table below:

Disabled economically inactive persons by reasons for inactivity and level of disability

specification	*total*	*persons not seeking a job*			
		total	*Reason for not seeking a job*		
			family and household responsibilities	*retirement*	*illness, disability*
	in thousands				
Total	3250	3242	30	922	2164
Males	1515	1513	6	378	1078
Females	1735	1729	23	544	1085

Graphic 5. Source: CSO BAEL 1st quarter of 2007.

We can see that the majority of people with disabilities gives their disability or illness as a reason for not being active in the labour market.

The reasons for inactivity for the entire population are shown in the table below:

Persons economically inactive by reason for inactivity

specification	total	persons not seeking a job						persons seeking a job but not ready to take it on	others
		total	reasons for not seeking a job						
			Discouragement caused by inefficiency of job seeking	education, training	family and household responsibilities	retirement	illness, disability		
	in thousands								
Total	14726	14601	554	3635	1527	5629	2645	94	31
Males	5764	5706	222	1792	127	2129	1211	36	21
Females	8962	8894	332	1843	1400	3500	1434	58	10

Graphic 6. Source: CSO BAEL 1st quarter of 2007.

The Department of Women, Family and Counteracting Discrimination in the Polish Ministry of Labour and Social Policy is conducting a project financed by the European Social Fund which aims to create a positive social climate for more active participation of women in the labour market. The project action is preparing TV programmes. One of the programmes was about disabled women who face multiple discrimination. This project proves that Polish authorities notice the problem of multiple discrimination.

When preparing this report, I searched internet for Polish NGO that act in favour of women with disabilities. I found one organization: Association of Disabled Women One.pl.

The other interesting thing was the Project Gisela website - GISELA – *Guidance and Information Services for Less-Abled Women: A European Study and Network.*

Nevertheless, I still have the impression that in Poland the fact of multiple discrimination of disabled women is still set aside. There are visible actions concerning non-discrimination in the workplace, but separately gender discrimination and discrimination of persons with disabilities. What is important in Poland - perceiving the population of disabled people as a whole. People with disabilities are perceived as people without sex.

Association "Disabled for the Environment EKON"

In the entire Social Enterprise EKON (constitute with EKON Association and two enterprises) the following are employed:

	without disabilities	*disabled*	*total*
Females	96	282	378
Males	48	635	683
Total	144	917	1061

The social enterprise EKON offers ecojobs in the field of environmental protection for persons threatened with social exclusion, especially mentally ill persons. This job is well adjusted to the needs of disabled persons because it is executed in mutual support groups. These groups are matched on the basis of “stronger” with “weaker”.

The most interesting effect of our project, that surpassed our greatest expectations, was the occupational and social rehabilitation of mentally ill persons. Doctors who take care of our workers observed that their health significantly improved already after a few weeks from the start of their work. These people got the will to live; they managed to break free from isolation and started to make contact with society. We noticed a strong identification of these people with the Association and with the work they do. Work connected with environmental protection became their lifestyle.

The work on offer is physical work, that is the reason that most of our employees are men, but when we compare employees without disabilities there are more women than men, and they work mainly in HR, financial, and other administrative departments. In the “production” department women with disabilities fulfil their duties and their productivity is equal to men.

Due to the observation made by psychologists employed in EKON, we have information that employed women do not feel discriminated because of their sex or their disabilities. Women that are employed at the same position as men receive equal remuneration.

We are proud that we were able to create a specific working climate which was named by a psychiatrist as a “Land of acceptance”. Persons with disabilities find in EKON understanding of their needs and assistance and they can tell us frankly about their needs and problems.

SITUATION OF GIRLS AND WOMEN WITH DISABILITIES IN POLAND

POLISH DISABILITY FORUM (PDF)
THE DISABLED WOMEN ASSOCIATION ONE.PL
DELEGATES: MAŁGORZATA RADZISZEWSKA AND MAGDA SZAROTA

Legal solutions in Poland prohibiting discrimination regarding sex or disability

There are two legal solutions in Polish law in the area and they are as follows:

— *The fundamental and supreme Act - the Constitution of the Republic of Poland* stating that:

> *"All people shall be equal before the law. All people shall have the right to be treated equally by public authorities. No-one can be discriminated in political, social and economic life by any reason" and "Women and men shall have equal rights in the Republic of Poland in family, political, social and economic life. In particular, women and men shall have equal right to education, employment and promotion, to equal remuneration for the work of equal value, to social security and to hold posts, public posts and to be given public titles and distinctions."*

As regards social security, the Constitution provides as follows:

> *"Every citizen shall have a right to social security in case of unfitness for work due to an illness or disability and after reaching a retirement age. The scope and forms of the social security shall be specified in an Act. According to the Act, public authorities shall grant assistance to persons with disabilities in securing their existence, preparation for work as well as social communication."*

The ***Labour Code*** as regards the Council Directive 2000/78/EC of 27th November 2000, setting out general framework conditions of equal treatment as regards work and employment. It states that:

> *"Any form of discrimination in employment, whether direct or indirect, is unacceptable, in particular on the grounds of sex, age, disability, race, religion, nationality, political convictions, membership in an organisation, ethnic origin, denomination, sexual orientation, as well as employment for an indefinite or definite period or full-time or part-time employment."*

Since 1991, legislation determining the rights and entitlements of employers and persons with disabilities as regards employment, establishing the State Foundation for Rehabilitation of Persons with Disabilities (PFRON), setting out the scope of measures financed from the funds of the State Foundation for Rehabilitation of Persons with Disabilities (PFRON) as well as territorial government units, and also setting out the scope of assistance the persons with disabilities can seek. However, the above-mentioned act contains no provisions on the prohibition of discrimination on grounds of sex or disability.

As it stands at the moment, it's the British legislation that is a closer model for us and the issue of introducing a similar legal solution in Poland is a difficult one for many reasons, not necessarily economic ones.

The Situation of Girls and Women with Disabilities in our Country and Organisation

There are around 5.5 million persons with disabilities living in Poland. According to the National Census of 2002 the so-called 'frequency of disability' amounted to 14.3%, including 13.9% of men and 14.7% of women, which shows that disability appears more frequently in women than men.

According to information from the Ministry of Labour and Social Policy (MPiPS), the unquestionable majority of persons with disabilities (84%) live mainly off social security benefits: disability pensions, retirement pensions and other social benefits.

Only 8% of this group declares work to be their main source of income, and the remaining 8% depends financially on other people.

There are 2,866,000 people without work in Poland, including over 1.5 million women, and according to the European Commission Report of 2006 on the Equality of Men and Women only 46% of Polish women have a job.

And how many disabled Polish women have a job? There are 967,000 disabled women of working age in Poland (data for the 4th quarter of 2005). 160,000 are working, the employment rate is 16.5% (it is 19.7% for men). The above data indicate that 807,000 disabled Polish Women do not have a job, that is over 80%. Hence, this data beyond all doubt show the difficult situation of women with disabilities as regards employment.

In 2006 the percentage of persons with disabilities with higher education was almost three times lower than healthy people: amongst the group of disabled persons only 5.5% had higher education, amongst non-disabled people the rate was 15%, and almost twice as many people with disabilities had finished their education at a junior high school at the most (24.6% to 40.3%), whereas the data from the National Census of 2002 shows that amongst the group of people with disabilities at production age there were 4.9% of men and 4.3% women. Also, amongst people with disabilities registered at public employment agencies women were better educated than men.

Number of Women in Management Bodies

To illustrate an average number of women in management bodies here we present the information on the main organisation (the umbrella organisation), our association and a number of other important non-governmental organisations acting for persons with disabilities:

— The main organisation (the umbrella organisation) - Polish Forum for Persons with Disabilities - management body consists of 5 people, including 2 women;

- — The Disabled Women Association ONE.pl - management body consists of 5 people - all women;
- — Polish Association for Persons with Mental Handicap - management body of 15 people, including 9 women;
- — The Foundation for Active Rehabilitation - chaired by a woman and 20% of all people taking part in the measures are women;
- — Polish Association of the Deaf - 11 people in the management body, including 5 women.

There is no special group dealing with women with disabilities within the Polish Foundation of Disabled Persons; therefore our Association has been asked to take part in the conference, as the only one from Poland.

The Disabled Women Association ONE.pl was founded in 2004 as the first and the only non-governmental organisation of this kind and which sets out as its goal and mission the work and for women with disabilities both regarding the systemic changes and solutions and direct assistance, education and activation.

The association began as an initiative of active women with disabilities (with various kinds of disabilities, mainly the ones in wheelchairs), representing different professions (including lawyers, social politics graduates, IT specialists, journalists, psychologists, sociologists, cultural studies graduates and musicians) and with experience both in the non-governmental sector, public administration and academic work.

The majority of the founding members do not come from big cities but, on the contrary, from economically and socially neglected areas, e.g. from the Warmia and Mazury province and Podlasie province. The founding members of ONE.pl association are examples that thanks to your own determination and courage you can overcome not only your own fears but also, and more importantly, the fears of your families as well as cultural barriers. Like the majority of women with disabilities they have heard from their nearest and dearest - stay, don't go, you won't make it, who will help you and so on; despite it all, and to prove to themselves and others that they can fulfil their potential, they have completed education, they are active, they work and are independent or independent to the extend that their kind of disabilities allows them to be. As they wish to support other people with disabilities they decided to act in the 'third sector' in order to, with all their passion and involvement, deal with and prevent the double discrimination of women in their social and professional lives.

Obstacles and Difficulties that Girls and Women with Disabilities face

Given the fact that the Disabled Women Association ONE.pl represents here mainly the Polish Forum for Persons with Disabilities, we shall first present the standpoint of the Forum in the matter. Women with disabilities often continue to experience the stereotypical attitude, which is deeply rooted in cultural patterns, i.e. they are brought up in families as asexual beings, the tendencies towards confining them to life "in the family" are instilled in them, giving no regard to the possibility of them fulfilling different social roles, e.g. a role of a wife or a mother.

Furthermore, the constraints put upon persons with disabilities extend to the field of education, personal development (hobbies), education to freedom or the right (and ability) to make independent choices in all aspects of life. It may happen that families will not allow a person with a disability to seek employment. It is often a result of an economic calculation – the fear of losing a social disability benefit, which is often the only permanent source of income vs. too high a risk involved in finding a job by a person with a disability on the open labour market.

The most dramatic example of "social constraints" and "incapacitation" and the accumulation of all negative stereotypes of persons with a disability seems to be the social situation of women with a mental handicap.

In the opinion of the Disabled Women Association ONE.pl, a disabled woman is discriminated twice - against her sex and against her disability. This is confirmed by the statistics, illustrating the situation occurring in their daily professional lives (relatively lower wages, significantly hindered path of professional progress, if not out of reach altogether) and their social life as well. Moreover, apart from problems shared by all disabled people there are problems specific to disabled women only, such as treating disabled women as asexual beings or a “third sex” (femininity being reserved for persons who do not differ from socially and culturally accepted norms, taboo concerning the sexuality of disabled women), confining to set social roles (a place “in the family” and so on).

Situation of Women with Disabilities in comparison to Men and Other Women without Disabilities

The situation of disabled women as compared with disabled men reflects to a large extent the situation of healthy women vs. healthy men i.e. in both cases, despite the fact they actually outnumber men, women come to constitute the discriminated “minority”.

Moreover, society does not take notice or seems to ignore the fact that as disabled women, we are discriminated twice - on grounds of sex and a disability, and the lack of this awareness is negatively reflected in the legislation, common laws, and the discriminating cultural norms, being preserved from generation to generation. The media also do not really work for the benefit of creating a normal image of a disable person, e.g. there is no place for a disabled woman in any of the soap operas (and paradoxically healthy actors play parts of disabled men).

Social consciousness is negatively tainted and bears traits of a strong tendency towards segregation of our social group. We are also concerned by a phenomenon concerning non-governmental organisations which, dominated by men, usually do not take any measures aiming at disabled women. This is mostly due not to ill-will but rather a lack of knowledge and experience (also one’s own experience) as regards the peculiar situation of women (and their problems) and they are disabled as well. The Disabled Women Association ONE.pl was founded to fill this huge gap with knowledge and experience, as in our opinion it is the only way for the needs and problems faced by the circles of disabled persons —regardless of the kind of disability and sex— to be taken under consideration by the healthy majority of the society. Only by these means are we able to bring about equal and long-lasting changes for all circles of disabled persons.

There is no special body of legislation in Poland containing a catalogue of anti-discriminatory measures to be undertaken for disabled persons by the government and local governments. There is no coherent system which would secure a comprehensive set of solutions aimed at the circles of these people.

The path to take if we want the double discrimination of disabled women to be noticed and defined in Parliamentary Acts leads first through the introduction of an anti-discriminatory Act concerning all circles of disabled people. In the Polish Forum for Persons with Disabilities, no special policy or special solutions are designed which are aimed at disabled women. The phenomenon of double discrimination of disabled women in their social and professional lives, despite being felt, has not been diagnosed in any way.

The Polish Association for Persons with Mental Handicap has started screen tests on sexual abuse of girls/ women with mental handicap in their family homes and institutions such as public social assistance houses. The association also follows the rules of the equality of the sexes when realising European Union projects and training for self-advocates.

Various projects regarding disabled women are being carried out by some non-governmental organisations, e.g. The Foundation for Active Rehabilitation has been organising specialised camps for women that have suffered spinal cord injuries.

The Disabled Women Association ONE.pl has been active in many fields continuously for 3 years, participating in public debates on double discrimination of disabled women (publications in newspapers, taking part in radio and television programmes), ONE.pl members are invited as experts to various advisory organs (including MISARN, UNDP, Committee for Social Dialogue Regarding Disabled Women at Warsaw City Council), taking part in panel discussions and conferences. It’s worth mentioning that on the initiative of the Association the first handbook for disabled women saw the light of day and it was created fully by experts who are at the same time disabled persons.

Future Action Plans

Here are our plans as presented in points. They are very ambitious but we hope to be able to meet these goals. The activities of ONE.pl Association will be undertaken on several levels:

Social campaigns of an educational-informative nature

Issuing a calendar promoting active disabled women; issuing a second handbook for disabled women allowing for the EU aspect.

Diagnostic-expert level

Undertaking sociological research in Poland on a considerable sample of the population concerning the situation of disabled women in their families and the workplace, as well as the problems faced by single mothers bringing up disabled children.

Building national coalition within the sector

Creating a strong lobby of disabled persons in Poland cooperating with local governments and parliamentary agencies.

Building a national and cross-sector coalition

Establishing cooperation with national and international organisations dealing with equal status of women and men.

Activating measures, psychological support

Creating a network of clubs bringing together disabled women, psychological workshops on activation.

Putting in practice the project of sheltered flats

Creating a network of flats at housing estates where persons with disabilities can function normally and, if needed, they will have access to organised assistance, cheaper than normal (assistants, transport).

SLOVAK REPUBLIC

SLOVAK DISABILITY COUNCIL (NROZP)
DELEGATE: LUCIA ANTALECOVA

The structure of Slovakia's population is characterized by the fact that the male population has been slightly outnumbered by women for a couple of years. It is assumed that given the demographic situation and the percentage of disabled women in EU countries, the number of disabled women is greater than that of disabled men. Up to the age of 18 there are more disabled males than females, while at the age of early maturity the difference in number between the sexes is becoming less apparent and after the age of 45 the number of disabled females significantly outnumbers the male population.

The percentage of disabled women is not monitored in Slovakia as there are no clear criteria defined upon which this statistical figure can be measured. Slovak legislation defines a disabled person as a citizen with a severe disability who is compensated by the State for their handicapped status compared to a non-disabled citizen. As of April 2006, in Slovakia there were almost 350,000 persons recognized to be severally disabled, accounting for about 6.5% of the total population and, when adding thereto 40,000 persons with 30 to 40% reduced functional ability, those with moderate to severe disabilities represent 7.4% of Slovakia's population.

The law also defines a disabled citizen whose functional disorder resulting from their disability causes their invalidity and entitlement to an invalidity pension. There are more than 180,000 persons receiving invalidity pensions. A citizen who does not meet the criteria for the status of a disabled person under any law is deemed a disabled citizen if he/she subjectively feels disabled, and may become a member of the disabled people association.

In Slovakia there is no organization that would cover disabled women. Disabled women may associate themselves within disabled people's organizations that support the rights of both men and women. On the contrary, female organizations fight for the rights of both healthy and disabled women. The National Council of Disabled Citizens is currently striving for attention being paid particularly to this group of women as they are being multifactorally disadvantaged and thereby increasingly becoming subject to exclusion from the society.

The situation of disabled women in Slovakia is still affected by historical and social factors such as the heritage of the past period, even though the situation has changed over the past years in connection with the aspirations, goals and subsequent entry of Slovakia into the European Union. Disabled women are faced with the biggest problems in the field of employment relationships and on the labour market. Their access to the labour market is largely limited due to the persisting prejudice against their inability and incompetence on the part of employers, even if there are state subsidies and other state contributions in support of the employment of disabled persons. A special problem is the different approach towards the remuneration of men and women. Disabled women encounter far more problems with their employment than their male counterparts.

Disabled women and girls have the same access to education as disabled men and boys. Compared to non-disabled woman and girls, they attain higher education only rarely. Although their school results are better, they are jeopardized by unemployment four times as much as men.

The situation of disabled women in families is relatively worse in comparison to that of healthy women. Disabled women are much more frequently abused and exposed to violence; in many cases their reproductive rights are restricted.

Disabled women of an older age live isolated; they often have no possibility to get out of their houses since they do not have enough money for all-day personal assistance. Barriers created by society cause disabled women to suffer from poverty much more frequently than healthy women.

