

**SHADOW REPORT TO THE UNITED NATIONS COMMITTEE ON THE
ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN
(CEDAW)**

EXECUTIVE SUMMARY

2009

SPANISH COMMITTEE OF PERSONS WITH DISABILITIES (CERMI)



PREFACE

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) was adopted in 1979 by the UN General Assembly and ratified by Spain on 5 January 1984. However, in spite of its many years of existence, it is known only by a minority of the Spanish population.

We wish to thank the Committee on the Elimination of All Forms of Discrimination against Women (CEDAW) for having given us the opportunity to present this shadow report. It is the first time that CERMI presents a report before a Committee on Human Rights and all its members, very especially the women members, feel very proud, because we believe that this situation shows the associative maturity and the experience in political dialogue that the disability movement in Spain has acquired over the years.

The Spanish Committee of Representatives of Persons with Disabilities (CERMI) is the platform for the representation, defence and action of over four million Spanish citizens with disabilities and their families (representing some five thousand associations and organizations) who, conscious of their situation as a disadvantaged social group, decide to join forces, through their organizations, to make progress in the recognition of their rights and to reach full citizenship on equal terms with the other members of society.

It must not be forgotten that the current Convention includes women with disabilities as part of the general women population, although they are not mentioned. They become visible only through its general recommendation 18 related to women with disabilities, recognizing through this recommendation their situation of greater vulnerability and inequality.

But this inequality is not the case only in Spain, it is also present in Europe and at international level, and it is sustained by the diversity of cultures and the socio-political and economic realities through an invisible heritage, a tradition of ignorance and obscurity, oblivious of borders and new paradigms. Generally speaking, we can say that gender policies conceal disability and that disability policies ignore gender, perpetuating thus the situation of multiple discrimination of women with disabilities.

When compiling this report, we have singled out certain articles and general recommendations in the CEDAW Convention which we feel are the most urgent to be highlighted and comment on as far as Spain is concerned. We have also taken into account the list of questions raised by the Committee in consideration of Spain's sixth periodical report, and more specifically the specific part of the report regarding the situation of the most vulnerable groups of women, such as those with a disability.

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Our objective with the presentation of this report is to provide valuable information on women with disabilities, in addition to the one presented by Spain as State Party before CEDAW, in order to share good practice, when it should be the case, as well as to put forward measures and actions aimed at designing future policies to improve the situation of an important group of women through their direct participation and implication.

The Government of Spain is noted for actively mainstreaming disability in its political agenda, and there is a positive dialogue between the Government and the Spanish disability movement. Proof of this is the fact that the Government has implemented very effective measures and performs very good practises in the field of disability which can be shared with other countries.

Nevertheless, despite the fact that the report submitted by the Spanish Government includes one point of information concerning women with disabilities, there is a surprising number of generic references to persons with disabilities and specific policies for this population which fail to go deeper and address the specific problems faced by women with disabilities. For this reason we recommend that, in addition to mainstreaming disability in the entire report, in future reports there should be a more concrete and specific reference to women with disabilities. Furthermore, when describing their situation we recommend the language is feminised and generic expressions which render their gender invisible, such as “persons with disabilities”, are avoided. In the responses delivered by Spain to the list of questions raised by CEDAW the vast majority of the measures which are mentioned are aimed at persons with disabilities and do not distinguish between men and women. Furthermore, no mention is made of the funds earmarked for such measures, and this is crucial in ensuring the measures are implemented effectively.

Major work on updating the national statistics on persons with disabilities through the *Survey on Disability, Personal Autonomy and Dependency* (EDAD in Spanish) is being finalised. Publication is scheduled for autumn of this year. Advance results from the

survey indicate that women with disabilities now account for 60%¹ of the total population of persons with disabilities. As this task is ongoing, we shall use statistics from the most up-to-date objective data available, the 1999 *Survey on Disabilities, Impairments and State of Health*². While providing a great deal of information, the survey is deficient in many areas; consequently, we have been unable to extract reliable data, among others, on women with disabilities in rural settings, the status of women with severe disabilities and women who are victims of gender-based violence.

Nonetheless, we can say that the main characteristic of this group of women is its heterogeneity, despite which they face the specific problem of suffering high levels of discrimination as a result of the double stigma of gender and disability. In most cases the marginalisation that has permanently affected women with disabilities is far more pronounced in comparison with men with disabilities. The consequences of this, in broad terms, include a higher illiteracy rate (15.95%), lower education levels (36.64% have no formal qualification, and only 4.1% have vocational, upper or university qualifications), a lower rate of activity in the labour market (an inactivity rate of 76.29%) and/or jobs carrying less responsibility and lower salaries, greater social isolation, lower self-esteem, greater financial dependency on the family and/or care persons, greater socioaffective and emotional dependency, greater risk of falling victim to all types of gender-based violence, lower levels of personal and social development, widespread ignorance regarding sexuality and the innumerable and catastrophic myths surrounding this issue, greater abandonment in social and health care and low self-evaluation of their body image.

