

# Guide to gender mainstreaming in public disability policies

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## FOREWORD

The reality faced by people with disabilities is, in most cases, something only the people themselves and their families are aware of. From my office as Secretary of State for Social Services and Equality and through the General Directorate for Disability, we are firmly committed to raising awareness among all citizens of the inequalities persons with disabilities face.

Inequality can be the result of gender, age, race, ethnic origin, ideology, religion or, as this book highlights, disability-related questions. If we add gender to the difficulties people with disabilities generally encounter, we find many women with disabilities are victims of discrimination and unequal treatment to a greater degree than men with disabilities.

Women currently represent more than half of our country's talent, and we are morally obliged to take advantage of it. If a woman needs to work sixty days more than a man right now to receive the same salary for the same job or a job of equal value, we can only imagine the difficulties a woman with disabilities has to overcome in the same circumstances.

Although women have played a major role in leading change in our country, their presence in decision-making roles could still be greatly improved. Men have a great responsibility in the battle to achieve equal opportunities in our country and, above all, we must demonstrate our true commitment in the fields of reconciliation and co-responsibility.

This book by CERMI helps us to focus social attention on those women with disabilities who suffer inequalities and discrimination on a daily basis in different areas of their lives.

I would like to take advantage of the opportunity given to me in this foreword to call upon authorities and organisations to make every effort and show every interest

to ensure all disability policies are highly sensitive towards the gender perspective, thus allowing women with disabilities to break the glass ceiling hindering their progress.

The State Secretariat for Social Services and Equality I have the honour of leading strongly supports all initiatives to ensure the individual - man or woman with disabilities, each with his or her singularities and specific needs - is at the centre of all actions undertaken.

I would like to congratulate CERMI on its unwavering dedication and efforts in advocating for the rights of persons with disabilities and its invaluable support in the fight for equal opportunities.

JUAN MANUEL MORENO BONILLA

*Secretary of State for Social Services and Equality*

MINISTRY FOR HEALTH, SOCIAL SERVICES AND EQUALITY

## PRESENTATION

The collective work we are presenting here, the *Guide to Gender Mainstreaming in Public Disability Policies*, is one more step forward in CERMI's strong and ongoing commitment in its advocacy efforts to securing recognition for women and girls with disabilities as rights holders worthy of the same protection and recognition as other citizens.

This guide, fundamentally technical in character, seeks to explore how to effectively include women and girls with disabilities in different areas of life, often overlooked in public policies, and to offer guidance to policy makers and third-sector activists on the topic. The main threads throughout the guide are the two benchmark United Nations treaties: the *Convention on the Elimination of all Forms of Discrimination against Women*, CEDAW, and the *Convention on the Rights of Persons with Disabilities*, CRPD, and the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers*, adopted by the General Assembly of the European Disability Forum in May 2011, on which the contents of the guide are based.

In eleven chapters the guide covers a number of themes including accessibility, independent living, training and employment, education, violence and abuse, health and sexual and reproductive rights, among others, under the guiding principles of equality and non-discrimination on the basis of gender or disability.

The international approach we have taken is complemented by publishing the guide in Spanish and English with a view to furthering a broader and more comprehensive reflection on the subject matter, which is still in its infancy in organisations of persons with disabilities and women's organisations in other countries and parts of the world, and almost non-existent in public disability policies regardless of their geographical scope in terms of validity and implementation.

This guide is undoubtedly of great value as the different chapters bring together the widely-acknowledged experience and expertise in gender affairs and disability of those who collaborated in writing it, either as coordinators for each chapter or as experts and resource persons supporting the coordinators. The methodology, based on an exchange of different viewpoints on one single reality, has enabled us at the same time to study the themes in more detail than perhaps many of us had initially anticipated, taking a new approach based on the intersection of gender and disability which has, until now, been largely unaddressed.

This methodology, used for the first time in a CERMI publication, facilitated co-operation among the coordinators for each chapter in the guide. The coordinators were chosen due to their acknowledged expertise in the field and come from the third social disability sector, academia and the political sphere, thus allowing many women and men to participate as experts. Their expertise facilitated the study of each of the themes covered based on a range of general documents and specific documentation for each group, in accordance with its thematic area.

As a result, during the months of work drafting the guide, the experts who have taken part in one way or another in putting it together were able to address those aspects which must be considered when formulating policies targeting women and girls with disabilities, many of which have been unknown or overlooked up to now. The importance of this guide, therefore, lies in the collective learning process it fuelled on a subject that is often unexplored and at times thought not to exist.