A special category of women affected by disability implications are women who take care of a disabled family member for a long time.

The Constitution and legislation of the Slovak Republic afford equal legal protection to both men and women. Any practices discriminating women are inconsistent with the Slovak Constitution. Art. 38 and 39 of the Constitution of the Slovak Republic provide that women shall enjoy more extensive health protection and special working conditions. This particularly applies to pregnant women, for whom special care, protection in labour-law relationships and adequate working conditions are provided. In 2000, the Slovak Republic signed and ratified the *Optional Protocol to the Convention on the Elimination of all Forms of Discrimination against Women*.

Among the most important legal regulations pertaining to the prevention of gender-based discrimination is *Act No. 365/2004 Coll. on Equal Treatment in Certain Areas and Protection against Discrimination and on Amendment and Supplementation of Certain Acts* (Antidiscriminatory Act). This Act prohibits gender-based discrimination in social security, health care, the provision of goods and services, education and labour-law and similar legal relationships. Gender-based discrimination shall be deemed to include discrimination on the grounds of pregnancy or maternity or on the basis of sexual or gender identification.

Act No. 311/2001 Coll. Labour Code as amended, which provides for equal treatment in the workplace, also stipulates rules preventing discriminating practices. It provides special working conditions for women and secures both men and women equal remuneration for the same work.

Act No. 5/2004 Coll. on Employment Services regulates relations in the rendering of employment services and also contains several antidiscriminatory provisions, as well as stipulating a citizen's right of unrestricted access to employment and prohibiting any publication of job offers that would imply any kind of discrimination.

Act No. 564/2001 Coll. embodies the institute of an ombudsman – a public protector of rights. Whereas gender equality is perceived as an integral part of the human rights agenda, no special ombudsman institute has been established for the issues of gender equality in Slovakia. According to the said Act, an ombudsman shall act upon a motion received or on his own initiative. The number of motions filed with regard to discrimination on the grounds of gender (as well as on the basis of age, race, nationality or affiliation to an ethnic group or religion) is relatively low compared to motions filed for other reasons.

Apart from the legislative framework, in order to foster gender equality and to prevent gender-based discrimination, the government has adopted several documents to coordinate the procedure to be followed by those concerned with securing gender equality at all levels:

- *National Action Plan for Women* (Resolution of the Government No. 650/1997);
- *Conception of Chances for Women and Men (*Resolution of the Government No. 232/2001);
- *National Strategy to Prevent and Eliminate Violence Committed against Women and in Families* (Resolution of the Government No. 1092/2004); and thereto-related;
- *National Action Plan to Prevent and Eliminate Violence Committed against Women for the Years 2005 – 2008*.

In 1999, the Ministry of Labour, Social Affairs and Family of the Slovak Republic established an Equality of Chances Department, with the Ministry being in charge of the implementation of measures and recommendations adopted by Resolution of the Slovak Government No. 232/2001 as the Conception of Chances for Women and Men on March 7, 2001. Slovakia has thus pledged to the policy of “gender mainstreaming”.

The Slovak Government discussed the observations of the Legislative Council of the Government and, on September 5, 2007, sanctioned the proposal to sign the *UN Convention on the Rights of Disabled Persons*.

Despite the existing legislation, discrimination against disabled women still exists. Gender stereotypes embedded in the general public's consciousness hinder their access to education and employment. Disabled women are not strong enough to fight back against such disadvantages. This primarily ensues from the lack of self-confidence and relevant information concerning their rights. The Slovak National Council of Disabled Citizens is intent on supporting disabled women through its member organizations operating on a nationwide basis.

SLOVENIA

SLOVENE NATIONAL COUNCIL OF DISABLED PEOPLE´S ORGANISATIONS (NSIOS)
SLOVENE ORGANIZATION OF PEOPLE WITH MOBILE DISABILITY VIZIJA[21]
DELEGATE: URŠA VALIČ

The problems of handicapped/disabled people in Slovenia are treated mostly as common for man and women without gender/sex differentiation. The main problems that affect handicapped/disabled persons of both gender/sex are architectural barriers and structural adaptations, residential problems, media representation, employment and education. On 30th November 2006 the government approved the *National action plan for disabled people 2007 – 2013* (based on documents, conventions and EU and UN legislation), which includes all the abovementioned problems and their solutions. This plan also involves problems faced by handicapped/disabled woman such as domestic violence, gender discrimination and rights to decide for their sexual life, family life and maternity.

Slovene organization of people with mobile disability VIZIJA (hereonin VIZIJA) is a non-profit making and non-governmental organization. We are the smallest member organization of the National Council of Organisations for Disable People of Slovenia.

VIZIJA arose from the specific needs of disabled/handicapped women who wanted to expose their problems and the problems faced by handicapped/disabled

---

[21] In English VIZIJA means VISION.

women on their own. VIZIJA is nowadays the only Slovene organization focusing on the specific problems of handicapped/disabled women. With its programmes, it covers the deficit of programmes in the field of handicapped/disabled women. For these reasons, VIZIJA works on local and national level. It has 43 regular members (of which ¾ are women and ¼ are men) and more than 180 supporters i.e. handicapped/disabled people who are not formal members but have the right and possibility to take part in VIZIJA activities, experts and professionals, relatives of handicapped/disabled persons and volunteers. Members have different disabilities causing reduced mobility: paraplegia, quadriplegia, tetraparesis, paraparesis, paralysis, spina bifida, multiple sclerosis, hemiplegia, dysmelia, amputations and so on. The majority of members represent elder women who are the most vulnerable in our society and often experience social exclusion.

The particular concern of our organization is to deal with specific, individual problems and develop individual services which are not covered by the public sector. Our activities are based on members' interests and needs. This freewill choice gives our members the possibility of different options and choosing between different alternatives. Through our members' needs and interests we recognise the specific problems of handicapped/disabled people.

VIZIJA works on several programmes and projects, which can be divided in three main groups:

Programmes for Social Inclusion

We understand social exclusion as exclusion from physical places and at the same time the exclusion from social/discursive places or from places of sociability. Due to their handicap/disability, most handicapped/disabled people can not fully and equally participate in social, cultural, political or decision-making and other activities. We organize art and craft workshops, visits to cultural and sports events, inter-familiar meetings, social visits to remote/distant members and to homes for aged, professional and expert seminars and excursions, day trips and many other activities that are suggested by our members. The main purposes of these activities are to relax and discharge handicapped/disabled women who are often under pressure by their families and society. A very important part of this is also to reduce the loneliness of remote/distant members.

VIZIJA also collaborates with schools, universities and educational institutions in promoting the social inclusion of handicapped/disabled people. It organises some seminars and training courses and gives information to educators, students and scholars.

We collaborate with municipalities and members of communities, offering them recommendations and advice about the problems of handicapped/disabled people. Especially, we take an active part in giving them advice for adaptations to the built environment in public structures or buildings. In the municipality Slovenske Konjice, where is the seat of organization, we organize several entertainments every year in which we promote social inclusion and stress the necessity of intergenerational communication and coexistence. We also took part in the EU campaign For Diversity Against Discrimination and organized an event in Slovenske Konjice with the title “Diversity Enrich”.

Programmes for Social Prevention

This is the most important programme of our organization and it is about preventing domestic violence. Statements by (mostly female) users of programme indicate that violence is often present in families. Violence affects mostly weak members of family, and therefore also handicapped/disabled women. The specific nature of violence on handicapped/disabled women is that victims are physically and economically dependent on family members, particularly on partners.

Another problem is that handicapped/disabled women can not quickly escape or withdraw from a violent person because of bad or entire immobility. Most women who experience domestic violence do not want to talk about it. They are accompanied with different feelings, mainly they feel ashamed about the fact that this happens in their families and that the violent person is someone on whom they are dependent.

VIZIJA has conducted several educational training courses in the form of seminars and workshops, spread information and material about domestic violence and offers informal, individual conversations and advice to users of the programme also by telephone (in collaboration with SOS telephone from Ljubljana). One of VIZIJA efforts is to acquire at least two apartments for temporarily or permanently residence for handicapped/disabled women who have decided to escape from domestic violence. Namely in Slovenia there are no adapted structures (such as “safe/secure houses”) for handicapped/disabled people who are victims of violence! The main reason for this situation is obviously lack of money.

In Slovenia we have begun to realize the seriousness and gravity of domestic violence. On 9th July 2007 The Ministry of Labour, Family and Social Affairs proposed a Law for the prevention of domestic violence. We hope that the law will be approved soon by the government and put into practice, because it is important for our work to have good legal support.

VIZIJA also suggested an initiative to the Directorate for the disabled at the Ministry of Labour, Family and Social Affairs to include domestic violence on handicapped/disabled women as a point in the National action plan for disabled people 2007 – 2013. And, happily, the point was included in the plan!

Special Social Programmes

These programmes are set for health prevention and health care. We give our members advice and suggestions on health care and on the consequences of harmful habits.

Most of the members in our organisation suffer from incontinence, lesions, burns and other physical problems which derive from their handicap/disability. These problems are related to their socio-economical status: several of them can not afford the necessary remedies and medicaments. We develop a programme called “Woman to woman” and it is a form of reciprocal help.

VIZIJA helps members by providing them with orthopaedic, medical and technical remedies. It also develops programmes for medical help at members’ homes.

All the work we do is voluntary, non-paid work, although sometimes we think that more financial support would improve the quality and quantity of our programmes. And, last but not least, we are happy to work for people and to see that some change has happened.

Slovene organization of people with mobile disability VIZIJA
Društvo gibalno oviranih invalidov Slovenije VIZIJA
Stari trg 23
3210 Slovenske Konjice
Slovenija
drustvo.vizija@guest.arnes.si
President of organisation: Julijana Kralj

(English info: Urša Valič ursa.valic@gmail.com)

SPAIN

SPANISH DISABILITY COUNCIL (CERMI)
ANA PELÁEZ NARVÁEZ
CERMI Commissioner for Women's Affairs

1. Introduction

Spanish society has evolved tremendously over the past decades. The situation in Spain has changed and we can say that in general terms the status of people with disabilities has improved.

Additionally, improvement has come about more recently in terms of equality between men and women. This is thanks to policies carried through by the Spanish government, including new legislation that has aroused significant debate in political circles.

What, then, is the current status of women with disabilities? Have their needs been taken into account? Although the disconnect between gender and disability persists, in the last few years we have witnessed a significant shift in the way issues related to this group are addressed and resolved. This is the result of direct advocacy by women with disabilities from within the disability movement in Spain.

In effect, thanks largely to concerted and prolonged action by the Spanish Disability Council (CERMI) in the course of its negotiations and contacts with public authorities and parliamentary groups, the most pressing needs and demands of women with disabilities have gradually begun to be addressed.

The signs of this breakthrough are evident: a Spanish Government Action Plan aimed specifically at women with disabilities (a more detailed study of which is the subject of a later section of this report), the introduction of specific articles and references in several acts and the offer of representation in several government bodies. Notwithstanding this progress, however, we have merely taken the first steps in the march towards equality.

The situation is reflected in Spain's 17 *Autonomous Communities* or regional governments – Spain is split in 17 regions, each with its own regional authority. This is of key importance as responsibility for social policies is largely devolved to the *Autonomous Communities*. At this level the disability movement, for example the Federation of Women with Disabilities *LUNA* in Andalusia or the Non-standard Women's Association in Catalonia, has notched up considerable progress, as we will see in the sections on these organisations in this paper.

2. Overall Status of Women with Disabilities in Spain

The most recent study carried out in Spain on the status of people with disabilities, conducted in 1999 by the National Statistics Institute in partnership with the Institute for Migrations and Social Services [IMSERSO] and the ONCE Foundation, is the **Survey on Disabilities, Impairments and State of Health**. This survey revealed that women make up more than half of all people with disabilities: 58% in total. In addition, two-thirds of this group are over 65 years old.

The survey shows that the key characteristic of the group is its diversity, despite suffering in common high levels of discrimination as a result of double prejudice: gender prejudice and prejudice against people with disabilities. The consequences of this are plain to see: higher illiteracy rates, low educational achievement, lower rate of economic activity and/or lower paid jobs with less responsibility, economic dependence and so on.

Inequality is evident also in the disability and women's movements, where political participation by women with disabilities remains insufficient in both areas.

A study of figures from the main organisations of people with disabilities in Spain shows that on average, around 30% of people on representative bodies are women, and the figure for leadership positions on boards and top management posts is ten percentage points lower. In the women's movement, direct participation by women with disabilities in women's organisations is the rare exception rather than the rule, and where it does occur it is on an individual basis and not as a representative of women with disabilities.

3. What is CERMI currently doing?

Since the Women's Commission was set up within CERMI in June 2000 following an agreement by its Executive Committee, a wide range of different events have been developed. Thanks to these activities, the Commission has consolidated its role in terms of acting as intermediaries, providing information and developing proposals by and for women with disabilities concerning their rights.

From the moment the Commission was created until the present, its development has been guided by firm and continuous steps enabling it to achieve success in the following areas:

3.1. *Within CERMI*

On February 24th 2005, the CERMI Executive Committee created the figure of "**Commissioner for Women's Affairs**", tasked with putting forward, promoting and developing specific policies to bridge the existing gap faced by women with disabilities in Spain.

Soon afterwards —on May 18th of the same year— the **1st Integrated Action Plan for Women with Disabilities 2005-2008** was adopted as a key reference document in social policy regarding the needs and demands of the group. It was subsequently published and distributed widely in Spain at both national and regional level.

It is worth mentioning at this point that a major part of the task of drafting the plan was carried out beforehand by many organisations of people with disabilities at a gathering called to reflect on the issues at hand. This meeting set down the basis for the content and demands in the plan and was led entirely by women with disabilities themselves. The plan includes proposals that normally need to be developed in co-operation with public authorities, the disability movement and a range of social organisations.

The following is a summary of the key proposals, which are divided in ten priority areas in the original plan:

Training:

- Courses in digital literacy for both women with disabilities who are in employment and those seeking work.

Employment:

- Support for self-employment initiatives by female entrepreneurs with disabilities by means of soft credits and non-recoverable subsidies;
- Promote teleworking for women with disabilities, including training programmes adapted to different needs depending on the type of disability;
- Conduct a study on the social reality in the field of employment, market evolution and job opportunities for women with disabilities.

Gender violence:

- Set up an early-detection system to identify cases of gender violence against women with disabilities in institutions and residences;
- Guarantee women with disabilities who are victims of gender violence are given priority in the allocation of public sector housing, support for adaptations in the home, home assistance and access to public care services in cases of gender violence;
- Give women with disabilities who are victims of gender violence priority in the allocation of public places in residential and day-care centres;

- Ensure urban and architectural accessibility, and accessibility in terms of communication, in emergency housing, refuges and sheltered housing for women (at least one accessible service per province);
- Set up an emergency sign language interpretation service to operate in police stations, night courts and with emergency services;
- Quotas for women with disabilities who are victims of gender violence in specific employment programmes in the Kingdom of Spain;
- Increased fiscal benefits for hiring a woman with disabilities;
- Geographic mobility in employment in the case of women with disabilities who are victims of gender violence.

Health:

- Develop legal provisions making it obligatory to secure the informed consent of all women with disabilities to any medical procedure;
- Introduction of technical adjustments and adaptations to devices to ensure gynaecology and obstetrics services are accessible for women with disabilities.

Motherhood:

- Develop specific preparing for labour and birth services that answer the individual needs of women with disabilities;
- Facilitate access to assisted reproduction programmes (staff awareness, guarantee of non-discrimination).

Sexuality:

- Develop and implement measures making it obligatory to secure the informed consent of women with disabilities prior to sterilisation and abortion procedures.

Media and social image:

- Carry out campaigns to challenge and debunk the widely held image of women with disabilities among the families of women and girls with disabilities and relevant organisations;
- Promote positive models of women with disabilities in all types of mass media.

Participation and leadership:

- Set up women's commissions within national and regional structures in the disability movement in order to strengthen the ongoing dialogue on priority issues concerning girls and women with disabilities and mothers of boys or girls with disabilities;
- Develop specific guidelines concerning participation quotas for women and men. These should go out from the National CERMI Executive Committee to all regional disability councils and organisations of people with disabilities in Spain, and campaigns to promote their implementation should be conducted;
- Conduct a review of the statutes of organisations of people with disabilities to ensure non-discrimination and equal opportunities for all members.

Also in 2005, the book **"In Favour of Equality, United in Diversity"** was published. The work was launched at a public presentation held in the Spanish Parliament. As was the case with the plan, it was distributed to public authorities and decision-makers in the fields of gender and disability. Briefings were also arranged with the Equality Departments of each of the main political parties and female members of the Spanish parliament involved in this issue.

All the work carried out to raise awareness of the inequalities faced by women with disabilities finally crystallised when CERMI's constitution was amended at its General Assembly in 2007 to incorporate the gender perspective as one of the council's basic principles and ensure it is included in all its action plans, research and initiatives.

3.2. *Public powers*

In line with CERMI's status as a representative body engaged in political action, the Women's Commission has appeared formally before the Congress of Deputies (lower house) and Senate on several occasions. These appearances have surely helped to place the demands raised by women with disabilities on the political agenda.

In addition, the Commission has appeared before the European Parliament (representing also the European Disability Forum on this occasion), thanks to an initiative taken by Elena Valenciano, a Spanish Member of the European Parliament, to include this issue on the agenda of the relevant European Parliament Commission.