CERMI, the organisation that represents the disability movement in Spain, wishes to underline the importance of introducing the following changes in policies and measures in different spheres in order to improve and enhance the status of women with disabilities in order to improve their quality of life and non discrimination.

1 Instituto Nacional de Estadística (INE), November 2008 press release on the Survey on Disability, Personal Autonomy and Dependency.

2 Instituto Nacional de Estadística in co-operation with the Instituto de Migraciones Servicios Sociales (IMERSO) and the ONCE Foundation. The aim of the survey was to address most of the needs in relation to data on disability, overall support needs, ageing and the state of health of people living in Spain. The approach taken in the survey was that of self-perception of disability, and this has key implications when interpreting the results. The survey can be accessed at the following URL: http://www.ine.es/en/prodyser/pubweb/discapa/discapamenu_en.htm.

Article 2 – Policy measures to be undertaken to eliminate discrimination.

The European Union is currently finalising an initiative to adopt a Directive on Anti-discrimination on grounds of religion or belief, disability, age or sexual orientation in areas outside employment. Although the Directive includes disability as possible grounds for discrimination, unfortunately it does not take into consideration the significant differences between men and women with disabilities.

Similarly, the European Union Disability Action Plan (DAP) 2003-2010 fails to take into account sex differences in any manner.

Furthermore, for some time CERMI has questioned the principle of non-discrimination in current Spanish legislation on the voluntary interruption of pregnancy and called for strict regulation in terms of the legal time limit which neither distinguishes nor differentiates on the grounds of disability. Should this not be the case, legislation would not contain elements which are contradictory to or incompatible with a view of human rights and disability that places a different value on the lives of persons with and without disabilities.

Article 3 – Guarantee of basic human rights and fundamental freedoms.

In general and legal terms, women with disabilities in Spain have the same constitutional rights, liberties and civil and political duties as all other citizens. Women with disabilities may only be deprived of these rights and duties in the event of legal incapacitation by means of a court judgement setting out the terms and remit of the incapacitation. However, the vulnerable situation in which they find themselves makes it difficult for them to exercise the aforesaid rights.

Positive action measures must be taken and the mainstreaming principle must be applied in any policies undertaken, and especially those related to gender and disability, to achieve equality for women with disabilities.

Article 4 – Temporary special measures to achieve equality.

Any action plan drawn up in the future should differentiate between men and women in terms of bringing about equality (whether these plans are directed to persons with disabilities or women). Furthermore, they should include separate budget lines for resources earmarked for the advancement of women with disabilities. These recommendations should already be introduced in the future Disability Action Plan and the Global Action Strategy for the Employment of Persons with Disabilities which is being rolled out between 2008 and 2012.

Article 5 – Sex roles and stereotyping

For decades history, attitudes and prejudices in the community, including in the family setting, have stereotyped women with disabilities negatively, thus bringing about their social isolation and exclusion.

Women with disabilities are practically completely ignored by the media. When they do appear in the media, the approach is basically to treat women with disabilities from a medical perspective and in terms of family, social and work-related issues, financial and legal aspects and education-related aspects.

CERMI respectfully requests that the following priority measures are undertaken:

- Visibilise women with disabilities in the media in a realistic fashion and promoting positive role models, specially in the media publicly-owned which should be an example of good practice and unfortunately it is not,;
- Mainstream the disability and gender perspectives in all communication policies which have a direct or indirect influence on the goal of achieving equality between persons with and without disability and between men and women (the principle of proactive intervention). At the same time, there is a need to introduce specific actions in favour of women with disabilities in the five following interdependent areas of intervention: economic life, equal participation and representation, social rights, civil life and masculine and feminine roles and stereotypes.

- Awareness campaigns involving the families of women and girls with disabilities and organisations aimed at combating and dismantling the widespread current image of women with disabilities.

Article 10 – Equality in Education

In general, although no major differences can be noted during childhood, women with disabilities have traditionally suffered inequality in the field of education. This can be seen in lower take-up rates among women with disabilities of middle, upper and permanent adult education, higher school drop-out rates, higher illiteracy rates and, as a result, lower rates of access to the labour market.