For too long women and girls with disabilities have been consigned to oblivion by the system, including the disability sector and women's rights defenders. Pretending the gender perspective does not exist in certain policies and arguing that the key is to further the interests of persons with disabilities as a whole serves no purpose. The gender perspective is present in all areas of life and, as such, must be mainstreamed in all disability policies.

We hope to be in a position to continue developing these questions in the near future by publishing a second volume focusing on thematic areas where we have started to work and which, for reasons of space and time, merit their own specific consideration. Social protection, political participation, women in rural areas and older women are just some of the thematic areas we will address to supplement the global perspective we offer in this first guide.

We gratefully acknowledge the support provided by the Women's Institute, which has always been sensitive to the task of promoting the rights and interests of women with disabilities.

It only remains for us to express CERMI's most sincere gratitude to everyone who has participated disinterestedly in this ambitious project.

ANA PELÁEZ NARVÁEZ

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*Technical management supervisors for the guide*



# Chapter I

## EQUALITY AND NON-DISCRIMINATION

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## Chapter I

# EQUALITY AND NON-DISCRIMINATION

### 1. INTRODUCTION

Discrimination is a complex phenomenon which in practical terms leads to exclusion and lack of social cohesion. It normally occurs in relation to inequities in standards of living and wellbeing for the individual in a range of settings (employment, health, education, leisure, etc,) and also through subjective manifestations involving rejection, stereotypes and stigmas which are not necessarily linked to the material life conditions of the individual. The discrimination women with disabilities face is particularly acute as the convergence of the gender and disability factors acts exponentially on the inequalities they suffer in society.

Although progress has been made in recognising rights and equality for women and persons with disabilities, the situation faced by women with disabilities is neither understood nor acknowledged. Although feminist movements have made efforts to raise awareness among women about their rights, this has not extended to include women with disabilities because the feminist movements themselves are ignorant of their needs and the disability movement has paid scant attention to the question.

Discriminatory practises and rejection towards women with disabilities are particularly subtle and involve ambivalence between a considerate discourse, on the one hand, and manifestations of rejection and exclusion on the other. As a result, the political and regulatory frameworks in the fields of gender and disability do not properly reflect the needs of women with disabilities; consequently, they condemn and subject them to permanent structural inequality.

Different reasons are put forward as excuses for the obscure and residual approach to the gender perspective in formulating disability policies. The non-existent link between the disability and gender approaches, a critical assessment of the topic of gender, dysfunctional administrative arrangements causing actions to be carried out

disjointedly, and the recurring excuse that there are insufficient financial resources, combined with a lack of statistical data on women and girls with disabilities, have prevented us from reaching a true understanding of the situation they are in, their specific needs and the types of discrimination they face.

To overcome the obstacles preventing women with disabilities from participating fully and on equal terms with others, a mixed strategy is needed involving greater awareness and participation in society, a renewed approach to equality measures by the Third Sector, and the formulation of disability policies and equality policies including the gender perspective and drawing on the rights and freedoms set out in the *International Convention on the Rights of Persons with Disabilities*, which specifically links the principle of non-discrimination to women with disabilities exercising their fundamental rights.

Ensuring the gender approach is mainstreamed in disability policies does not simply mean combating intersectional discrimination due to disability and sex: it involves a real shift towards strong equality policies covering everyone to enable structural inequalities to be broken down and, in short, seek to extend social cohesion.

## 2. THE POLITICAL AND REGULATORY FRAMEWORK IN EQUALITY, NON-DISCRIMINATION AND WOMEN WITH DISABILITIES

Claiming and advocating for the rights of girls and women with disabilities was unknown until fairly recently. The idea that the interaction of gender and disability was the root cause of a complex and structural type of discrimination did not form part of political and legal discourse.

The problems relating to recognising and addressing the specific situation of women and girls with disabilities point to one fact in particular<sup>1</sup>: gender and disability have been addressed separately when formulating and implementing equality policies, and this has prevented greater progress from being made in understanding the ways in which these two factors, causes of discrimination, interact, and in joint actions to combat discrimination.

To understand why discussions on targeted protection to combat discrimination for women and girls with disabilities did not begin until relatively recently and did so

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<sup>1</sup> The lack of fit between feminist and disability thinking was studied in detail by Ana Peláez Narváez in 'Gender and Disability', in 'Treatise on Disability', edited by PÉREZ BUENO, L. and GARCÍA, R., Thomson Aranzadi, 2007, pages 143-172.

hesitantly, we must consider how the ideological suppositions present in the fight against discrimination evolved. In general terms, equality and non-discrimination policies have gone through four stages. These show how outlawing discrimination has, until very recently, invariably been approached by considering just one factor leading to discrimination; as a result, gender and disability have evolved along parallel tramlines without ever converging.