The following is a list of formal appearances, in chronological order and starting with the most recent:

- Appearance before the Employment and Social Affairs Commission of the Congress of Deputies to present the 1st CERMI Integrated Action Plan for Women with Disabilities (19th June 2007);

- Appearance before the Ad Hoc Commission for Integrated Disability Policies of the Congress of Deputies with respect to the White Paper on Assistance for People with Dependency Needs (4th October 2005);

- Appearance before the Employment and Social Affairs Commission of the Congress of Deputies regarding the Draft Organic Law on Integrated Protection Measures against Gender Violence (7th September 2004);

- Appearance before the Women's Rights and Equal Opportunities Commission of the European Parliament regarding women and disability (18th February 2004);

- Appearance before the Joint Congress of Deputies/Senate Commission on Women's Rights regarding women and disability (11th February 2003).

In addition, the CERMI Women's Commission has engaged in cross-cutting issues of political interest to women with disabilities, both by drafting amendments that have been sent to political parties for submission and developing and monitoring these matters where appropriate. The following are examples of issues in which the Commission has participated:

- Organic Law 1/2004 (December 28th) on Integrated Protection Measures against Gender Violence;
- Law 39/2006 (14th December) to Promote Personal Autonomy and Assistance for People with Dependency Needs;
- Organic Law 3/2007 (22nd March) for Effective Equality between Men and Women;
- First Draft of the Sustainable Development in Rural Settings Act.

Furthermore, the CERMI Women's Commission took part in the final phase of the preparatory work for the UN Convention on the Rights of Persons with Disabilities; its efforts were instrumental in securing European Union support (the EU spoke with one voice at that stage) for the inclusion of a specific article on gender in the Convention and the incorporation of a number of additional references to gender in other articles.

In addition, in 2007 the CERMI Commissioner for Women's Affairs (who also chairs the Women's Commission) was given the opportunity to accompany the Minister for Employment and Social Affairs when he travelled to New York to sign the Convention on behalf of Spain on March 30th and act as a witness to the signing, along with the Spanish Ambassador to the United Nations, at the signing ceremony. Some months later, she was also part of the CERMI delegation accompanying the Vice-President of the Spanish Government to New York for the official deposit at the United Nations on December 3rd 2007.

3.3. *Empowerment and Leadership*

There has been notable progress in recent times in terms of increased engagement by women with disabilities in their organisations and regional disability councils. This was evident at a national gathering organised by CERMI for female leaders with disabilities in Zaragoza in September 2006 under the slogan **"Gender and Disability: Compatible Realities"**.

In effect, women's commissions have been set up within regional disability councils (Regional CERMIs); Andalusia, Aragon, Asturias, Catalonia and Valencia all now have such commissions. Furthermore, commissions and working groups addressing gender issues are being created in organisations of people with disabilities and their families, above all in bigger organisations such as the Spanish Confederation of People with Physical and Organic Disabilities (COCEMFE), the National Confederation of Deaf People (CNSE) and the National Organisation of the Blind (ONCE). This trend facilitates disability-specific progress in demands and needs.

In addition, however —and this is particularly significant—, regional public authorities, through their social affairs structures, have begun to create joint commissions involving regional government representatives and women with disabilities (such as for example in Madrid and Andalusia).

At the same time and complementing the above, the preparations to develop a **National Network of Female Experts in Gender and Disability** have been concluded. The aim of the network, which is Internet-based and is also open to women without disabilities, is to exchange information and work together on these issues.

A CERMI representative has sat on the European Disability Forum Women's Committee since it was created and played a particularly active role in its work.

In the near future, nevertheless, efforts must undoubtedly focus on the mainstream women's movement.

3.4. *Communications*

In this section we should distinguish between actions in the field of communications that are aimed at the disability movement itself and those targeted at a wider audience.

In the first of the two, the Women's Commission has expended great efforts in terms of communications in relation both to the national council (CERMI) and its constituent parts. Notably, the Commission has developed sector-specific position papers for each of CERMI's commissions (employment, education, accessibility, etc.). These documents were presented to and discussed with the chairperson of each commission. Direct contact has been made with the president of each and every regional council to encourage them to create and support specific work themes related to women with disabilities.

As regards communication with wider audiences, the CERMI web site now has a section devoted to gender. Documents are prepared specifically to be posted and made available on the web site for anyone who visits the page and an E-mail account has been created (mujer@cermi.es). The Commission also works closely with the newspaper ***cermi.es***, playing an active role in the design and content of the section the paper devotes to issues related to women with disabilities. A blind female journalist has been involved in this work since 2007.

In addition, in 2002 CERMI instituted national awards, known as *cermi.es*, to acknowledge and express gratitude to recipients for their solidarity with the aims and goals expressed by the organisation that represents people with disabilities and their families. Since 2005, there is now an award for an ***Action Benefiting Women with Disabilities*** for the outstanding individual, project, initiative, enterprise, entity or public power in the field of women with disabilities and gender equality.

At the same time, it is worth highlighting the engagement and participation of members of the Women's Commission, both in their own organisations and in wider terms, in the media, congresses, seminars and meetings, and underlining the work done in writing articles, speeches and chapters for specialist books on the subject to present the gender and disability perspectives in a number of subject matters (health, employment, sexuality and education, among others).

CERMI is currently involved in preparing a new publication titled ***Pregnancy and Motherhood*** and drafting a guide aimed at girls and women with disabilities on ***Gender Violence and Sexual Abuse***.

3.5. *Representation*

CERMI, through its Women's Commission or directly in the person of its Commissioner for Women's Affairs, is currently represented formally in the following official bodies:

- Since June 2004, in the ***Royal Board on Disability***, which is chaired by Her Majesty the Queen of Spain, with a seat on the board as an expert on women and disability;
- Since 2005, through a permanent representative on the **Women's Health Observatory** under the **Spanish Ministry for Health and Consumer Affairs**. CERMI has taken part in a range of seminars and conferences and has been involved in drafting material on key issues for women with disabilities;
- **National Observatory on Gender Violence:** CERMI has played an active role in meetings held by the observatory and in drafting all the documentation issued by it.

Finally and just recently, in December 2007 CERMI secured representation through one of the eleven ordinary positions on the Governing Council of the Ministry for Employment and Social Affairs' Women's Institute. This achievement meets a long-standing demand held by the disability movement.

A large part of the Institute's work in the coming years will focus on rolling out the Action Plan on Equal Opportunities for Women and Men, recently adopted by Spain's Council of Ministers, in which women with disabilities should enjoy the position they deserve.

Success has not been forthcoming, however, in all fields. Although efforts have been ongoing over the past four years to secure representation for women with disabilities on the Spanish Coordinating Body for the European Women's Lobby (CELEM), there has, as yet, been no positive outcome due to the fact that this organisation has a statutory obligation to accept only women's organisations as members.

4. Best Practises

The last section of this report is given over to presenting the work carried out by two organisations of women with disabilities; thanks to their efforts, determination and good judgement they represent a clear point of reference and best practises in the work undertaken in different parts of Spain for the benefit of women with disabilities.

4.1. *Association of Non-Standard Women*

The Association of Non-Standard Women (www.donesnoestandards.cat) was founded in Barcelona in 1995 with the aim of making the voice of women with disabilities heard and securing positive mainstreaming for women with disabilities in society, while respecting their diversity and avoiding social exclusion. As indicated on its web site, it has 698 female members with different types of disability and resident in all parts of Catalonia.

The association's work gained relevance thanks to a pioneering project called "*Women from Barcelona*", winner of the Mª Aurelia Capmany Award in 1996. The project's main goal was to address the psychosocial barriers faced by women with disabilities, raise awareness of the situation in which non-standard women find themselves and gather data on the general public's opinion on women with disabilities.

Further examples of best practises in raising awareness and respect for diversity by the association include the following projects:

- *Link with Diversity (1997):* Secondary school pupils write essays and use teaching material in order to encourage them to identify and reflect on differences which we all have but may not like, and understand that these differences contribute to each individual's personality;
- *Women with Disabilities: Social Exclusion Indicators (2001-2002):* A study of the lack of opportunities for social integration faced by women with disabilities in Europe by means of a prioritised indicator system;
- *People in Our World (2000-2004):* Aimed at mainstreaming women with disabilities in a worldwide cultural event to enable citizens to enjoy their message, studies and artistic expression in their relations with women with disabilities;
- *Training Module in Gender and Disability (2004):* A practical exercise aimed at promoting the development of training activities in gender and disability and working on systematised types of behaviour through categorisations caused by the socialisation process itself. The goal is to eliminate the root causes that bring about the current situation of discrimination faced by non-standard women;
- *Psychosocial intervention service for women with disabilities*: Aimed at facilitating women's participation in public life, their independence and an active working life, favouring new attitudes both in women themselves and among professionals in the health care sector, the world of work and society in general.

4.2. *Andalusian Confederation of People with Physical and Organic Disabilities: work in favour of women with disabilities*

The Andalusian Confederation of People with Physical and Organic Disabilities (CANF-COCEMFE) set up its Women's Commission, tasked with promoting policies to boost equality between women and men within the disability movement, in Andalusia in 1999.

The following year the LUNA Association for the Promotion of Women with Disabilities was created. It was the first organisation of its type in Andalusia and was led by women with disabilities who had great experience in the disability movement. In 2001 the Women's Department was set up, thus consolidating the integrated approach taken with regard to gender in the organisation's overall strategy.

The *Integrated Assistance Programme for Women with Physical Disabilities in Andalusia* was developed and initiated. The programme's main goal is to mobilise the full potential women in the movement have, boost their engagement and offer the chance to take part in self-help groups and create solidarity networks among women. More than 3 000 Andalusian women have taken part, thus enabling a detailed study on the issue to be conducted.

Over the past years the Women's Department, in close partnership with the LUNA Association, has participated in events related to gender, such as for example events to commemorate International Women's Day, where a statement outlining demands is read out, and the International Day for the Elimination of Violence against Women. The Department also produces its own newsletter: "Entangled…Andalusian Women with Disabilities' Network".

Studies have also been carried out in Andalusia. These have helped to raise awareness and mobilise women in the movement belonging to organisations engaged with physical and organic disabilities in regions outwith Andalusia. The ultimate aim is to set up a national organisation of women with these types of disability.

The action areas are as follows:

- Conduct studies, including statistical information, and carry out research;
- Lobby for changes in legislation to boost women with disabilities' participation in society;
- Call for specialised resources offering women guidance and peer-to-peer support;

- Provide resources to prevent and combat all types of violence against women and develop programmes to mainstream women with disabilities;
- Develop a provincial structure in order to boost the participation of women in all aspects of political and social life.

One of the organisations that makes up CANF-COCEMFE Andalusia is the LUNA Federation of Associations for the Promotion of Women with Disabilities Andalusia, created in 2007 and composed of eight LUNA provincial associations. The LUNA Federation and LUNA Association are currently in the process of handing over the activities the association has been developing to the Federation.

SWEDEN

SWEDISH DISABILITY FEDERATION/HANDIKAPPFÖRBUNDENS SAMARBETSORGAN
DELEGATES: ANNELI JONEKEN AND AGNETA LINDQVIST

The Swedish Disability Federation consists of 43 disability associations with about 500.000 individual members. More than 50 percent of the individual members are women. The Swedish Disability Federation is working with common policy issues. Within the federation, member associations work together based on the view of all people's equal value and all people's equal rights.

The Federation has a board consisting of 7 members, of which two are women. The highest decision-making body is the presidency meeting where all associations have a seat. A member of the presidency meeting shall be the president of his/her association or elected representative in the association board. Representatives of the staff have no voting rights. In the 43 associations there are today 23 female presidents. The highest director in the associations' offices is a woman in 26 of the associations. Regarding work on gender equality, the Swedish Disability Federation's office has begun to draw up an equality plan. There is no special committee or working group of women.

Since 1997 there is within the Swedish NGO-movement a special disabled women's organization: Forum - Women and Disability in Sweden (FQ), which is a member of Swedish Women's Lobby (the umbrella organisation for Swedish women's organisations) but not a member of the Swedish Disability Federation. Members in FQ are individual disabled women, disability organizations and their women's committees/groups. FQ also has supporting members. For more details on FQ see enclosure on the last two pages of this document.

Some Statistics

The total population of Sweden in March 2006 was 9.047.752, with 4.561.202 women and 4.486.550 men.

1.2 million Swedes are considered to have some form of permanent disability.

One million people between 16-64 years old in Sweden have some disability, which corresponds to 20% of the population.

Around 560.000 people over 16 years of age have mobility impairments. Of these, around 100 000 need a wheelchair.

Just over 165.000 people over the age of 16 have impaired vision. Of these, around 23.000 are blind or severely visually impaired.

Around 980.000 people are hard of hearing.

150.000 over the age of 16 are completely deaf or are severely hard of hearing.

Around 36.000 people are calculated to have some form of intellectual disability.

Around 2.000.000 people are estimated to have some kind of allergy.

The proportion of people with disabilities and the severity of the disability increase with age. Between 2000 and 2020, the proportion of people over the age of 65 is expected to rise from around 17 per cent to close on 22 per cent.

After 2020, the proportion of people over the age of 80 is expected to rise sharply.

Labour market statistics: 6 of 10 have a disability which means that their working ability is reduced. 313.000 women and 243.000 men estimate that their working ability is reduced, representing 65 % of women with disabilities and 56 % of men with disabilities. The percentage of full-time employees has declined since 2000 and is now 66% compared to 70% in 2004.

Women with disabilities are working part-time to a considerably greater extent than men. Persons with disabilities are employed within the municipal sector to a greater extent than the population. Women mention to a greater extent that they need adapted working time and personal adapted technical aids at work. Regarding adjustment of the workplace and working tasks it appears that men to a greater extent than women have their needs met.

49.9 % of women with reduced working ability have a job compared to 54 % of men. The unemployment rate for persons with disabilities with reduced working ability is 8.7 % compared to 4.3% of the population. The unemployment rate is declining in Sweden but not among the group of persons with disabilities with reduced working ability.

7% of persons with disabilities with reduced working ability mention that they have been harassed, bullied and violated due to their disability. Especially women experience that they have being harassed at work.

Education among women is higher than among men. 26% have a post-secondary education compared to 21% of men. Among those with reduced working ability, 22% of women and 16% of men have a post-secondary education.

Some more Information on the Situation of Women With Disabilities

There has been a national action plan for disability since 1999, but gender equality aspects are not integrated into disability policies even though women's and men's roles and living conditions differ in many ways. Power relations based on gender exist in the disability field as well and women and men are not treated equally even though they would have the same needs. This means that women and men with disability do not today have the same possibilities to the support systems in society.

In the follow up of the action plan on disability the government is pointing out that consideration of a gender perspective needs to increase within disability policy and that methods and knowledge on gender perspective in activities within the disability field need to be further developed.

There is little knowledge on how women and men with disability are discriminated against due to their sex. Most studies of persons with disabilities do not have a gender perspective. Also the feminist research has left women with disabilities invisible through not integrating this group of women when studying different women's living conditions and experiences. Within research on violence, women with disabilities have long been neglected and it is only in recent years that research has started to take up the violence that women with disabilities are facing.

Studies show that women with disabilities are facing negative special treatment and discrimination within fields such as the labour market and education. Some studies show that women have less education than men and do not have a place in the labour market which affects their economy negatively. One study shows that women more frequently receive passive rehabilitation which entails sickness contributions with the lowest level of compensation, while men receive more active rehabilitation that is linked to work in the form of pay contribution services and training contributions. Women receive shorter periods of vocational training than men.

Handu's standard of living study, dating from 2005, shows that women with disabilities have lower incomes than men. It is therefore more frequently women who have a smaller cash reserve than men and who have had difficulties paying ongoing household expenses over the previous 12 months. With regard to support for housing, it is apparent from the National Board of Health and Welfare report on the situation of disability care, dating from 2006, that the proportion of men and women is very evenly split in terms of initiatives pursuant to LSS, except for contacts, housing for adults and daily activities, in which men are in the majority. Men also constitute a majority of those granted assistance compensation pursuant to LASS. More adult men than women receive personal assistance. Men also receive more hours of assistance. The gender differences are the same for all three groups of people within LSS. In terms of initiatives from players other than social services, too, there are gender differences. Men are, for example, more frequently given vehicle support, while women are more frequently granted subsidised transport.

The 2004 National Board of Health and Welfare report on the situation of disability care criticises the fact that, though not great, the difference between men and women recurs systematically. However, despite the fact that women are given more home help, rehabilitation and early retirement than men, there are more women who do not receive full pre-retirement benefits or the help they need from the home help service.

The number of initiatives for children with disabilities has grown since 1998, particularly for boys, who are more frequently the object of LSS initiatives than girls.

There are more women who use assistive devices, but they pay for them more frequently than men. There are more men than women who receive individually-tested assistive devices.

Men receive a greater share of rehabilitation resources, more assistance compensation and find it easier to secure disability allowance than women with disabilities. Women use more medication than men, but the medicines prescribed to them are less expensive than those received by men. The action plan for national disability policy highlights the fact that women live longer and have poorer health than men, which means that overall they need more help from society.

The situation assessment by the National Board of Health and Welfare, dating from 2002, states that the elements of the social insurance system that are based on income give more to men with disabilities than to women with disabilities. Women also have greater financial difficulties. In addition, it is stated that the social insurance provisions relating to economic compensation for illness and disability have differing effects for women and men and that work-related insurance provides better coverage for injuries that afflict men.

Women with disabilities more frequently consider their standard of health to be worse than men with disabilities. Women often have lower income than men and therefore live in a more vulnerable economic situation. Many women testify to difficulties coping with ongoing expenses and the costs of necessary care and rehabilitation initiatives. Women feel to a somewhat greater extent than men that they have been improperly or unfairly treated in terms of medical treatment.

A study by the Swedish Association of the Visually Impaired showed that visually impaired persons generally have a worse health status than the population at large.Of Sweden's population, 75% consider that they have good health while 55% of visually impaired persons consider this.