The most striking figures we have in the field of education are in the *Survey on Disabilities, Impairments and State of Health (1999)* and show that 74.79% of all women with disabilities lack any type of academic qualification or have only completed primary-level education, the illiteracy rate is 10.91%, 25.10% lack any type of academic qualification and 38.78% have only studied primary-level education or to an equivalent level.

Given this situation of clear inequality, CERMI respectfully requests that the following priority measures are undertaken:

- Develop programmes aimed at identifying the educational needs of girls and women with disabilities, including immigrant girls and women, those in rural setting, girls and women with severe disabilities or with more than one disability, as well as those included in other vulnerable groups.
- Strengthen lifelong inclusive education by means of specific schemes designed for adult women, taking into consideration the fact that two thirds of all women with disabilities are over 65 years of age.
- Boost digital literacy teaching programmes for adult women with disabilities who can learn a new reading and writing method, adapting the programmes to their disability, and developing actions that promote the acquisition of

information technology and development of networks, focussing particularly on women in rural settings.

Article 11 - Employment

The key facts regarding women with disabilities in Spain and employment are: high unemployment rate, financial insecurity and additional difficulties in terms of entering the labour market, personal issues which make it difficult for them to go through the normal processes of social participation, dependence on third parties and institutions, poor qualifications and a lack of a well-defined profession. As a result of this situation and the perception society holds about women with disabilities, they often find themselves isolated, discriminated, disheartened and excluded from participating actively in working and family life.

The activity rate among women with disabilities, at 27.10%, is lower than that of women in general (42%) and twelve percentage points lower than among men with disabilities (39.30%) according to the report *Persons with Disabilities and their relationship with Employment*, which includes data from the Survey on Active Population, 2nd quarter 2002, (INE 2003). The unemployment rate among women with disabilities (19.70%) is three and a half percentage points higher than among women without disabilities (16.20%) and almost seven percentage points higher than that of men with disabilities (12.80%) (INE 2003).

Given this situation of clear inequality, CERMI respectfully requests that the following priority measures are undertaken:

- Include a true gender perspective in the current Employment Plan for Persons with Disabilities, including positive action measures to enhance the inclusion of women with disabilities. This given Plan should be published alongside a budgetary report.
- Promote the integration of women with disabilities in the labour market by means of making available subsidies aimed at the following: promoting stable and quality employment for women with disabilities, boosting skills levels, improving employability among women with disabilities, developing projects

that promote the reconciliation of family and working life, campaigns to boost awareness regarding equal opportunities, training social and professional agents in this topic and promoting social integration and integration in the labour market among the most vulnerable groups of women with disabilities.

- Facilitate accessible information to women with disabilities on the overall labour market and on existing opportunities for access to public- and private-sector employment, including the delivery of advisory services and assistance.
- Offer women with disabilities training courses in new sectors of the economy (the environment, sustainable development, new technologies, quality control, communications, etc.).
- Funds should be earmarked in order to promote and support the capacity of women with disabilities to initiate their own enterprises.
- Promote public-sector employment among women with disabilities by providing specific support to prepare them to enter the workforce and creating employment data bases for women with disabilities.
- Inform employers about available subsidies and reductions when hiring women with disabilities.
- Co-operate with social and economic agents to ensure their lifelong training plans include negotiation strategies to promote equal opportunities for women with disabilities in collective bargaining agreements.
- Organise forums and meetings in order to study and disseminate existing good practises, with the aim of improving the status of women with disabilities in the area of employment.
- Introduce measures to address reconciling family and professional life for mothers and fathers with disabilities and the parents of boys and girls with disabilities.

Article 12 – Health and family planning

Women with disabilities are among the most important consumers of medical attention. Numerous studies have shown they are more likely to remain in institutions for longer than men. Moreover, they face particular inequality in relation to health services due to

poor accessibility, a lack of information and the specific needs they have as a result of their particular condition.

We also believe it is necessary to highlight an area of great concern for the disability network that affects more directly teenagers and women with intellectual disabilities. This is the area of forced sterilisation.

The term “sterilisation” refers to a medical intervention which, either directly or indirectly, results in the individual’s capacity to reproduce being terminated. “Forced sterilisation” refers to this procedure taking place without the consent or permission of the person on whom it is undertaken and when it is performed without there being a threat or serious risk to health or life.

For many girls and women with disabilities, this experience denies them access to appropriate services and involves them being obliged against their will, intimidated and put under pressure. Without them knowing it, fundamental human rights they enjoy, such as the right to body integrity and to control their own reproductive health, are infringed or even removed.