The first policies in the field of discrimination were linked to a liberal conception of equality that stressed formal equality or, in other words, formal acknowledgement in legal measures as is normally seen in such measures, that is to say by means of implicit and formulaic statements used repeatedly in international instruments and constitutions which state that “everyone enjoys the right to equality”, or “each individual has...”, “each person”, “all human beings” or “nobody shall...”. This approach to anti-discrimination involved strictly equal treatment based on legal provisions and applicable *erga omnes*, and general and impersonal limits to applying the provisions which also failed to consider collective, social or individual reasons for discrimination.

In the next stage, and due to the limited nature of the formal equality approach, the eighties and nineties saw an increase in the use of *equal opportunities* and *positive action* as means to re-establish equality and secure protection. In this phase, the experience gained in the struggle against gender-based discrimination and in the fight for gender equality, the first battlefield<sup>2</sup>, was used to combat other types of discrimination, including discrimination on the grounds of disability. However, measures to eliminate discrimination on the basis of gender and on the grounds of disability each went their own way and their paths never crossed. On the one hand, targeted public policies were introduced to integrate women, considered overall and without distinction<sup>3</sup>. On the other hand and in relation to disability, the 1993 United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities became the legal instrument and tool for action to ensure girls and boys, women and men with disabilities enjoyed the same rights and obligations as others. However, the specific reference in the Standard Rules to the need to pay particular attention to

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<sup>2</sup> The first anti-discrimination laws in Europe were the Sex Discrimination Act (SDA) and the Equal Pay Act, both in the United Kingdom and both adopted in 1975. The first European Community action in anti-discrimination legislation is the provision for equality between men and women in pay in former article 119 of the 1957 Rome Treaty. The limited nature of these measures to outlaw discrimination was superseded by a range of directives, programmes and awareness-raising campaigns, the most important of which is Directive 76/207/EEC on the implementation of the principle of equal treatment for men and women as regards access to employment, vocational training and promotion, and working conditions.

<sup>3</sup> See the European Union’s 1st Action Programme for Equal Opportunities for Women 1982-1985 and 2nd Action Programme for Equal Opportunities for Women 1986-1990.

groups such as women meant it was possible to take on board the demands and needs of women with disabilities and set the foundations for the *Manifesto by Disabled Women in Europe*<sup>4</sup>, which was used to promote equality and non-discrimination for women with disabilities in the European Union and its Member States.

Subsequently, the model or strategy for equality and eliminating discrimination became known as mainstreaming. Mainstreaming has been conceptualised and interpreted in several ways, but the definition used in most public policies and regulations holds that mainstreaming as a concept is a strategic tool that allows the principle of equal treatment and opportunities to be included in the formulation and management of public policies<sup>5</sup>.

Gender mainstreaming was taken up explicitly in the *Platform for Action* adopted at the *4th UN World Conference on Women* in Beijing in 1995. From that moment on several European government agencies promoted positive action measures and the principle of mainstreaming in an attempt to overcome inequalities between men and women, applicable also in policies specifically targeting women with disabilities.

From then on, and based on the analysis of multiple discrimination in anti-discrimination legislation, there was a move on from generalisations and the needs of different women began to be addressed. Although some progress has been made in implementing policies aimed at women with disabilities, based on the premise that the situation of vulnerability each woman experiences is the result of the intersection of several of her identities (woman, disability, lives in a rural area, etc.), there is still dissociation in how gender and disability are addressed.

This segregation in including the disability perspective in gender policies and the gender perspective in disability policies is also reflected in initiatives taken by United Nations agencies and in UN instruments<sup>6</sup>. Following a number of difficulties and

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<sup>4</sup> The Manifesto was adopted by the European Disability Forum on 22nd February 1997. It was based on the recommendations from the United Nations Experts Seminar on Disabled Women in Vienna in 1990, and on the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. Through its Helios II programme, the European Commission gave strong support allowing a permanent women's committee to be set up within the European Disability Forum.

<sup>5</sup> The principle of mainstreaming has been defined by the European Commission as, "*the organisation or reorganisation, improvement, development and assessment of all policies to ensure that an equal-opportunity approach is incorporated into all policies at all levels and at all stages by those normally involved in policy-making*".