Even though some 20% of the population are persons with disabilities, this is not reflected in the media, which rarely takes up issues relating to persons with disabilities. And if they do the portrayal is often negative and persons seem passive, helpless and in need of care. Of the total transmitted time from Swedish TV in the years 1956-2000, only 1.8 per thousand dealt with disability and persons with disability. No TV program took up the specific situations of women with disabilities. The media has a very important role in how we regard womanhood and how to be a woman. The stereotype message of a well-trained slim young woman's body image that is spread through media strengthens the image of women with disabilities as not normal but different. Even though it is more common than expected that women with disabilities are victims of sexual violence, women with disabilities not considered as persons with sexual needs.

There have been several reports lately carried out regarding violence against women with disabilities. In a report from women with psychiatric problems it is shown that 70% of women seeking help in psychiatry have a history of violence and abuse in their childhood, adult life or both. Women also themselves saw a link between their health and the abuse. These women are not offered any help to treat the trauma they have experienced, neither in the health care system nor in crisis centres. Another report published in 2007 by Handu shows that 31% of women with disabilities who have received the enquete (some 1 200) have been victims of violence and abuse. Women with mobility impairments often have no access to secure housing since the crisis and refuge centres are not accessible.

In the health care system it is not customary to ask questions about violence and abuse to women with disabilities when they come with damages in their body. It is often the disability which gets the main focus. A government action plan on violence against women will be published soon and will, according to available information, include action points regarding women with disabilities.

Reports on UN conventions

Reports on UN conventions Swedish Disability Federation has been active in compiling alternative reports to the *UN Conventions on Economic, Social and Cultural Rights and Civil and Political* Rights on the situation of girls, boys, women and men with disabilities as regards the fulfilment of the convention articles in Sweden. Two comprehensive reports have been submitted and they will be reviewed by the Convention committees at the same time as the Swedish Government's reports. Swedish NGOs have also submitted an alternative report to the *Convention on the Elimination of All Discrimination against Women CEDAW*. Forum Women and Disability in Sweden has taken part in all these three processes of alternative report writing.

Discrimination Legislation in Sweden

Information in this chapter comes from the alternative report the Swedish Disability Federation in 2006 submitted to the UN on the *UN Convention on Economic, Social and Cultural rights* and in 2007 to the *UN Convention on Civil and Political Rights.*

Summing up about discrimination legislation, the Swedish Disability Federation concluded with the following recommendations:

- Review discrimination legislation so that girls, boys, women and men with disabilities are given the necessary protection against discrimination;

— Work to ensure that a lack of accessibility comes to be classed as discrimination;

— Ensure that anti-discrimination clauses are adopted in all public procurement.

Despite the fact that Sweden has legal protection against certain forms of discrimination, discrimination for reasons of disability is common in Sweden. One in every two persons with disabilities feels that he/she is discriminated against! This is shown by a survey conducted in 2005 by Statistics Sweden on behalf of, among others, the Swedish Disability Ombudsman. In most cases, this involves experiences in everyday life. More than one in every four people state that they: cannot use buildings, cannot read information and cannot use aeroplanes/buses/trains.

Women with disabilities feel more highly discriminated against then men. Nearly 40 per cent of women feel discriminated against when purchasing goods or services. In healthcare and medical treatment, nearly one third feel discriminated against, while just over one quarter feel discriminated against in relation to public transport.

Younger people feel more discriminated against than the elderly. In cafés, restaurants and other places where people go out, younger people feel more vulnerable, with just over 40 per cent stating this. Just as many feel discriminated against when purchasing goods and services. Nearly half of those who responded state that the discrimination involves being the object of derogatory comments and suffering bullying, teasing and ridicule.

A ban on discrimination for reasons of disability is enshrined in the *Swedish Constitution.* The provisions of the Constitution cannot be referred to at the courts; however, no other laws or ordinances may violate its provisions. To bolster the protection against discrimination further, there have since 1999 been four laws that prohibit discrimination for reasons of disability. These Acts relate to working life, training, the purchasing of goods and services, and housing.

The Working Life Discrimination Act. The first Act was adopted in 1999. This is an Act that prohibits discrimination in working life on grounds of disability.

The Act applies, for example, to recruitment, wage-setting and the provision of notice of dismissal. An employer is not allowed to treat someone seeking work or an employee worse owing to disability. An employer is also obliged to adopt supportive and adaptation measures in certain situations. The Act was tightened up on 1 July 2003 and was extended to encompass professional practice as well. From solely protecting people with disabilities, people with links to someone with a disability are now also protected.

Since the *Working Life Discrimination Act* was passed, a number of settlements have been achieved between the Swedish Disability Ombudsman HO and employers and between trade unions and employers. The Act was tested for the first time in court in 2003 when the Swedish Labour Court found that a man with diabetes had been discriminated against when he applied for a job at an oil refinery. The number of notifications is growing steadily. In 2004, the Swedish Disability Ombudsman received 81 notifications of discrimination in working life compared with 50 in 2003.

The *"Equal Treatment of College Students Act"* has been in effect since 1 March 2002. The Act was the first one to ban discrimination for reasons of gender, ethnic background, religion, sexual orientation and disability in one and the same law. The object of the Act is to promote equal rights for students and applicants and to counter discrimination. Colleges must plan and document what measures are needed to promote equal treatment and prevent harassment.

The number of notifications of discrimination at college received by the Swedish Disability Ombudsman has fluctuated in recent years. In 2002, 9 notifications were received, while in 2003 25 notifications were received. In 2004, the number of cases fell to 12, while in 2005 11 notifications were received. The area that predominates is accessibility. Accessibility cases account for 47 per cent of the number of notifications.

The third Act is the *"Discrimination Prohibition Act".* This Act was enacted in 2003 and stipulates that nobody should suffer inferior treatment on grounds relating to ethnic background, religion or faith, disability or sexual orientation. The Act protects individuals in the purchasing of goods and services and also when purchasing a home or in housing. The Act also contains a number of provisions relating to working life in the broad sense of the term. For example, it protects against discrimination in employment mediation and when starting up one's own business.

The discrimination reason of disability does not, however, apply in all sections of the Act. The areas not covered are social services, the subsidised transport service, the national subsided transport service, home adaptation, social insurance, unemployment insurance, healthcare and medical treatment (sections 10-13). According to the Swedish Disability Ombudsman's "wish list" for the discrimination committee, it is apparent that "it is the HO's experience that negative special treatment of people with disabilities occurs within all the areas listed in sections 10-13." It is also apparent that many feel that they have inadequate opportunities for influence and self-determination, particularly within social services, healthcare and medical treatment. Unwarranted waiting times, ignorance and questioning of the disability in question are some of the other problems faced by people with disabilities.

A concrete example that can be cited is the problems surrounding abusers of people with mental disabilities who fall between two chairs, and do not receive the care they need. It also happens that people with mental disabilities who seek care for somatic problems are referred to the psychiatry service. People with HIV feel that they are discriminated against by dentists who refuse to treat them. The same problem is experienced by people with intellectual disabilities, while people with mobility impairments have problems entering dental practices. Notifications concerning the *Discrimination Prohibition Act* increased during 2004. During 2004, 57 notifications were received by the Swedish Disability Ombudsman, compared with 25 in 2003. The Act is still relatively new and therefore not as well known as discrimination protection at work.

The Act Prohibiting Discrimination and other Mistreatment of Children and Pupils This Act is the latest one and came into force on 1 April 2006. The Act prohibits discrimination for reasons of gender, ethnic background, religion, sexual orientation and disability. The Act covers all activities described in the School Act: preschool activity, schoolchildren care, compulsory schools, upper secondary schools and local authority adult education.

The Act also means that children and pupils are afforded protection against other mistreatment, such as bullying. The Act stipulates that every school activity must have an equal treatment plan. The plan must describe what measures are planned to eliminate direct and indirect discrimination and other mistreatment. The plan must form an active tool that is used in day-to-day activities. If the obligation to draw up an equal treatment plan is not discharged, the principal becomes liable for damages. If a pupil asserts that he or she has been the object of bullying and other mistreatment, the principal must investigate and prevent continued harassment. This applies also to offensive behaviour between the pupils. The Swedish National Agency for Education and the various ombudsmen must, based on their areas of responsibility, ensure compliance with the Act.

Need for Extended Discrimination Protection

The Swedish Disability Federation can state that there are two different shortcomings in the Swedish discrimination laws:

— People with disabilities are not covered by all the provisions of the "Act Prohibiting Discrimination";

— A lack of accessibility is a major reason why people with disabilities in Sweden cannot participate in society under equal conditions. Discrimination against individuals with disabilities owing to a lack of accessibility needs to be addressed in areas of society other than the world of work and colleges.

In February 2006, a Discrimination Committee appointed by the Swedish Government presented a final report on discrimination legislation in Sweden. In the final report, the committee proposes, among other things, the introduction of a new Act relating to prohibition and other measures to combat discrimination. The new Act must largely replace the current discrimination legislation, but also provide extended protection for more people and in a number of areas of society. The Act should have the aim of countering discrimination and otherwise promoting equal rights and opportunities regardless of gender, sexual identity, ethnic background, religion or other faith, disability, sexual orientation or age. The Committee's point of departure has been that protection against discrimination should be as equal as possible for the various grounds of discrimination.

The new Act relating to prohibition and other measures to combat discrimination proposes that failure to adopt accessibility measures is to be regarded as discrimination. In addition, it must not be possible to make any distinction between the various grounds of discriminations, as currently happens. This new Act may thus rectify some of the deficiencies that the disability movement considers to exist in current legislation in relation to people with disabilities. The Discrimination Committee also proposes that the various ombudsmen be combined into a single authority, "the Discrimination Ombudsman". The new ombudsman is to supervise discrimination connected with the grounds of discrimination referred to above. It is also proposed that the new Ombudsman be given independent authority to participate in the Government's reporting to the human rights treaty bodies. The Ombudsman must, under the proposal, also be granted authority to communicate independently with the treaty bodies.

The Swedish Disability Federation welcomes the fact that one of the Discrimination Committee's guiding principles has been that protection should be as equal as possible for the various grounds of discrimination. The Federation also welcomes the fact that it is proposed that lack of accessibility be covered by the new Act. There are however differing opinions among disability and women's organizations, as well as in society, about merging all the ombudsmen into one authority. The Swedish Government will be putting forward its proposal probably in late 2007.

Anti-discrimination clauses in public procurement. Public procurement in Sweden amounts to SEK 300 billion SEK per annum. Rules against discrimination may in this context play an important part in work to achieve equal rights in society. The Swedish Disability Federation raised this issue in the alternative report and considers that the Government must take greater responsibility for ensuring that anti-discrimination clauses are adopted in public procurement. Public funds should not be assigned to activities in which human rights are violated. The Swedish Government should investigate the possibility of linking State support to requirements of non-discrimination or active measures to promote diversity.

Action Plan for Disability Policy

In 1999, the Swedish Government adopted a national action plan for the disability policy *"From patient to citizen*" (government bill 1999/2000:79). The action plan extends until the year 2010 and involves all areas of society. Disability policy work is to be specifically geared to identifying and eliminating obstacles to full participation in society for people with disabilities, preventing and combating discrimination and giving children, young people and adults with disabilities opportunities for achieving independence and self-determination. Until 2010, three areas of work are specifically prioritised:

- Ensuring that a disability perspective permeates all sectors of society;
- Creating an accessible society;
- Improving the treatment of people with disabilities.

The national action plan gives the national authorities clearer responsibility than in the past for disability policy work. Fourteen authorities have been designated as "sector authorities" with specific responsibility for implementing disability policy within their respective areas of society. *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities* for ensuring the participation and equality of people with disabilities underlie disability policy.

A new authority, "*The authority for disability policy co-ordination*" (Handisam), was established on 1 January 2006. This authority's task is to promote effective implementation of the national action plan. The work entails, among other things, taking responsibility for the co-ordination of disability policy measures by supporting and encouraging players at various levels to consider disability policy targets in their respective activities.

Gender Equality

The objective of Swedish equality policy is for women and men to have the same rights, obligations and opportunities in all spheres of life. In the government bill on equality policy entitled "*Divided power – divided responsibility*", the Swedish Government stated that gender equality should permeate all areas of policy and all activities. Among action plans in the gender equality area a new action plan on violence against women is currently being developed by the government.

The National Action Plan for Human Rights

In spring 2006, the Swedish Government presented the second national action plan for human rights (for the period 2006 – 2009). The plan is intended to provide guidelines and a structure for human rights work and in this way speed up the implementation of the rights. The proposed measures in the action plan are aimed at the entire public administration, at national, regional, local council and municipal level and are based on various discrimination grounds, such as sex, ethnic background, religion or other conception of faith, sexual orientation and disability. There are several action points mentioned in the human rights action plan on persons with disabilities, including one study regarding violence against women with disabilities.

Ratification of the UN Disability Convention

There is a process going on in Sweden to prepare a decision to ratify the disability convention and the optional protocol. A review of all legislation is taking place. The disability organizations have been asked to appoint a working group to cooperate with the person who has been commissioned to undertake the review this autumn.

So far two meetings have been held in the enlarged working group. Among other things article 6, a gender perspective as well as the issue of multiple discrimination have been discussed.

ENCLOSURE

FORUM – WOMEN AND DISABILITY IN SWEDEN is a women's organisation with a number of Swedish disability organisations as well as individual women with disabilities as members. Established in 1997 as a continuation and development of a project with the same name, which existed between 1988/89-1997.

FQ aims to actively strengthen the inner powers of women and girls with disabilities and improve their situation in all fields of society such as working life, family life, leisure, culture, rehabilitation and education.

FQ works against all forms of discrimination and violence against girls and women with disabilities and in favour of better possibilities to influence society and organisations.

FQ works through awareness raising, empowerment training, cooperation with other organisations, lobbying and advocacy. FQ works to ensure that women and girls with disabilities have full access to their human rights.

FQ is a member of the Swedish Women's Lobby, active in women's and disability organisations at local, national and international levels and represented in the Gender Equality Council of the Swedish government.

FQ has both individuals and organisations as members.

FQ contributes with the women's dimension within the disability movement and the disability dimension within the women's movement.

The Mission Statement

According to the statutes, the Forum Women and Disability in Sweden is a democratic and feministic organisation of women, which is independent as regards party politics and religion. The aim of the association is:

- To actively strengthen the inner powers of women and girls with disabilities and within all fields of society act for improvements in the situation of girls and women with disabilities;
- To contribute to better possibilities for influence and power in society for girls and women with disabilities;
- To work against all forms of discrimination and violence against girls and women with disabilities;
- To work for increased influence for girls and women with disabilities in their own organisations.

How does the Association work

FQ has an annual meeting which elects the board, makes decisions on the policies and the plan of action.

FQ focuses on the following priority areas through various ways of empowerment and growth: Employment and education/ Health and rehabilitation/ Violence, abuse, discrimination/Culture/Human rights of women.

FQ has contact persons to work in cooperation with other organisations where FQ is a member, such as Swedish Women's Lobby, UNIFEM Sweden, KSAN the Cooperation Council of Sweden Women's organisations in Alcohol and Drug issues and the Association on Disability History.

FQ cooperates in projects and in policy work with disability organisations in Sweden at national, regional and local levels and with the Swedish Disability Federation. The Forum works to establish active regional networks among its members, and to cooperate with other interested organisations and networks at national and regional level. There are regional network-groups in Göteborg and Stockholm.

FQ has a representative in the Council on Gender Equality of the Swedish government and in a Council linked to the National Board of Health and Welfare. In priority issues, FQ sends written statements to current proposals from government.

Recently, the Forum Women and Disability had a gender awareness training-dialogue with the staff at Handisam.

FQ has produced a photo exhibition called EN GARDE, with black and white photos and poetic texts showing the strength and sexuality of women with disabilities. The exhibition is also available as a video. Forum is involved in projects to develop methods for disabled women's empowerment, especially in the field of culture. The projects MUSTEA and KULTURKÄLLAN have produced four music theatre performances, in which women with and without disabilities develop their creativity in different fields. A book of literary writings of women with disabilities has been published and a new book-project is ongoing. Another ongoing project is a pre-study to look at educational background and training of women with disabilities.

From our prehistory in the Project Women and Disability there are eight seminar reports and the book "*Images of Women*". A publication covering the ten year project period has been drafted. FQ takes an active part in international cooperation with other organisations through projects, conferences and seminars. FQ is part of a Nordic–Baltic informal network among women with disabilities and has links to the European Disability Forum EDF Committee on Disabled Women and Girls' Issues and to the European Women's Lobby (EWL).

FQ has been a partner in an EU-Phare/Lien project with organisations in Spain, Estonia and Latvia, a Daphne project with Spain, Germany and Denmark and a Socrates/Adult education project with Finland and Romania.

Membership

Forum is open for membership to both individual women with disabilities and to disability organisations at national, regional and local levels, as well as for supporting membership to both individuals and organisations. In 2007, FQ has some 90 individual members, 4 disabled women's groups and 14 organisations as full members. The specific disabled women's groups/organisations are: Deaf women's association in Stockholm, Swedish Breast Cancer Association, Women's group within Grunden in Gothenburg, Danish Women with Disabilities. There are also some 10 supportive individual and organizational members.

Forum – Women and Disability in Sweden/Forum – Kvinnor och Funktionshinder
Krukmakargatan 73,
SE-117 41 Stockholm
Tel +46-(0)8-673 15 31
Fax-22 95 11
kvinnor.handikapp@swipnet.se
www.kvinnor-handikapp.se

Reports from European Non Governmental Organisations of and for People with Disabilities

ASSOCIATION DE RECHERCHE ET DE FORMATION SUR L'INSERTION EN EUROPE (ARFIE)

FÉDÉRATION MÉDICO-SOCIALE DES VOSGES (FMS)
DELEGATE: VÉRONIQUE LAFONTAINE

Women make up 28.81% of the workforce in ESAT (Service d'aide par le travail = support service through work). They are a minority. There are no women in decision-making bodies. The President has a disability.