Sterilisation is currently regulated by law in Spain. In terms of therapeutic sterilisation as a measure to safeguard life, it can be performed on any person provided they give their informed consent beforehand. Voluntary non-therapeutic sterilisation as a means to control childbirth is also legal; any man or woman who so desires can undergo a medical operation (vasectomy, tubal ligation, hysterectomy) as a temporary or permanent way to control childbirth.

However, in the case of sterilisation of persons with intellectual or mental disabilities who have been legally incapacitated, the law allows it to be performed without the consent of the person involved - and even without them knowing about it - under the precept of their own wellbeing.

We find ourselves, therefore, faced with a situation that requires maximum attention and urgency; not only is the integrity of persons with disabilities violated as a result of carrying out non-voluntary sterilisation, but also and in order to perform the operation,

they suffer legal incapacitation, thus depriving them of any ability to act in redress against others.

The forced sterilisation of persons with intellectual or mental disabilities can not be considered a legal or medical problem; it is a social problem and an infringement of human rights. Legalising forced sterilization in the case of persons with severe intellectual disabilities reflects the majority views in society, which considers the right these people enjoy to maintaining their physical integrity and personal inviolability to be an issue for public consideration and debate, rather than fundamental human rights.

CERMI respectfully requests that the following priority measures are undertaken:

- Introduce legal measures that make it obligatory to have the informed consent of women with disabilities to any medical procedure. In this sense, it is necessary to make adjustments in the current Spanish Penal code, so that forced sterilisation of persons with disabilities does not continue being legal.
- Control the possibility of using women with disabilities in medical tests and experiments.
- Introduce the technical accommodations and adaptations to devices necessary to ensure gynaecology, obstetrics and childbirth services, as well as all other general medical services, are accessible to women with disabilities.
- Develop specific services to prepare for childbirth which address the individual needs of women with disabilities.
- Facilitate access to assisted reproduction programmes and adoption schemes by means of, *inter alia*, staff awareness training and improving accessibility.
- Carry out research and develop accessible information resources for women and girls with disabilities on sterilisation and the consequences of such procedures.
- Carry out research and develop service models based on best practises in order to provide support to women and girls with disabilities who have suffered forced sterilisation, and those who are seeking information and support on the decision to undergo sterilisation and other issues related to reproductive health in general.
- Engage directly with the families of the most vulnerable persons with disabilities faced with the possibility of their sons or daughters undergoing sterilisation.

They must be provided with counselling and support services regarding assistance in reproductive health as well as information on contraception, sexual health, fertility control, pregnancy, the menopause, and screening programmes for breast cancer and cervical cancer in the case of women with disabilities.

- Provide spaces to allow for reflection and understanding of the issues surrounding sterilisation in the case of persons with disabilities as a human-rights issue, including offering alternative options for menstruation control and avoiding unwanted pregnancies through the use of contraceptives.
- Professionals working in this field must be trained, especially doctors and other medical staff, in order to make them understand to what extent they may influence the lives of women and girls with disabilities, change their attitudes and comprehend that they should listen to the views of women and girls with disabilities when investigating.

Article 16 – Marriage and family relations

(General Recommendation 21)

Maternity and the responsibility that comes with it take on a special meaning in the case of mothers with disabilities. The environment, what is expected of them and the feeling that everyone around them is watching them determine and affect their self-perception and how they behave with their sons and daughters.

Although there are significant human rights instruments³ which recognise the right of women with disabilities to maternity, and many other manifestos and recommendations supporting it⁴, real life leads us to affirm that in practise women with disabilities are still far from fully enjoying and exercising such rights. These instruments point out the need to introduce changes in maternity, above all in terms of the right to reproduce, legal custody of children following divorce, adoption and fostering, in addition to the use of artificial insemination.

³ The most important instrument is the *UN Convention on the Rights of Persons with Disabilities*, available in English at <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.

⁴ Such as the *European Disability Forum Manifesto of Women with Disabilities* <http://edfwomen.org.uk/manifesto.htm>

Despite this, in our country social barriers – which eventually have an impact on professional practises – persist when it comes to women’s right to reproduction, especially in the case of women with intellectual disabilities, granting legal custody of children to mothers with disabilities in divorce cases, access to adoption and fostering and, of course, in assisted reproduction. In addition to this discrimination, we also find that health sector staff regularly discourage women with disabilities from getting pregnant, especially in the case of women with severe physical disabilities, because they consider the resulting pregnancy to be high risk and to hide their lack of professional skills in dealing with a woman with disabilities in such a situation.