<sup>6</sup> A detailed analysis of how gender was included in the United Nations Convention on the Rights of Persons with Disabilities is given by Ana Peláez Narváez in '*Non-discrimination, women*

arduous negotiations, gender was included in the 2006 Convention on the Rights of Persons with Disabilities. Discussions on protecting women and girls with disabilities from discrimination and, therefore, including this issue in the Convention did not take place at the beginning of the drafting stage. The issue was not raised until a later stage because neither the government delegations nor the non-governmental organisations involved in the process realised how important the matter was. In addition, no activist movement engaged in the negotiations raised the matter. Moreover, those opposed to the proposal to include the gender perspective in the Convention based their arguments on the general terminology covering all people and without distinguishing between genders which is used in human rights instruments. Women with disabilities were therefore held to be included already in a specific treaty.

During negotiations two moves developed to include women with disabilities in the text of the Convention. The first, supported by South Korea, involved adding a specific article addressing women's issues, while the second, backed by the European Union, sought to mainstream the principle of equality throughout the text of the Convention. Finally and in an effort to reach a consensus and bring together the two positions, the solution adopted was the so called 'twin-track approach' which allowed article 6, addressing women with disabilities separately and specifically, to be included in the final text, in addition to references to women and gender in other articles (preamble, article 3 'General Principles', article 8 'Awareness-raising', article 16 'Freedom from exploitation, violence and abuse', article 25 'Health', article 28 'Adequate standard of living and social protection', and article 34 'Committee on the Rights of Persons with Disabilities').

### 3. WOMEN WITH DISABILITIES: CURRENT STATUS

#### 3.1. Women with disabilities: statistical overview and living conditions

It is estimated there are some 1 000 million people with some type of disability in the world, and women outnumber men. In some low- and medium-income countries, women constitute up to three quarters of all persons with disabilities. Between 65% and 70% of these women live in rural areas<sup>7</sup>.

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*and girls with disabilities and the International Convention on the Rights of Persons with Disabilities* in '2003-2012: 10 years of anti-discrimination legislation for people with disabilities. Studies in tribute to Miguel Ángel Cabra de Luna', CERMI, Fundación Derecho y Discapacidad, Madrid, 2012, pages 244-271: <http://www.fderechoydiscapacidad.es/>.

<sup>7</sup> World Report on Disability, World Health Organisation and World Bank, 2011.

Despite the estimated figures above, and in line with international recommendations<sup>8</sup> to promote data gathering on this population group, many countries have developed surveys and censuses with the aim of finding out the exact number of men, women, boys and girls with disabilities. Often the outcomes are not considered to be accurate as they tend to minimise the number of people with disabilities. This is because of a lack of disability-awareness training and training on the consequences of disability among those carrying out the surveys and census takers; the exclusion, rejection and discrimination people with disabilities face, all practises which are often deeply seated and held to be normal by a social culture that decides many people with disabilities should be hidden away by their families or placed in institutions; because people with disabilities themselves are reluctant to consider themselves as having a disability as they fear greater or additional types of discrimination; and due to the lack of real and long-lasting commitments by states to detect and update statistics on this group within the population.

The paucity of bibliographical material on the specific problems women with disabilities have is highlighted in periodic reports submitted by States Parties to the UN Convention on the Elimination of all Forms of Discrimination against Women. These reports either don't include information on women with disabilities, or do include information in an incoherent fashion<sup>9</sup>.

The lack of information on the number of women with disabilities poses a serious problem in clearly determining their specific needs in all areas of their lives: education, health, employment, leisure, etc. It also prevents policies which are appropriate to the reality they experience from being formulated and assessment of the efficacy of these policies<sup>10</sup>.

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<sup>8</sup> Gathering data on persons with disabilities in order to understand their living conditions is recommended in the *World Programme of Action concerning Disabled Persons*, adopted by the United Nations General Assembly at its 37th ordinary period of sessions on 3rd December 1982 by Resolution 37/52; in the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, adopted by the United Nations General Assembly at its 48th ordinary period of sessions on 20th November 1993 by Resolution 48/96; and in the *Manual for the Development of Statistical Information for Disability Programmes and Policies*, United Nations, Statistics on vulnerable groups in the population, number 8, New York, 1997.

<sup>9</sup> See Gerard Quinn and Theresia Degener, *Human Rights and Disability: the Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, 2002.

<sup>10</sup> This situation was highlighted already in 1993 by the then United Nations Special Rapporteur of the Commission on Social Development for monitoring compliance with the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Mr Leandro Despouy, in the report *Human Rights and Disabled Persons*.

Bearing in mind this lack of information, the following study on some of the living conditions faced by women and girls with disabilities is based mainly on documents from international organisations which are sensitive to this group<sup>11</sup>.

### *Employment*

The study *'The Right to Decent Work of Persons with Disabilities'* states that, "People with disabilities in general face difficulties in entering the open labour market, but, seen from a gender perspective, men with disabilities are almost twice as likely to have jobs than disabled women."<sup>12</sup>

According to US statistics, men with disabilities earn 55% more than women with disabilities<sup>13</sup>.