In the group home, 35% of residents are women. Three people represent the service-users (one of them is a woman).

Only 28.5% of women are getting support and advice in their wish to lead an autonomous life. If we take the figures from the 2005 report, 179 men get support whereas only 110 women receive it.

It should also be noted that women get less home support. They leave their families later than men, and they suffer more from unemployment than men.

The families of women with disabilities are not really helpful when it comes to finding a job. They are given the housework to do; employment is not a priority. Moreover, when their parents get older, they are needed at home to support them as they depend on them.

Affective and sexual life is often denied to women with disabilities. This right is not recognized as such by their families and institutions. There is some reluctance to recognize it as a right. The same applies for pregnancy and motherhood, where the situation is even worse.

We can say that womanhood is not taken into account when it comes to women with a disability. There is hardly any work done on self-esteem or self-confidence as it is not considered important in their upbringing.

Women with disabilities are hardly ever asked their opinion on important decisions (even when these decisions are about them!). Consequently, they are not used to making decisions, giving their point of view, taking definite positions.

They can attend training courses, but only in limited fields that will allow them to do housework, cooking, cleaning or ironing. They don't have the same job opportunities as men.

Women with disabilities suffer more from unemployment than men. About 2/3 of all people with disabilities who have a job are men (Source: AGEFIPH – 2007).

Women with disabilities face more violent situations and sexual aggression.

There are no examples of good practice, but some suggestions can be given here:

- It would be good to set up group meetings of women with disabilities, so that they could get to know each other and talk about their problems and issues. This could be done also with a few women without disabilities who can join these groups and share ideas;
- Self-esteem workshops could be very useful too;
- Women with disabilities need to take part a lot more in decision-making processes. Setting up decision groups with disabled women would be a good idea, as well as support groups. This could be done in cooperation with their supporters and families;
- Develop actions for equality between women and men with disabilities;
- Raise awareness in society regarding the situation of women with disabilities, in order to change the way people look at them.

Some case studies

These case studies have been carried out individually within ESAT. Two men also wished to participate.

Mrs F has been working in ESAT (Service d'aide par le travail) for 20 years. She has been working in the kitchen (cooking, cleaning dishes, housework). She liked the job, but there was no room for her in the group home. She has changed institution and she is now in the gardening section. She is happy, since she has just learned to use a chain saw.

She says that there are no differences between men and women in the "foyer". She likes living there. The support is the same for everyone, she says. She reports that life seems easier for men because they can carry heavy things and do odd jobs about the house. However, she adds that "women with disabilities can sort things out themselves and are sometimes better with other things!".

To those bearing a negative judgement on women with disabilities, she gives this answer: "They should look at themselves first".

Mrs L has started a CAP (Vocational Qualification Certificate) in sales, but she didn't get it. She sent many resumes to find work in that field, but she didn't receive any answers. So she worked in a restaurant and cleaned dishes. It was a bad experience because her colleagues found that she was too slow and not very efficient. She quit the job. Her father often reproached her for being unsuccessful. He had not really admitted that she had a disability.

Mrs L enjoys living in ESAT. She says that there are no differences between women and men. She had the opportunity to choose the job she wanted, and she works in a factory. She feels she is treated as an adult person. Unlike her father, here no one says that she is 'good for nothing'. 'Men and women work on the same things', she says.

Mrs L suffered when her father forbade her to get married and have children. She concludes: "Even if some people have a disability, they deserve to live like everyone else…".

Other comments from women in the group home

Mrs Y has a boyfriend, and she is worried about pregnancy. She says that if she is pregnant, she will undergo tests to see if the baby is “normal”. If it is not, she won’t keep it, because she is afraid of the things he/she could not do, of health problems and of the way people would treat him/her. She adds that she would like to have a child, and thinks that she would be able to look after him/her, but that it would be more complicated when the child becomes a teenager.

Regarding self-assertion, she says that her mother has told her to respond to negative remarks. When someone is mocking her, she answers “If you were in my situation, you wouldn’t say that”.

She adds that life is harder for women with disabilities because men can take advantage of them. It once happened to her.

The discussion with the two men was about what they had heard in the women’s discussion:

Mr N says that women with disabilities are often laughed at. He says that in ESAT it is the same situation for men and women. However, the situation is different in factories: it is more difficult because they have to carry heavy things and keep their rights (be respected, etc.).

He thinks that men have an easier life than women because “it is difficult for women to protect themselves against aggressive behaviour. They are more shy. It is easier for men to move around …”.

Mr S adds that “some people think that women with disabilities cannot sort things out themselves. Why not? They are people like others! If they have problems, this cannot prevent them from having their own autonomy. And also, there is a support service (Service d’accompagnement) to help them out if they need it.”

He concludes: “People with disabilities should be respected. Other people should not be mean but should help them out. And also … What makes them think that we cannot raise children?”.

AUTISM EUROPE

MARIA PAULA FIGUEIREDO
Member of the Council of Administration of Autism-Europe

Object

Introduction

In the context of the EDF/CERMI Conference on Women and Disability, "*Recognizing the rights of girls and women with disability – an added value for tomorrow's society*", it is up to Autism Europe to report on the situation regarding girls and women with autism.

When speaking about disability caused by autism, a wide range of situations are concerned for autistic spectrum disorders (ASD) affect social functioning, communication and learning ability in many ways and with very different degrees of severity. And yet it is certain that, either "high functioning" or "low functioning" (and in about 70% of cases there is mental retardation), every person with autism is likely to experience difficulties in adjusting to the usual patterns of life in society, if not exclusion.

The difficulties mentioned above impair the exercise of fundamental rights and are experienced in fields that are determinant of the quality of life, such as access to health care, education, habilitation, work and employment and many more.

The number of people diagnosed with ASD has increased in recent years in a way that tends to be considered dramatic. In the 1960s. 1970s and 1980s we were speaking of rates of 20 per 10 000; today, the rate more frequently referred to is 30 per 10 000, but in more recent studies there are references to rates of 60 per 10 000. Although some studies attribute this to environmental or health causes (vaccines), it may be more consistently attributed to better and earlier diagnosis[22].

The rights of the disabled person

In the last decades, society has become more and more aware of the situation of disabled persons, mainly through the action of organizations that represent their interests.

In this path, international organizations have adopted instruments and some governments have issued laws that aim to improve this situation by means of

- Emphasizing the dignity of the disabled and the rights that they are entitled to, on an equal basis, as persons and citizens;
- Establishing that measures must be taken in order to enable the exercise of rights and integration in society, through positive discrimination.

We all recognize these documents as significant steps that have already been taken, but there is still a long way to go to achieve the goal of an inclusive society.

A very important one, considering its wide range and its potential global application, is the recent *UN Convention on the Rights of Persons with Disabilities*, adopted by the General Assembly on 13 December 2006. However, for its provisions to become effective there is a lot of work to be done, not only to have the Convention ratified by the largest possible number of States but also to make sure that the legislation and policies of those states that ratify are in accordance with it.

---

[22] Fombonne, E. “Epidemiological surveys of autism and other pervasive developmental disorders: an update” -7th Autism Europe Congress – Lisbon 2003 – Proceedings.

Fombonne, E. “The tale of immunizations and Autism” - 8th Autism-Europe Congress – Oslo 2007 - Proceedings.

As far as ASD are concerned, for instance, it may be stressed that the right to an inclusive education can only be properly exercised when measures are taken to ensure that teachers are themselves educated about autism, when the necessary support, in material and human resources, is provided for the specific needs and when all those in close contact with the person with ASD are made aware of what to expect from that person (and that sometimes it means to have to deal with the unexpected).

Perhaps even more difficult to exercise is the right to work and employment, due to the variety and dispersion of the environment where it usually is exercised. Here, again, for a relation to succeed, not only proper adaptations of the work environment are necessary, but also some measures should be taken (including training, if needed) concerning those in close contact with the person with ASD.

Another important aspect to be considered is the need to protect the more severely disabled not only against the risk of being deprived of their rights, but also of being led to misuse them, taking into account their level of awareness of what is implied in the exercise of any right (which sometimes takes such a simple gesture as putting your name, or even a cross, on a piece of paper).

Because we are addressing the situation of women and girls, we have to be aware that ASD are "discriminatory", for studies have shown, right from the beginning, that there are many more males than females affected. The rate is generally set at 4.3 to 1. This rate is completely reversed when strictly considering another developmental disorder, the Rett Syndrome, which affects mainly girls and causes severe disability.

AE has no data on the situation of women and girls with ASD, as far as inclusion is concerned or the use of discriminatory practices. Several studies focus on groups of persons with ASD, following their social integration, their access to independent living, the way they perform in work and employment, etc. The rates of integration are usually very low, though an increase in success numbers may be found in the more recent and related to the outcome of adequate measures.[23]

---

[23] Evelyne Friedel, 8th Autism Europe Congress – Oslo 2007 - Proceedings.

As far as we know, no studies or other data has shown discrimination and exclusion concerning persons with ASD to be gender motivated.

Another factor to be taken into account when this particular form of disability is at stake is the way families of persons with ASD are affected. Namely, the impairment of the social and professional lives of the parents of persons with autism, either because they have to provide constant care, or because they cannot cope with the emotional stress. Here, the gender issue has to be taken into account, for the mother is usually the one that carries the heavier burden, the one that more often gives up her career or jobs in order to provide care to the autistic child.

In fact, the problems raised by the constant attention, the demanding cares and the stress involved in parenting a child with ASD cannot be met by the usual measures in the field of conciliation between professional and family life. Different measures are required, including family support and training by professionals.

Probably because of their deeper involvement in the care of children with ASD, women are in the majority on the boards of ONG that concern this disability. Autism Europe is no exception: the majority of the members of the Council of Administration are women and both its present and its future Presidents are mothers of children with ASD.

Action of Autism Europe

AE, whose main objective is to advance the rights of persons with autism and their families and to help them improve their quality of life, has always been in the front line with respect to the rights of people with disabilities, taking part in the discussion, soliciting the adoption and, afterwards, the enforcement of a number of relevant international instruments in this area.

On the adoption and the enforcement of the abovementioned rules on the specific field of ASD, of the many actions taken the following may be singled out:

- The *Charter of Rights*, presented at the 4th Autism-Europe Congress, Den Haag-1992 and adopted as a Written Declaration by the European Parliament on 9 May 1996 as *"Declaration on the Rights of People with Autism";*
- The Collective Complaint against France (the first of its kind) at the European Committee of Social Rights (Council of Europe); the Committee's decision of 4 November 2003 found France to have failed to fulfill its educational obligations to persons with autism under the European Social Charter.

On the topic of "raising awareness", the following are particularly worth mentioning:

- Socrates Grundtvig "*Side by Side*" Project (2003-2005), to be followed from the beginning of 2008 by the "*Accompanying Measures"* Project;
- "*Autism Europe Recommendations on Education*", "*Tool Kit: The Right to Education*" and "*European Case Law on the Right to Education*" (2006);
- Communication on *"Human and fundamental rights*"[24];
- 2006-2007 Survey on Discrimination in Education and Health (results under analysis).

---

[24] Evelyne friedel. 8th Autism Europe Congress- Oslo 2007- Proceedings.

CENTRAL AND EASTERN EUROPEAN COUNTRIES

ELISABETH SZÖLLÖSI
Board member of MEOSZ
Coordinator, FIMITIC Expert Group “Women with disabilities”

The General Situation of Men and Women with Disabilities

Co-operation between disability organizations in the Central and Eastern European countries has been very active for the last 30 years. The similar economic and social structure of these countries resulted in the same problems for people with disabilities.

The National Federation of Disabled Persons’ Associations in Hungary (MEOSZ) has always played an active part in European and international disability organizations and networks and has always held leading position in these organizations. In addition, MEOSZ provides Vice-Presidents for FIMITIC and DPI-Europe. Our involvement in the activities of European and international organizations, as well as our close co-operation with individual Central and Eastern European countries, has given us a very good opportunity to exchange views about the situation of disabled people all over Central and Eastern Europe.

The underprivileged social status of people with disabilities is manifest in two fundamental ways in Central and Eastern European countries. One of these is the condition of our physical environment, including infrastructure - access to goods and services in general, and the availability of these to people living with disabilities in particular. The other area concerns the social milieu, the attitudes of the public towards people with disabilities and the general social perception of people living with disabilities.

Societies in these countries are generally going through a process of transition where the habits associated with the former social structure are still surviving side by side with new expectations fashioned after a European set of values.

The mentioned obsolete social attitudes include people's confidence in an omnipotent state which offers little scope for individual initiative or assertiveness. There used to be no general acceptance of the primacy of human rights, as it was not the individual human being that was projected into the focus of our perception of the world but rather an all-powerful, paternalistic state that was in control of all walks of life. This attitude used to be characteristic of the entire society, but even more so in the case of people with disabilities.

Society did not rely upon its disabled members as an “asset” in production. At the same time, it was acknowledged that society had an obligation to look after these people, even if at a relatively low standard, and provide them with some basic assistance.

Apparently, this approach meant that people with disabilities, too, thought of themselves as eligible to being supported by the state and resigned themselves to the idea of being second-class citizens, as they could always rely on a relative safety according to the development level of the economy and society at the time, even if mostly within a segregated environment.

The period of political changes implied a significant turnaround in ideology and attitudes in the ex-socialist countries, at least at the level of political expression.

The question of universal human rights has been brought to the forefront of attention, and anti-discrimination has become the norm in all social strata. The movements of people with disabilities have gained momentum and become more strident in claiming their human rights with respect to both the physical and the social environment.

As a result of considered efforts, legislation now shows an increasing willingness to assume a human rights approach in setting the legislative rules and measures applicable to the life of disabled people. New laws have been created that prohibit negative discrimination against disabled people, and provisions ensuring general access to facilities have been added to the legislation applicable to the construction of the physical environment. Regulations on education and employment have also taken into account the requirement of equal rights. That is to say, radically new developments, reflecting a substantially changed attitude, have started in Central and Eastern European countries, regardless of their being members of the European Union or not.

Women with Disability in Legislation

In 2003 a questionnaire was drafted by the Women's Special Committee in FIMITIC to investigate regulations on the specific issues concerning women with disabilities. (the survey was carried out by FIMITIC Associations in Austria, Croatia, Finland, Hungary, Slovenia, Slovakia, Poland, Romania and Spain). A lack of adequate national, regional and local regulations on the specific issues concerning women with disabilities was identified. It was confirmed by the FIMITIC survey about the national regulations and programs relating to women with disabilities. This survey investigated programs and undertakings with regard to women with disabilities both on the central administration level and on the level of the disability movement as well. The aim was to collect information about national regulations and programs relating to women with disabilities, as well as programs by disability organisations in this field.

The results showed that women with disabilities were paid scant attention not only at state level but by the disability rights movements as well. It was clear that national disability associations or federations did not recognise to any great degree the combined discrimination of gender and disability experienced by women with disabilities. The survey stated that equity of women with disabilities needed to develop a better understanding of their special situation. The survey concluded by revealing the necessity to establish separate legal instruments concerning women with disabilities distinct from those concerning women without disabilities and men with disabilities. It was agreed also that —in spite of the fact that in these countries women's participation in the decision making bodies is very low— women with disabilities should themselves be involved in the design and evaluation of policies and measures in order to achieve a real impact. Policies which appear gender neutral in the field of disability may, on closer investigation, turn out to affect women and men differently. They have to take into account particularities pertaining to the lives of both women and men with disabilities and must aim to eliminate inequalities and promote an equal distribution of resources.

Women with Disabilities in Employment

Expectations of the socialist system in these countries resulted in the increasing number of employed women. In Hungary before 1989 nearly 100% of women were employed. The employment rate among disabled women was much higher than now, although a majority of them lived on social benefits. The expectation of full employment among women was based on the underdeveloped economy in these countries where only a few mothers could afford not to work but stay at home with small children. It was not the decision of the mother to choose work or a full-time job as a mother.

Women with disabilities could not meet both expectations. Either taking a job or raising children exceeded their abilities due to the lack of a barrier-free environment and social services. The lack of a barrier-free environment prevented them from going to work or take part in any field of social life. Due to financial difficulties their household activities could not be assisted by modern appliances like dishwashers, adjustable furniture, electrical appliances, or by a cleaner. Therefore playing the "sole" role of a mother was a big challenge for most women with severe disability.

While women in these countries have undertaken more and more social responsibilities (e.g. going out to work and raising children at the same time), those responsibilities taken over by men did not increase so much and household tasks and every day problems associated with raising children are not considered to be necessarily distributed equally between men and women. Due to the conservative family model nearly all tasks involving care for the family remained with women. Under these social circumstances women with disability —without any assistance— could hardly cope with the social expectations.

This situation has not changed too much. The ideal modern woman is highly successful both in her career and her family life, although more and more efforts are made to harmonize and strike a balance between these two important tasks. Women with disabilities cannot meet these requirements. Only a negligible percentage of people with disabilities are employed in these countries (9% of disabled persons are employed in Hungary. That means that around 90% of disabled people are not in employment, and among them women with disabilities represent more than 50%). Disabled women therefore cannot achieve successes at work. Most of them are employed in sheltered workshops doing low-quality work and a professional career for them is very rare. Only a few women with disabilities can meet the expectation of the society as they are not provided with equal opportunities; therefore they are considered to be helpless and reliant on social benefits.