So the prevalence of negative portrayals of women with disabilities in society in terms of maternity, together with the lack of public services (and even private-sector services) to support what is a key social function that facilitates personal autonomy and independence in all women, means women with disabilities continue to be deprived of the opportunity to become mothers; or, in the best-case scenario, they are forced to delegate responsibility for taking care of their sons and daughters to people close to them whom they trust.

It is also true, however, that in other cases social services have assumed guardianship and custody of children whose mothers have a disability as a result of professionals questioning the capacity of the mother to care for her children.

As regards adoption, although there are no specific references to disability in the screening process to become adoptive parents in Spain, the truth is that many women who have attempted to adopt have felt they suffered discrimination due to their disability.

Difficulties in the adoption process arise when one applies for the eligibility and suitability certificate required under the Hague Convention on Inter-Country Adoption. According to this study, prospective adoptive couples must undergo psychosocial assessment and must be adjudged to “enjoy a state of physical and mental health that does not hinder the normal care of the child”. However, the ambiguous wording of this article leaves it in the hands of the people responsible in each autonomous community

in Spain to interpret, assess who meets the physical conditions required and decide what instruments can be used to carry out such an assessment.

Given this situation of clear inequality, CERMI respectfully requests that the following priority measures are undertaken:

- Development of specific support services towards mothers and fathers with disabilities in the caring of their children such as personal assistance for the care of minors and home support.
- Revision of current legislation and rules regarding adoption measures by persons with disabilities, in order to make proposals of changes to the corresponding bodies in case of discrimination.
- Research of the situation of parental custody of minors with mothers with disabilities.

General recommendation 19 – Violence against women

The dearth of specific studies into gender violence and disability is a fact which has an impact on the situation faced by girls and women in Spain.

It has been shown that the combination of factors - gender and disability - means women with disabilities form a group which is at serious risk of suffering some type of abuse. The current estimates for Europe talk of around 40% of women with disabilities suffering or having suffered some type of violence. Political parties, equality organisations and society in general are becoming more and more aware of the existence of violence against women, thus resulting in more programmes aimed at providing information, counselling and protecting women who have been the victims of some type of violence. Nevertheless, such schemes have not taken into consideration the specificities of women with disabilities, thus rendering them inaccessible to this group.

CERMI respectfully requests that the following priority measures are undertaken:

- Disability should be effectively included as an indicator and in any reports drawn up in order to make violence suffered by women with disabilities more visible.
- Funds should be earmarked for support to the disability movement to set up a support network for women with disabilities who are victims of gender violence and need an environment which is close at hand to be able to escape from this situation.
- Research should be undertaken to detect gender violence. Many women with disabilities may live in closed or segregated environments, and they may be unaware they are the victims of violence and depend on the person perpetrating the violence for survival. They may have no access to information and may not even be able to travel independently to a police station to report the case.
- An early detection system should be put in place to detect situations in which violence against women with disabilities who are institutionalised or in closed or segregated settings may occur.
- Women with disabilities who are victims of violence should be guaranteed priority access to social housing, grants for adapting the home environment, home support and public services attending to cases of gender violence.
- Urban accessibility, architectural accessibility and accessibility in terms of communication must be assured at emergency refuges, shelters and supported flats for women. There should be at least one accessible service per province.
- Emergency sign language interpretation services should be created to handle cases in all police stations, permanent courts and emergency services.

This report has been produced by CERMI and it includes the requests and concerns of its associative movement of women, compiled in various publications; mainly in its 1st Plan for Women with Disabilities, and in the different public hearings at the Spanish Congress⁵.

5 *Recognising the Rights of Girls and Women with Disabilities: An Added Value for Tomorrow's Society*. (CERMI/ EDF, 2008)
<http://www.cermi.es/NR/rdonlyres/01DB88F5-F478-4B95-95D8-24CD83F01C3F/16166/Reconociendolosderechosdelasniasymujerescondiscapa.pdf>

Por la Igualdad, Unidas en la Diversidad (CERMI, 2005)
<http://www.cermi.es/NR/rdonlyres/6F8B0682-9D65-4ABF-A87F-C34CC4321A88/2099/Libro19.pdf>

Plan Integral de acción para las Mujeres con discapacidad. (CERMI, 2005)
<http://www.cermi.es/NR/rdonlyres/83764073-E460-49BB-BAF9-A003DB65A677/2209/Libro188905.pdf>

Maternidad y Discapacidad (CERMI, 2008)
http://www.cermi.es/NR/rdonlyres/9D2274ED-0BC3-41C5-BA35-602A81329284/23153/Maternidadydiscapacidad_cuartaspruebas.pdf