Of course it is not only national regulations and the employment situation of women with disabilities that is worth writing about. Women with disabilities face discrimination every day in Central and Eastern European countries. These countries are still not aware of the fact that by creating equal opportunities the whole society gains from equality for women with disabilities from equal distribution of benefits, tasks and responsibilities.

CEREBRAL PALSY EUROPEAN COMMUNITIES ASSOCIATION (CP-ECA)

AIMO STRÖMBERG
Secretary General

CP-ECA is a sub-organisation of the International Cerebral Palsy Society (ICPS). The European members of ICPS are members of CP-ECA. It has 20 member organisations and 9 associate member organisations. There are also some individuals who are members. We don't have any statistical details about member organisations. They are, however, quite similar in all countries. They have been founded to be parents' organisations, while nowadays there are both parents and adults with CP as members.

It is said that the incidence of Cerebral Palsy is 2 in 1000 births. This means that there are about 700.000 people with CP in Europe. There is the same incidence of CP among men and women. It means that there are about 350.000 women with Cerebral Palsy in Europe.

There are 7 board members in EP-ECA, five of whom are women. One lady in the board has Cerebral Palsy herself. One lady is a mother of a child with CP and one man is a father of a child with CP. The rest of the board members are working in the national organisations.

At the International level CP-ECA does not have any committee or group on women and girls with disabilities. I know there are women with CP at the national level who are active in different groups of women with disabilities. I don't know of any national groups of women with CP either.

CP-ECA has never discussed differences between men and women with CP. The main issue has until today been problems caused by Cerebral Palsy. In some seminars there have been papers about the subject given by women with disabilities.

It is very difficult to get a job. It is possible that a woman with CP has two or three university degrees but can’t get a job. This problem is common to most of the groups and both men and women. However there are differences between men and women in common, especially finding a job where higher education is needed. It makes it still more difficult for women with disabilities.

One of the problems is that there is not enough support in secondary education. That’s why there are many women with CP who can’t get a proper education.

The most difficult situation among women is faced by those who have speech difficulties. People often think that a person who is not able to speak can’t think either. That is one reason they are often treated as children.

EUROPEAN DOWN SYNDROME ASSOCIATION

CORA HALDER
Vice-president

The first crucial point in which the situation of girls and women with Down Syndrome differs from that of women with other disabilities is the fact that, because of cognitive disabilities as well as difficulties with speech and communication, they are, generally, unable to assert their special situation and effectively speak up for themselves. This makes them even more vulnerable and means that they will always be dependent on others to see and understand their needs, speak on their behalf and to represent them where necessary.

Only a few girls and women with Down Syndrome have the means of making their voice heard, but —as women and, more importantly, as women with cognitive disabilities— they are often not taken seriously and, therefore, cannot make their own decisions or actively participate in community life.

It is seldom possible for women with Down Syndrome to achieve generally accepted feminine characteristics or traits - neither in appearance, through a professional career, nor through assuming family responsibilities.

Because they do not match the model promoted by the media, women with Down Syndrome often have to deal with rude and hurtful comments about their figures, fashion, looks, hair, or weight, which makes it extremely difficult for them to develop a healthy self-esteem.

Most of these women work in sheltered workplaces, which is the lowest level in the employment hierarchy. The payment is often not more than pocket-money, meaning that they will be financially dependent on other sources, such as their families or the State throughout the entirety of their lives. Sheltered workplaces offer little job variation and the kind of activities is mainly mechanical, technical assembly line work. It is boring and uninspiring, and the work environment is often very loud. None of this meets the needs or preferences of those women, but they are forced to accept these working conditions because of the lack of viable alternatives.

In several European countries, women with Down Syndrome, often more so than their male counterparts, are not employed at all but spend all of their time in the family home or in institutions, without occupation and contact with others. Furthermore, fewer women than men with Down Syndrome are employed in the mainstream job market.

For women with Down Syndrome, it is extremely difficult to find a partner as choices are few. Falling in love with someone out of reach is common, and having to deal with unacknowledged affections or learning to outgrow pain associated with these unfulfilled dreams are extremely difficult situations in the lives of women with Down Syndrome.

Maintaining a relationship, though it may require external assistance, is not impossible for a woman with Down Syndrome. Yet it is still not widely accepted, nor is it considered a realistic objective. Many women with Down Syndrome do not get the choices regarding their lifestyles or with whom they live by themselves. Rather, well-intentioned parents make decisions regarding what they believe is best for their daughter with little consideration for the resulting limitations upon the quality of life or the right to self-determination.

For women with cognitive disabilities, the right to express their sexuality is even less accepted than it is for men with the same condition. Very often, these women are seen as sexless. Out of fear, parents seek to protect their daughters from sexual abuse by keeping them home, but by doing so these women have no opportunities for social interactions with other young people, are unable to develop a sexual identity, and are often prevented from leading a normal life.

For women with Down Syndrome, the pressures not to become pregnant are extremely high. Even though it may be illegal to do so, many women with cognitive disabilities are subject to sterilization without their consent or without being informed about the exact purpose of the surgical operation. Society expects them not to have children.

Nevertheless, women with Down Syndrome yearn for children just like many other young women. Even if the concerns surrounding the issue of a woman with Down Syndrome becoming pregnant and having a child are valid, the decision to deny a woman with Down Syndrome the right to motherhood should not be made a priori. And, as a mother, she should be entitled to the same support for childcare, just as other women or families encountering difficulties with the care and upbringing of their children receive.

However, developing a realistic understanding of pregnancy, child birth and child care and coming to terms with this (almost always) unrealistic dream of having a child is another of the many difficulties that women with Down Syndrome must face. Again, their self-esteem and self-image suffer, because this again is an area in which they clearly experience their deficits that do not allow them the personal joy of motherhood, nor to prove their womanhood.

Girls and women with Down Syndrome are often victims of sexual exploitation and abuse, more so than men with DS or even other women. Such violence is even more insufferable when one considers the inability of the victim with Down Syndrome to defend herself or, because of poor communication skills, the inability to report the violent incident. The fact that a man who rapes an intellectually disabled woman may receive a lesser degree of punishment is another intolerable violation of the basic human rights of these girls and women.

Girls and women with Down Syndrome are entitled to sexuality, as are other women. Sexual education from childhood onwards, awareness about sexual abuse, self-defence, training in independent living, opportunities to develop social interaction skills are important necessities, and doing so with other young people is also necessary to enable this. Yet these things are still neglected and not considered a natural part in the education of girls and women with Down-Syndrome.

EUROPEAN BLIND UNION

BIRGITTA BLOKLAND
Secretary General

EBU and Women in Leadership

The European Blind Union was founded in 1984 and currently has a membership of national organisations of the blind and partially sighted from 45 countries in Europe.

The first woman was elected to the EBU board in 1993, the following mandate periods, 1996, 1999 and 2003, EBU had two women out of 11 board members. Now, in 2007, three women (two ordinary members and 1 secretary general) have been elected to an expanded board of 13 members.

At the EBU general assemblies, around 30 percent of voting delegates were women since 1999.

Not all member organisations of EBU have a women's committee or group working with gender issues.

BARRIERS to Equal Participation

These start on a national level and work the same at international level. Everybody has their own network. If the board of a (inter)national organisation consists of only men, they usually will look around in their own male network to recruit a new member. Women are less visible for them. With women on the board that is balanced out and with an active women's group in place, it is easier to recruit new leaders from there. Also, practical barriers like the time of meetings, no facilities for children, transport problems, infrastructure etc., do keep women from actively participating in their organisations.

Secondly, for a women's group to be active you need motivated people, there are plenty of us there. But for activities to have maximum impact it makes it so much easier if a budget is available. Although most organisations budget for different areas of work, not all include an earmarked budget for gender activities.

These and other barriers to full and equal participation have to be identified and eliminated. Both genders must have equal possibilities to be full and active members of society. The EBU board has actively supported gender work and women's participation, but depends on its national members to nominate women for the different positions. It is therefore the national members that we have to continue lobbying to make sure they will do so, because it makes the organisation better and stronger. At the same time we have to actively motivate and recruit women for different positions.

It is a joint effort and a shared responsibility of EBU, its member organisations, women and men, to take all necessary action to ensure that equal opportunities and balanced representation become a reality and that men and women of all ages feel that their concerns and needs are taken into account in the organisation to which they belong and in which they can play an active role to make a difference.

EBU Women's Commission

The commission on the advancement of the interests of blind and partially sighted women, in short the EBU Women's commission, was established in 1994.

Objectives

The EBU women's commission works for the advancement of the interests of all EBU women by making women and their often specific situation visible, promoting their interests and getting those included in all EBU decision making. We strive for equal representation and participation of age and gender in boards and commissions of EBU and its member organisations. We want to offer a platform for blind and partially sighted women in the EBU member countries to exchange ideas, knowledge, experience and to support eeach other in their national activities. We want to contribute to a firm and good basis for a strong and democratic organisation, that in all its diversity strives for the same goal: equal opportunities for all blind and partially sighted in society.

Activities of the EBU Women's Commission

The activities of the commission have been, and are, aimed at a higher participation of women in leadership positions in EBU and its member organisations and at offering a platform for blind and partially sighted women in the EBU member countries. By appointing champions in each working area of EBU we have tried to ensure that the gender perspective is included in all areas.

An overview of the main activities over the last decade

FORUM - women's forums have been held immediately prior to the EBU general assemblies since 1999. Empowerment, leadership and fundraising workshops for example, being part of the programme (that has also included, amongst other themes: parenthood, employment, technology, violence etc.).

This year, 2007, a diversity and equality forum was held for the first time, replacing the women's forum with a forum of and for women, youth and elderly blind and partially sighted people. Joint and separate sessions were held and the concept was widely accepted by the participants and the experience was defined as enriching. Together, the three groups were more visible and this also was clear at their report session to the general assembly.

NETWORK. - The EBU women's network was set up 1999. It is aimed at blind and partially sighted women who are active in EBU member organisations, those who work with a women's commission, but also blind and partially sighted women in Europe can sign up to the email list, without necessarily being a member of their national organisation of the blind and partially sighted. EBU Women's Network members receive the EBU women's news bulletin and other information via the email list. Fewer women than expected have made use of the email list to post information on their national activities or to put forward questions.

PRACTICAL GUIDE. - 'Towards a culture of Equality, a user's guide' was produced by the women's commission in 2003. A practical tool on how to implement the diversity and equality principle in all working areas and on all levels of EBU, it is not a static document and will evolve with the changes in our organisation.

NEWS BULLETIN. - The EBU women's news bulletin was issued together with the EBU general newsletter, containing information on gender and equality issues. The bulletin was issued until 2003. The EBU website contains information on women's activities, which will be further developed as a source of information.

EBU CONSTITUTION. - In 1999 a constitutional amendment was adopted at the EBU general assembly regarding gender balanced delegations to the general assembly and the phrasing 'men and women' was used instead of 'people'

RESOLUTIONS. - Were prepared and adopted at the EBU women's forums in 1999, 2003 and 2007. These were then also adopted at the EBU General Assemblies that immediately followed the forums. Adopted resolutions form part of the four year work plans of EBU. The women's commission also prepared resolutions for other EBU conferences, like for example the Employment Conference.

SURVEYS. - The first survey was held in 1994 to inventorise the needs and priority areas for blind and partially sighted women in EBU member countries. One of the main areas of concern that resulted from the survey was employment, or rather unemployment. A second survey in 1997 showed that that hadn't changed much. Other areas were motherhood and the participation in leading positions at (inter)national level in organisations of the blind and partially sighted.

In 1998 the women's commission proposed the rule which was adopted by the EBU board, that all surveys undertaken in EBU must include gender and age differentiation.

DAPHNE PROJECT. - One of the most difficult, but important issues the EBU women's commission has dealt with was violence. We all know it exists, but on what scale? No information was available until we came across a report from Sweden about violence against women with disabilities. We invited the author and held a discussion workshop during one of our meetings and listed a number of recommendations (amongst others, that self-defence training must be part of the rehabilitation process). Our French member took the initiative further and soon the women's commission and seven EBU member countries participated in the project funded by EU- DAPHNE. The project consisted of a survey to make the scale on which blind and partially sighted women encounter violence, a series of group discussions at national/regional level about violence, self-defence training and two seminars (2002-2003). The results were presented at the 2003 Women's Forum.

COOPERATION. - The EBU has been represented in the EDF women's committee, has become a member of the European Women's Lobby and will definitely become a member of the European network of women with disabilities.

Working Period 2007-2011: new faces, new plans

EBU celebrated its 8th General Assembly last October, in which a new board was elected and commission and working group membership was confirmed shortly after in the first meeting of the new board.

The leader of the women's group is Luisa Bartolucci from Italy, who also led the group from 2003-2007. Members are Jivka Pavlova from Bulgaria and

Anne Rigby from the UK. The women's group will be expanded with a network of contact persons in each EBU member country. The portfolio holder at board level is Birgitta Blokland.

More Information

If you wish to receive further information on topics from this report, or on the plans for the coming four years, you are welcome to contact Luisa Bartolucci at inter@uiciechi.it or Birgitta Blokland at bjb202@hotmail.com or Skype: bjb.ebu.

Information on EBU women's activities will also be published on the EBU website: www.euroblind.org

INTERNATIONAL FEDERATION OF PERSONS WITH PHYSICAL DISABILITY (FIMITIC)

MARIJA STIGLIC
Secretary General

FIMITIC regards itself as the International Federation of Persons with Physical Disability, focusing its activities on ensuring equalization of opportunities and full participation and fight against all kinds of discrimination which persons with physical disability are victims of.

For FIMITIC it has been essential since its foundation in 1953 that disabled women's concerns are included in all discussions when women's issues are on the agenda.

Structure

A women and disability expert group with the goal to build up a network in the FIMITIC member countries and beyond was established in 1992, later called the Expert Commission on Women and Disability, giving priority to employability and also dealing with self-determination, human rights and equal opportunities.

Networking provided possibilities for exchange of views, experiences and good examples for member associations. Networking has been a tool to empower, form and confirm self-confidence as well as demonstrate the role of women with disabilities in society. Positive impulses, energy and strength gained from this cooperation could certainly contributed to the fact that some of our members took decision-making positions in various fields of life in their countries, a position enabling them to enhance disability issues effectively.

Conferences organised (resolutions, statements and demands launched)

1994 - Bonn, Germany: “Disabled women on the move” - family, daughter, single mother, late disability, family and/or career.

1996 - Graz: “Disability and Motherhood = Human Right?” - Sexuality, partnership, pregnancy, reactions of the environment/personal assistance and technical aids for mother and child/experiences of children of disabled mothers.

2001 - Prague: basic initiative for the FIMITIC Employment Conference.

2003 - Zagreb: “Improving Quality of Life of Women with Disability” as well as many internal meetings related to different items took place.

Questionnaires

Questionnaires were distributed among FIMITIC member associations on:

- The situation of women with disabilities; and
- The available legal instrument and measures focusing on women with disability.

These enquiries were aiming at supporting women to develop and put forward a strategy for implementation of a clause in the legislation of the individual member countries with regard to the special need of women with disabilities.

The results of this questionnaire were presented in the FIMITIC Zagreb conference, 2003 and are shown below.

Women with Disability in Legislation

ELISABETH SZÖLLÖSI
FIMITIC Women´s Expert Co-ordinator

In 2003 a questionnaire was drawn up by the Women's Special Committee of FIMITIC to investigate regulations on the specific issues concerning women with disabilities (survey made by FIMITIC Associations in Austria, Croatia, Finland, Hungary, Slovenia, Slovakia, Poland, Romania and Spain). A lack of adequate national, regional and local regulations on the specific issues concerning women with disabilities was identified. It was confirmed by the FIMITIC survey about the national regulations and programs relating to women with disabilities. This survey investigated programs and undertakings with regard to women with disabilities, both on the central administration level and on the level of the disability movement as well. The aim was to collect information about national regulations and programs relating to women with disabilities, as well as programs of disability organisations in this field.

The results showed that women with disabilities were paid only scant attention, not only on state level but by disability rights movements as well. It was clear that the national disability associations or federations did not recognise to a great degree the combined discrimination of gender and disability experienced by women with disabilities. The survey stated that equity of women with disabilities needed to develop a better understanding of their special situation. The survey concluded by revealing the necessity of establishing legal instruments concerning women with disabilities independent of those on women without disabilities and men with disabilities. It was agreed also that – in spite of the fact that in these countries women's participation in decision-making bodies is very low - women with disabilities themselves should be involved in the design and evaluation of policies and measures to achieve a real impact. Policies which appear gender neutral in the field of disability may, on closer investigation, turn out to affect women and men differently. They have to take into account particularities pertaining to the lives of both women and men with disabilities and have to aim at eliminating inequalities and promoting an equal distribution of resources.

International and European Initiatives

It was on the suggestion of FIMITIC that a “Study Group on Women with Disability” was established by the EU Commission during the European Disability Forum HELIOS II in 1996, taken over by the independent EDF afterwards.

On initiative of FIMITIC, the subject Women with Disability was included in the list of demands for the European Day of Disabled Persons 1996.

The co-operation of FIMITIC women with disability representatives within the EDF Women with Disability Committee is known.

The hearings and statements given on the level of the United Nations, its Human Rights Committee, the preparatory work for the UN Convention, Council of Europe Action plan, ILO decent work concept and women with disability.

FIMITIC Women’s Committee representatives took part in many international actions and events (for example Valencia 2003, Berlin 2007).

Strengthening and developing networks in order to promote solidarity among women with disability and also with non-disabled women, and improving the exchange of information and experience, was the leading part of the FIMITIC Women with disability working programme to increase public awareness in order to challenge negative attitudes to disabled women and help to integrate disabled women into mainstream culture.

Thus from the point of view of FIMITIC, we strongly support the initiatives taken by CERMI and EDF towards the goals of the European Women with disability movement and are of course most interested in remaining part of it.

EUROPEAN KIDNEY PATIENTS’ ASSOCIATION (CEAPIR)

CARINE BERENDSEN

The European Kidney Patients’ Federation, also known as CEAPIR, is an umbrella organisation for 21 national kidney associations across Europe. CEAPIR is a non-profit organisation led by an Executive Committee consisting of five members, one of whom is a woman. From the 21 national kidney associations there are 5 female leaders. The Dutch Kidney Association, however, has no female representatives on its board.

Within the organisational structure of CEAPIR and the national associations, no particular barriers for women have been reported. However, women with ESKD face challenges that women without ESKD do not.

Pregnancy and Chronic Kidney Disease

For dialysis patients, the chances of getting pregnant are significantly lower than for those with a kidney transplant or without ESKD.

Only one-half of pregnancies in dialysis patients result in a surviving baby.

Successful kidney transplantation significantly increases the chances of having a baby, approaching those of non-ESKD women.

Uncontrolled hypertension is the major risk factor for complications.

Pregnant ESKD patients require close monitoring by a team of experienced medical professionals.

In transplant patients, the risk of worsening kidney function, including graft loss, depends on pre-pregnancy renal function.

A pregnancy leads to the woman developing antibodies and this can lead to complications in getting a successful match should a future transplant be required.

Effects of Kidney Disease and Treatment on Employment

In 2000, 67% of the general population in the USA over the age of 16 worked full or part-time, whereas amongst those who had started treatment for ESRD, the figure was only 23%.

One of the reasons behind this is the lack of energy that often comes hand in hand with ESKD.

Given the fact that in a relationship, traditionally the man is the bread-winner, if the woman had been working prior to developing ESKD there is often more of a social expectation that the woman will withdraw from the work-force, especially whilst on dialysis.

If and when a woman receives a transplant, depending on the length of time they were on dialysis, it can be quite difficult to get back into the work-place.

Quite often, one finds that middle-aged women affected by ESKD will be expected to take early retirement, even if they subsequently get a transplant, whereas there is a better chance that after a man has had a transplant he will be able to get back into the work-force.

References

Life Options Renal Rehabilitation Report, Vol. 11, No. 3, Fall 2003.

AAKP Website: Pregnancy in ESRD and Transplant Patients.

The Situation of Women with ESRD compared to Men in Society in General

Kidney patients face a special problem because the different stages of the disease have different consequences for employment. When one suffers from kidney insufficiency, one has a bad physical condition and a variety of complaints due to inadequate blood levels and anaemia. It can be hard to explain to an employer what measures are needed, because the complaints are very vague. When a patient is on dialysis, he/she is often not able to work. In the Netherlands, the government institution that is responsible for providing financial aid for people with disabilities counts the time on dialysis as personal free-time, which has a negative impact on the amount of financial aid the patient will receive. Still, most patients on dialysis receive some amount of money for their inability to work.

After one has received a transplant, one is normally declared healthy and deemed to be able to work full-time. This is not always the case; some people continue to experience health problems after transplant, and the emotional weight of this event can sometimes cause psychological problems. This makes it more difficult to work full time, even if they are expected to do so. For women these problems are more complicated. A disabled person only receives financial aid for disability if he/she has been employed previously. This is not always the case for women.

Education

Women with disabilities are sometimes constrained in their opportunities and motivation to attend higher education. It has been reported that women who are fully work-disabled are discouraged from starting education because they won't be able to work anyway. Also, young women with disabilities who have already completed high school are discouraged from pursuing further education. The common expectation underlying these implications is that women with disabilities are not expected to be employed. More specifically, often there are no expectations of them other than that they will be a burden on society!

The kind of issues people with ESRD face in accessing education can involve juggling their education and treatment regimes (dialysis, regular visits to the hospital for review). Whilst it is easier for someone who has had a kidney transplant, they must still be conscious of the fact that their immune system is compromised and that they must keep taking their medication at the prescribed intervals.

Fortunately, in the Netherlands, there are several patient representative organisations (for example the Dutch Kidney Association) and one very successful student organization (‘Studie en Handicap’) who are dealing with problems of young people with disabilities who are in education. The knowledge about specific problems is growing, and people with disabilities have nowadays a wide variety of ‘tools’ to face the daily problems involved in attending school or college. The internet is a major help for students with disabilities as it provides them access to education materials, notes and also existing legislation which can be helpful in specific personal situations. The government provides scholarships for all students in the Netherlands. For students with a disability, it is possible to receive a one year extra scholarship, and they may take additional time to finish their education without consequences.

Health Care

Home care has been more and more restricted in the last decade in the Netherlands. The problem is the financial costs for society and the fact that fewer people want to work in the home care sector. Because of this development, it is more difficult for anyone with a disability to receive home care.

Kidney patients who have just received a donor kidney are victims of this tendency. Because a person who has just been transplanted is able to manage in daily activities, home care is not often provided, especially if this person is living with a partner. Still, these daily activities can be very overwhelming and exhausting, and home care is necessary. Women who are responsible for the household face difficulties, because their partner is seen as someone who can take over the daily activities, while this is not always the case in practice. In most cases, the partner has a fulltime job to attend to and has not got time to take care of his recovering partner and the household.

Legal Instruments

- Algemene Wet Gelijke Behandeling- General Law on Equal Treatment*.

Guarantees equal treatment on grounds of handicap and chronic illness (April 3rd 2003).

- Wet Reintegratie Arbeidsgehandicapten (REA)– Law Reintegration Fully-Work Disabled People*.

Provides supervision to reintegrate disabled people to paid labour, and financial rewards for employers who hire disabled people.

- Wet arbeidsongeschiktheidsvoorziening jonggehandicapten (Wajong) – Law Young Disabled People and Inability to Work*.

Provides supervision to reintegrate young disabled people to paid labour, and financial aid for young disabled people who are not able to work.

These are the most important legal instruments for kidney patients in the Netherlands. No specific instruments exist for women with ESKD.

---

* The names of the laws are translated into English and may not cover the exact meaning as the laws do in the Dutch language.

MENTAL HEALTH EUROPE (MHE-SME)

DELEGATE: JOSEÉ VAN REMOORTEL
EDF Board Member

Mental Health Europe is a European non-governmental organisation created in 1985 and committed to:

- The promotion of positive mental health;
- The prevention of mental distress;
- The improvement of care;
- Advocacy for social inclusion; and
- The protection of human rights of (ex-)users of mental health services, their families and carers.

Since the very beginning of its existence, Mental Health Europe has a “Committee on Mental Health and Women” which meets as many times as possible per year (in 2007 their meetings took place in Vienna in June and in Brussels in September).

Once the Daphne III programme to combat violence against children, young people and women is published by the European Commission, Mental Health Europe will prepare together with this Committee an awareness raising project on the mental health impacts of violence against women.

The aspects of women who are victims of "trafficking" will be treated at the next European congress of Mental Health Europe, which is taking place on 07-09 August 2008 in Aalborg in Denmark.

Mental Health Europe is a member of the World Health Organisation working group on mental health in prisons, and Mental Health Europe has raised the specific problems of women, and in particular women with mental health problems, in this group.

Introduction

The mental health needs of women have been a matter of concern for well over a century – since the pioneering work in the late 1800s of such women as Susan B. Anthony and Elizabeth Cady Stanton, Georgina Weldon *("How I escaped the Mad Doctor*"), Rosina Bulwer-Lytton ("*A Blighted Life*") and Charlotte Perkins Gilman. Almost a century later the ideas expressed by these early writers were renewed by Phyllis Chesler (1972) in her ground breaking work "Women and Madness" in which she argued:

> *"there is a double standard of mental health – one for men, the other for women – existing among clinicians… For a woman to be healthy she must 'adjust' to the behavioural norms of her sex – passivity, acquiescence, self-sacrifice and lack of ambition*.

In 1991, Louise Pembroke, chair of Survivors Speak Out, has described how she:

> *"discovered at an early age that women's worth is gauged by her appearance: expressions of anger and assertion are not easily tolerated; that my low place in society's pecking order … is connected to the maintenance of a hierarchy based on white male dominance."*

Five main themes can be found in the work on women and mental health:

- The ways in which some of what has conventionally been described as 'madness' is in fact ordinary 'normal' behaviour for women;

- The ways in which mental distress and disability is caused by the discrimination and oppression that women experience;
- The ways in which more serious disability is exacerbated by oppression and discrimination;
- The ways in which services fail to meet the needs of women who experience mental distress and disability and often actively exacerbate such women's problems;
- The diversity of women's experience and ways in which lesbians, women from minority racial and ethnic groups, older women, younger women and women with physical disabilities are multiply disadvantaged both by mental health services and male definitions of madness.

Recent years have seen increased efforts to improve mental health services for women. These endeavours can be seen in the work of numerous local groups and national endeavours, work in the area of purchasing mental health services for women and core group work on good practices in relation to women and mental health.

Work initiated by the European Regional Council of the World Federation for Mental Health, now Mental Health Europe, in 1995-1996 (1995 Year of Opportunity) led to the creation of an informal network of women working in mental health services and women who experience mental health problems themselves. The network worked on the following themes:

- Physical and emotional abuse;
- Racism and ethnic issues;
- Sexual abuse and sexual identity;
- Increasing the influence of women on mental health.

The following countries were part of the network: Albania, Belgium, Bulgaria, Croatia, Czech Republic, Estonia, Finland, Ireland, Italy, Poland, Romania, Slovenia, Switzerland and the United Kingdom. Nearly all the participating women created in turn networks in their own regions/countries. Information packages were put together, translated and disseminated.

Unfortunately, due to lack of financial resources in the late nineties of the previous century and beginning of the 21^{st} century, the network no longer had the means to meet.

Issues that affect Women's Mental Health

Hunger

Women's complaints of "nervousness" are explained less as symptomatic of psychological distress and more as an expression of chronic hunger and hunger anxiety. The World Health Organization estimates that more than 60% of women in "developing countries" are undernourished.

Work

Many women spend more hours working than do men from the same social class, because they earn money while also being fully responsible for domestic chores, child care, and the care of ageing relatives. This burden of work is expressed through symptoms of "nerves" and a lack of rest.

Sexual and Reproductive Violence

Emotional trauma and depression result from rape (especially prevalent in situations of societal breakdown and political violence), involuntary prostitution, women not being in a position to refuse sexual relations, involuntary abortions, forced sterilisations, abortion of the female foetus and female circumcision.

Domestic Violence

It is estimated that domestic violence and rape account for approximately 5% of the global health burden for women in the reproductive years. Major depression, alcohol and drug dependency, and post-traumatic stress syndromes are linked with a history of domestic violence. In many parts of Europe, wife beating is directly related to depression and suicide. Female infanticide not only kills girl children, but brings grief, remorse, and other mental distress to mothers and other family members.

Economic Development

Women's control over their labour and earnings directly contributes to their mental health. It also indirectly advances their mental health by allowing women to escape situations of violence and abuse. Yet although women have always been economically productive, their contributions have been underestimated, ignored, or rendered invisible by economic development policies that do not count women's work. Many such initiatives have rendered women poorer, more dependent, and with less decision-making power in the family.

In 2005-2006, Mental Health Europe's female Board members wanted to re-initiate work on the specific issues of women's mental health.

They agreed that women's health concerns more than reproductive and maternal issues. As with everyone else, women's health means emotional wellbeing, physical health, and general quality of life.

Psychological distress for women often has social origins. Discrimination against females in employment, education, food distribution, health care and resources for economic development renders them vulnerable to physical and sexual violence, psychiatric disorders, and psychological distress.

Awareness raising of health professionals in better recognising the psychological consequences of violence against women

The MHE Committee on Women and Mental Health, composed of the women on MHE's Board, was particularly active in preparing an application in the framework of the DAPHNE programme.

A consultation of MHE member organisations made clear that violence and abuse of women is not properly detected by general practitioners and social services, and certainly not in the early stage. After years of suffering and not being believed by these professionals, women end up with seriously "damaged" mental health.

The work of the Committee on this issue was concluded with an application for a Daphne project on awareness raising of mental health professionals.

MHE as well as the Committee members having longstanding experience in the area of women's mental health, wished to develop this project because most projects dealing with violence against women are restricted, either to physical consequences, human rights or discrimination. If accepted for funding, attention will be given to specific groups such as young and older women, migrant women, women in prostitution, etc.

The project aims to address the mental health consequences of violence against women by raising awareness and training health professionals (general practitioners, nurses and social workers) in better recognising violence and providing care, support and referral to shelters and other services.

Gender-based violence, regardless of whether it results in physical, sexual or psychological harm or suffering to women, has been associated with serious mental health consequences including depression, anxiety, phobias, substance abuse, sleep and psychosomatic disorders, and increased suicidal behaviour.

The project will:

1) identify and collect available projects and studies dealing with the mental health consequences of violence against women, and extract the existing good practices for raising awareness of health professionals;
2) develop or adapt a training package for health professionals contributing to a better recognition of violence and mental health problems.

The project is needed because evidence suggests that despite the success and good practices in and across Europe, health professionals are still reluctant to recognise their crucial role in responding to violence against women, even though the opportunities are evident: they are repeatedly in contact with women, from childhood until late into reproductive life. Moreover. most health professionals limit their intervention to the treatment of symptoms and do not take into account the relationship between violence and its physical and psychological consequences and clinical presentations.

The expected results of the project are:

- An awareness raising brochure for health professionals to be dispatched by European associations of health professionals, social services, women organisations, etc.;
- A training package for health professionals to be dispatched by European associations of health professionals, social services, women organisations, etc.;
- Promotional material (poster and leaflet) to be dispatched in Europe through MHE and the project partners.

A start was made by looking at the situation of (illegal) female migrant workers.

Migrant workers are more often victims of discrimination, exploitation and abuse at different levels:

- As women: women still do not benefit from the same rights and opportunities as men;

- As foreigners: migrant women, like migrant men, do not benefit from the same rights or the same level of protection as the inhabitants in the host country. However, migrant women are more vulnerable as they usually work in sectors that are not protected by social legislation. Also, there is a general perception of migrant women in a traditional role, having no public life, only looking after their families. This, and the fact that they feel they are "locked up" in a completely strange country, having little knowledge of the culture and traditions of the host country, causes severe mental health problems for these women. Most of them dare not seek help, and find it very difficult to talk to their husbands about their feelings of despair and their problems because they do not want to put an extra burden on them. They do not find the way to mental health services and even if they do, they cannot afford to pay for psychological help;

- As dependents: women suffer from discrimination and restrictions in the host country in relation to housing, the right to work, access to social welfare, etc. This is more specifically the case for women who emigrate as dependents of male migrants;

- As illegal immigrants: women are particularly vulnerable to exploitation and abuse. Without a legal status, they have no defence when their rights are violated. They are too scared to make a complaint from fear of being expelled to their country of origin immediately. Many of them are women who leave their countries and families in order to support them financially. Although it is often carried out in extremely difficult conditions, undeclared domestic work is often the only way for these women to send money to their families who have stayed home, to reimburse their debts, etc. They work very long hours and have feelings of guilt when for one reason or another they cannot send enough money to the families. They often endure psychological traumas due to the separation and so do their children.

The Committee formulated some recommendations:

- Immigration policies should be developed which take into consideration the gender dimension;

- Migratory policies should be developed which take into consideration the existence of emerging needs in particular in the domestic work sector, care of children and elderly people;

- Domestic work should be regulated to guarantee that domestic workers have social rights and social protection;

- All migrant workers, regardless of their status, should have basic human rights;

- Networking of organisations of migrant women should be supported;

- And, last but not least, more research on the mental health of female migrant workers should be supported.

The Committee also looked at the situation of women as carers. Women often have jobs and professional responsibilities, and at the same time continue to be in charge of their children, do the housework and take care of their dependent (sometimes demented) parents or children with mental health problems. This double burden has severe consequences for the mental health situation of the women. It is important to evaluate the mental health risks of these women and to find a "way out".

The European Commission's Roadmap for equality between women and men (2006-2010) highlights the importance of reconciliating work and private life. MHE together with the European Women's Lobby and Age is campaigning for better care provision in the EU.

Care for children, older parents, disabled relatives and others in our society is without any doubt a women's business. Statistics proved that 85% of women between 60 and 65 are caring mainly for their older parent(s) or grandchildren, or for a disabled partner.

In the framework of intergenerational solidarity women have the moral and practical obligation to do this. This caring role – certainly when it is of long duration – is a heavy physical and emotional burden.

Mental Health Europe's Committee on Women and Mental Health wishes to ask for more attention for the specific needs of the often forgotten group of women.

Demographic and social changes in society influence the lives of women in several ways. In this context attention has been given to 3 groups of caring women:

- Mothers caring for a disabled child;
- Women as informal carers;
- Women as formal carers.

1) *Mothers caring for a disabled child*

Children with disabilities can now be regarded as having increased opportunities to stay in the family environment in which the parents —but in reality the mother— are the key person in the emotional, social, intellectual and spiritual development of their disabled child.

Practice has shown that in reality, caring for children in the community is a very demanding and stressful process. Mothers face real uncertainty and insecurity about the future of their child in the event of illness of even death. The mental health problems of those mothers are often feelings of despair, loneliness, burnout and breakdowns, and the scale of challenges facing an enlarged European Union is therefore significant.

A number of recommendations could be made to support parents – and mothers in particular – in the care for their disabled child:

- Short term breaks for children to enable their mothers to regain strength and cope better with stress;
- Access to advocacy services for parents;
- Setting up of buddy-systems with other parents;

- grants to improve home living such as a lift or adapted toilet;
- direct payments to parents of disabled children to cover the costs of daily living but also allowing short breaks and live-in carers.

2) *Women as informal carers*

Women live longer than men, but this does not ensure them of relaxed and relaxing "old age". All over the world, women take up the majority of the care-activities. Even women getting older look after their grandchildren and or their own older parents. Different forms of stress, depression and isolation are frequent in older women. The actual "older women" are also less visible than men, due to the hidden caring role they play within the family.

Women between 50 and 60

Women between 50 and 60 are the so called "sandwich generation" since they are squeezed between care for their older parents and care for their grandchildren. In Europe, a family situation with a grandmother of 80-90 years old, a daughter (the caring woman) of 60-70, their daughters of 30-40 and their grandchildren aged between 0-15 years, is often a quite 'normal' situation. The difference with the past century is that each of them —except the grandchildren— live apart, which is requesting a flexibility and mobility of our caring women that have a huge impact on their mental health.

The growth of the elderly population means also inevitably age-related diseases such as dementia.

Women over 75

Women over 75 are also the 'normal' carers for their disabled or ill male partners in more than 75% of cases. In return, when these women become ill or disturbed, they will be put in hospital or older peoples' homes. The burden on caring women can be very heavy.

Their leisure time is limited (1 out of 3 families spend more than 6 hours a day nursing and caring for mentally ill elderly). One out of 3 find that their own health is declining (less sleep, loss of appetite,…). They become anxious, irritated, depressed. They get feelings of guilt. They have financial problems.

It is also important to mention the fears that mothers and other women suffer, fear for the unpredictable ups and downs of their partner or relative, risk of unexpected aggression or unknown prognosis.

Here again support programmes should be set up:

- To develop befriending schemes;
- To give emotional support;
- To organise temporary relief through respite care or weekend admissions;
- To provide financial support;
- To give information and good and clear care arrangements

3) *Women as formal carers*

Women are not only "champions" in informal care but also in the formal care. Due to the increasing need of care for a growing group of elderly with dementia, professional help in all kinds of settings is requested (home care, residential facilities, etc.). Nurses, auxiliaries, cleaning staff and lots of volunteers are nearly all women. Statistics show that only 7% are men!

Research at different levels —national and European— is mainly reporting the problems and need for staff in residential settings. The job in residential facilities is very heavy and demanding, both physically as well as emotionally. 90% of the staff complain about stress, burnout, fatigue, lower-back pains, working time pressure and the confrontation with difficult emotional situations. The negative perception of elderly people is also an additional problem for the caring staff.

Improving the quality of care would certainly improve the perception of the carers and improve their coping capacities. The burden on carers is also depending on the support they receive in their work. This support can be:

- Flexible working hours;
- Part-time work;
- Support by senior staff;
- Regular information and training sessions;
- Better organisation of the workload.

The problem of women carers is often a problem of ageing women. Mental Health Europe would like to start further negotiations with EUFAMI and with AGE in order to develop a consolidated policy paper on this issue.

A third issue that was discussed was parenting. A significant proportion of mothers with severe mental health problems have parenting difficulties or lose the parenting role of their children.

Research in this area is scarce and there is little evidence suggesting that women diagnosed with mental illness cannot be good parents. In the UK a number of studies show evidence that women lose custody of their children far more frequently than the general population. Mental health services do not pay much attention to this. In general terms it is fair to say that there may be considerable discrimination against mentally ill women in this field and that more work on this topic has to be done. (Actions speak Louder … Tackling discrimination against people with mental illness. Graham Thornicroft, 2006).

The Committee will look further at this issue during the following years.

References

European survey of good practices in mental health care for the elderly.

J. Steenhaut, Edinburgh, September 1994.

Mental Health for midlife and older women.

J. Steenhaut – Launch of EU Policy Paper “Women in Europe: towards healthy ageing”.

Oudere Vrouwen

Nederlandstalige Vrouwenraad, 1999.

Supporting families of disabled children.

M. Kmita – ECCL Focus Report 2006.

This part of MHE’s work programme was carried out with the support of the European Commission, DG Employment, Social Affairs and Equal Opportunities, Non-Discrimination Unit.

EUROPEAN MULTIPLE SCLEROSIS PLATFORM (EMSP)

ALIKI VRIENNIOU
Member of the Executive Committee

To start with, we must point out that there is no separate data on women with MS. On the other hand, because MS affects twice as many women as men, every action taken to help against discrimination of people with MS from EMSP, consequently is beneficial to more women than men.

Some facts about MS in Europe

- Approximately 500 000 people across EU are directly affected by MS;
- MS affects twice as many women as men;
- On average, only 28% of people affected by MS in Europe have access to disease modifying drugs. In Poland this figure falls to 4%;
- In many countries of the European Union, there is a dire shortage of medical experts with specialist knowledge of MS. In the Republic of Ireland, for example, there were only 14 neurologists throughout the country in May 2007, a shocking number, which meanwhile has been increased slightly only due to the media pressure following the EMSP report on this scandal;
- In every EU member state, employment rates and job retention rates among people affected by MS, despite stark evidence of the health benefits of

remaining in work, are two to three times lower than for the remainder of the population.

The most significant characteristic of MS is that it affects people who are at the prime of their life (contrary to almost all other incapacitating diseases affecting people in similar numbers) at a time when most will have young families and considerable career prospects.

MS, as an unpredictable and progressive disease, affects profoundly the quality of life of the persons from the moment of diagnosis until the end of their life.

There is highly robust scientific evidence and expert opinion of the very beneficial, indeed, critical effects of professional and high standard treatments, therapies and services on the quality of life of people affected by MS and their capacity to continue to contribute to society as workers, as consumers, as citizens. And from a purely cost benefit perspective, studies have demonstrated unequivocally that the investment this entails is significantly less than the negative economic and social consequences of mismanagement of multiple sclerosis.

There is disparity in the way in which people affected by MS are treated across the European Union, and consequently their quality of life.

EMSP, in order to raise the block of discrimination between people with MS in different countries of EU, has launched a campaign for the implementation of the Code of Good Practice all across EU countries.

The Code has been drawn up as a crucial follow up to a European Parliament Resolution[26] and report that identified the root causes of discrimination and inequality for EU citizens affected by MS and outlined a number of political and programme initiatives needed to redress this issue.

The Code is a political instrument that outlines briefly the issues of fundamental importance to people affected by MS. It provides a practical framework that describes in general terms:

---

[26] A5-0451/3003 European Parliament Resolution on Petition 842/2001 concerning the effects of discriminatory treatment afforded to persons with multiple sclerosis within the European Union.

The Code focuses instead on the core issues relating specifically to rights and quality of life of people affected by MS. European wide surveys and analysis reveal the positive psychological and physical benefits of job retention that can reduce the progression of the disease, yet many people affected by MS are forced to give up work because of lack of support.

The Framework Directive on equal treatment in the work place[27] is an important basis upon which to challenge this discrimination; the concept of 'reasonable accommodation' within the Directive should be interpreted to include flexible working, rest periods, the necessary work adaptations and a social protection safety net, that respond effectively to the symptoms of MS and ensure both access and dignity.

Much more focus is required, however, to ensure that the Directive has the impact it could in relation to people affected by MS. This Code calls for information and awareness-raising programmes for employers, co-workers, and for those diagnosed with MS about the Directive, its scope and its potential both as an advocacy tool and to seek individual redress.

Alongside a strong legal framework, this code also calls for high quality vocational rehabilitation recognising its crucial role in identifying appropriate assistive equipment, environmental modifications, task re-structuring, task modification and support from co-workers or others as needed. It is important to identify and challenge workplace barriers using creative solutions made possible through open communication with the employer.

Most importantly for both patients and medical experts, the Code —with its reference consensus papers on immunomodulatory therapies, on symptomatic treatment, on rehabilitation and on palliative care— pushes successfully the establishment of Europe-wide standards in MS management. In May 2007, the European Commission, the European Parliament and German Health Minister Ulla Schmidt endorsed the Code and its reference documents on European level.

---

[27] Directive 2000/78/EC – A Framework Directive on Equal Treatment in the Work Pace.

The key task ahead of us is now the implementation and use of the Code and its consensus papers into daily practice on national level in all EU Member States and beyond.

Once this is achieved, the current discrimination of PwMS by inequality in access to therapies and services will not be gone, but will surely be much smaller than today.

EUROPEAN NETWORK OF (EX-) USERS AND SURVIVORS OF PSYCHIATRY (ENUSP)

MARY NETTLE AND PAULA CHRISTIE

ENUSP is a European Network of Users (ex) users and Survivors of Psychiatry we also have support members who are interested in our work and we include in our memberships groups which include support members. Only user & survivors have voting rights and can be elected to the board. More information can be found on www.enusp.org

Our member organisations do not provide us with gender information about their members and total number of members varies considerably. We have no paid workers. The ENUSP board has 16 members of which half are women.

People with psychosocial disabilities, which is the definition used by the UN Convention, would be considered to be users of psychiatry by ENUSP. We are a network of people with psychosocial or as we would call it mental health problems.We campaign against mental health laws which force us to have treatment against our will, the only group of disabled people treated this way. Our Dresden Declaration[28] clearly outlines our viewpoint on this.

The general public often confuse people with psychosocial disabilities with people with intellectual disabilities in the UK called people with learning difficulties and often wrongly described as mentally handicapped.

---

[28] Dresden Declaration: http://www.enusp.org/index.htm

Stigma and discrimination apply to both men and women but as parents women in particular who become pregnant are considered to put their child at risk and are subject to pressure and may even be given a cesarean operation in order for the child to be taken away at birth. Services are often not child friendly and help with parenting is not available.

An ENUSP board member works with vulnerable individuals who have sustance missuse issues and are involved in prostitution, through their habits using heroin they can become disabled through injecting which can lead to ulcers which can effect them severly often with the posibily of loosing a limb, the effect of this can effect their mobility and their responsiblilty as a parent, this can lead to services being involved with the family purely for the safety issues that may effect the children. I work closely with other agencies to engage this client group into services that can help them.

PEOPLE WITH ARTHRITIS/RHEUMATISM IN EUROPE (PARE)

BIRGITTA BLOKLAND
International relations of ConArtritis Spain
Member of PARE

About 'Women in RA' and 'Women in RA - A Union of Voices'

Women in RA is a series of national initiatives bringing together women with rheumatoid arthritis (RA), doctors, national health advocacy groups, as well as national and European members of parliament to inform and mobilize medical, public health and political decision makers. The program focuses on RA by illustrating —beyond facts and figures— the disease's physical, emotional and financial impact on the lives of women and their families. National Women in RA campaigns have been implemented in 11 countries including Belgium, Denmark, Finland, France, Germany, Greece, Italy, the Netherlands, Spain, Sweden and the United Kingdom.

The European Women in RA – A Union of Voices campaign is an initiative led by People with Arthritis/Rheumatism in Europe (PARE) Manifesto. Its objective is to unite the efforts of the 11 national campaigns.

The project aims to increase awareness amongst EU decisionmakers on the impact of rheumatoid arthritis on women and their families, and the importance of establishing a better public health policy to ensure prevention, early diagnosis and better management of the disease. Women in RA – A Union of Voices also aims to promote closer involvement of patients in deciding health policy at both national and European level.

From a policy level, Women in RA – A Union of Voices demands that national and European policy measures be devised and implemented in parallel. A coherent European strategy is needed and each EU Member State needs to develop and implement effective national plans. Last but not least, access to the full range of treatments across the EU must be available to all.

PARE

Organisation and initiative: PARE Manifesto established the European initiative as a follow up to the national projects and named it Women in RA – A Union of Voices.

More information is available at www.womeninra.org.

European Women in RA – A Union of Voices is supported by an unrestricted educational grant from Abbott.

Rheumatic Diseases in Europe: Call to Action

More than 100 million people in Europe live with arthritis, rheumatism or some other rheumatic disease. These are the most common chronic illnesses in Europe. The quality of life of millions of people in Europe is severely and permanently reduced by daily pain and functional impairment caused by rheumatic diseases. Rheumatic/musculoskeletal conditions represent 40% of all chronic conditions and 54% of all long-term disability.

The economic and social impact of rheumatic diseases, including rheumatoid arthritis, is substantial, not only for individuals but also for society. The cost of medical treatment and the combined loss of productivity and of contributions to social and fiscal systems because of disease-linked disability adds up to more than 200 billion euro per year.

People with rheumatic diseases can lead full and independent lives but require appropriate support. Therefore PARE and the European Women in RA – A Union of Voices initiative call upon:

- The European Commission, the European Parliament and the Council to:

MAKE rheumatic diseases a European health priority;

ADOPT a European-wide strategic approach which promotes early diagnosis, better prevention and care to combat rheumatic diseases.

- The European Commission, the European Parliament, the Council and national decision-makers to:

INVOLVE people with rheumatic diseases in all relevant decision-making processes;

GUARANTEE disabled persons' rights through an active inclusion policy and a commitment against any form of discrimination based on effective legislation;

ENCOURAGE the exchange of best practices between Member States to make sure that expertise is available throughout the whole continent;

PRIORITISE research in rheumatic diseases as well as research about the economic significance of rheumatic diseases in our society.

- National decision-makers to:

DEVELOP and implement national action plans on rheumatic diseases which can ensure early diagnosis, better prevention and care;

ENSURE better access for persons with arthritis to the full range of treatments across the EU;

INITIATE information campaigns to ensure that there is sufficient knowledge about the diseases, in particular about the benefits of early diagnosis and prevention.

Declaration on Recognising the Rights of Girls and Women with Disabilities

DECLARATION ON RECOGNISING THE RIGHTS OF GIRLS AND WOMEN WITH DISABILITIES

MADRID, SPAIN, 18th NOVEMBER 2007

PREAMBLE

Recalling the 10th Anniversary of the adoption of the European Disability Forum Manifesto of Women with Disabilities, which is a reference document, in order to address the fight of girls and women with disabilities for non-discrimination;

Acknowledging the United Nations Convention on the Rights of People with Disabilities, its Article 6 on women with disabilities, and all other articles;

Having regard to Article 13 of the Treaty on European Union;

Noting the Beijing UN World Conference on Women Declaration and Platform for Action;

Noting the Resolution for the formation of a European network for women with disabilities, adopted in Berlin 2- 4 May 2007;

Noting that girls and women with disabilities face multiple discrimination which has been expressed in different arenas and public reports,

Participants at the Madrid Conference organised by CERMI (Spanish Committee of Representatives of People with Disabilities) and EDF (European

Disability Forum), representing 23 national councils of disability organisations, 12 EDF full member organisations, 8 EDF ordinary members, the EDF Women's Committee and the CERMI Women's Commission, as well as a high number of observers with expertise in gender and disability,

DECLARE

That girls and women with disabilities are facing the effects of clear and profound discrimination. Even though important advances have been made during the last years, this sort of discrimination represents a serious and alarming problem. This may be seen in the data and through experiences of women and girls with disabilities, that show lack of education, more unemployment, lower salaries, limited access to health and maternity services, limitations to their sexual and reproductive rights, scarce or no access to services or programmes available for woman in general, greater risk to suffer violence and all kind of abuses, limited availability of data broken down by gender and disability, under-representation in our associations, etc.

Girls and women with disabilities experience even more discrimination than men with disabilities and women without disabilities. The existence of prejudices and stereotypes distort their image of themselves and their perception of being citizens with full human and civil rights. In this sense, women with disabilities generally lack the effective resources or legal tools to eliminate and correct this discriminatory behaviour.

Therefore, we

DEMAND

That EDF, as the European umbrella association of disability organisations in Europe, and its member organisations, should adopt and implement these principles, by means of the following action points:

1. To take urgent actions towards awareness raising and develop positive action measures specifically designed for girls and women with disabilities, that involve joint efforts and oblige different actions at local, national, regional and European level to work together towards the same goal;

2. To ensure that women participate equally and effectively in the decision-making processes within all EDF structures. This should also take place in EDF member organisations;

3. To review the EDF statutes and bylaws to ensure that women and men have equal access to the decision-making bodies of the organisation;

4. To promote effective work in the priority fields of women with disabilities, adequate resources, active fundraising and a fair allocation of resources need to be ensured by EDF structures. In order to support this, EDF should explore existing budget lines in the European Institutions;

5. To ensure that all EDF communication channels are used to promote the views and opinions of girls and women with disabilities as well as mothers of girls and boys with disabilities who are unable to represent themselves. EDF and its member organisations should include information about the situation of girls and women with disabilities in all aspects of its work. At the same time, it is necessary to prepare specific documents directed to women, stakeholders and society in general;

6. To ensure the allocation of funds from its budget for training and the development of meetings and seminars for the empowerment, leadership-training and capacity-building of and for women with disabilities, and to support girls and women with disabilities in their self-identification process;

7. To recommend all disability organisations to develop actions in order to create equal opportunities and eliminate discrimination of their women members, through the creation of working groups to monitor and work to ensure respect for their fundamental rights;

8. To establish contact with the different European, regional, national and local authorities responsible for gender issues, non-discrimination, disability and

equal opportunities, and request information and action about the situation of women and girls with disabilities, including those living in institutions, and to promote research in co-operation with the organisations of people with disabilities and develop specific action plans on how to improve the situation of women and girls with disabilities;

9. To recommend women's commissions and networks are established and supported in their respective regional, national and local structures. This will strengthen a continuous dialogue on priority topics related to women and girls with disabilities, as well as mothers of boys and girls with disabilities who are unable to represent themselves;

10. To promote and support the work of EDF's women's committee as well as ensuring that all annual general assemblies include a session addressing priority issues of women and girls with disabilities, encouraging to this aim that all women and men in decision-making positions within the disability movement at all levels work towards the realization of these demands.

Madrid, Spain, 18th November 2007.