According to United Nations, only 25% of all women with disabilities in the world have a job<sup>14</sup>.

The World Bank and the International Labour Organisation have stated that discrimination in the workplace is one of the most insidious types of discrimination that people with disabilities can suffer in many societies<sup>15</sup>.

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<sup>11</sup> The statistical data in the following sections was compiled by the United States Agency for International Development (USAID). The data were taken from the web site of the National Disability Observatory: <http://www.observatoriodeladisapacidad.es>. The statistics are also available on the European Women's Lobby web site: <http://www.womenlobby.org>.

<sup>12</sup> O'REILLY, A., *The right to decent work of persons with disabilities*, International Labour Office in Geneva, 2007.

<sup>13</sup> According to a study carried out in the United States in 1984 which found that approximately 42% of men with some type of disabilities were part of the workforce, in comparison with 24% of all women with disabilities. In addition, while over 30% of men with disabilities worked full time, only 12% of women with disabilities were in full time employment. Women with disabilities working full time earned only 56% of the salaries of men with disabilities in full time employment. BOWE, F. 1984, *Disabled women in America: A statistical report drawn from census data* (Washington, DC, President's Committee on Employment of the Handicapped).

<sup>14</sup> United States Agency for International Development (USAID). The statistic was taken from the web site of the National Disability Observatory: <http://www.observatoriodeladisapacidad.es>.

<sup>15</sup> The ILO Committee of Experts on the Application of Conventions and Recommendations, in its Overview of Convention number 159 and Recommendation number 168, states that government reports indicated that most countries applied the principle of equal opportunities in employment without distinction on any grounds, including disability. Nevertheless, a general trend was noted to set up special programmes for persons with disabilities without considering women with disabilities as a vulnerable group in need of targeted support. As a result and bearing in mind that the legal framework is gender-neutral, discrimination faced by women with disabilities can easily go unnoticed. See Vocational Rehabilitation and Employment (Disabled

### *Education*

According to the United Nations Development Programme (UNDP), the literacy rate among people with disabilities is 3%, while for women and girls with disabilities it is barely 1%<sup>16</sup>.

### *Health and nutrition*<sup>17</sup>

In developing countries, statistics reveal that the mortality rate for girls and women with disabilities is higher due to negligence, lack of medical care and restricted access to food and related resources.

According to the World Bank, women with disabilities face singular challenges to avoid HIV infection due to the heightened risk of gender-based violence, a lack of access to reproductive health services, and a lack of knowledge that the virus can be transmitted from mother to child.

The popular belief that people with sexually transmitted diseases can be cured if they have sexual relations with a virgin creates a particular risk for girls with disabilities due to the misconception that persons with disabilities are sexually inactive and, therefore, virgins.

### *Gender-based violence*

Studies in Europe, North America and Australia show that more than half of all women with disabilities have suffered physical abuse. This compares to a third in the case of women with no disability<sup>18</sup>.

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Persons): Overview of reports on Convention 159 and Recommendation 168 on Vocational Rehabilitation and Employment (Disabled Persons), 1983, Report III (Part 1B) by the Committee of Experts on the Application of Conventions and Recommendations, International Labour Conference, 86th meeting, Geneva, 1998.

<sup>16</sup> HELANDER, E., *'Prejudice and dignity. An introduction to Community-Based Rehabilitation'*, UNDP, New York, 1998.

<sup>17</sup> United States Agency for International Development (USAID). The statistic was taken from the web site of the National Disability Observatory: <http://www.observatoriodeladisapacidad.es>.

<sup>18</sup> Human Rights Watch, *Women and girls with disabilities*. Available at: <http://hrw.org/women/disabled.html>

A World Bank study indicated that women with disabilities are more exposed to violence and rape than women without disabilities, and less likely to ask the police to intervene or seek legal protection<sup>19</sup>.

EOCD studies indicate that between 39% and 68% of girls and 16% - 30% of boys with intellectual or developmental disabilities suffer sexual abuse before the age of 18<sup>20</sup>.

### 3.2. Multiple discrimination: related factors

Although some anti-discrimination and equal opportunities legal instruments<sup>21</sup> refer to a comprehensive approach to eliminate discrimination and further equality between men and women, and recognise that some people are victims of multiple discrimination, in practise it has been shown that the use of such terminology is not in line with the situation faced by women with disabilities.

Multiple or intersectional discrimination occurs when there is interaction between various factors which, together, produce a type of discrimination that is specific and different from single-cause discrimination. Multiple discrimination considers social, historic, political and cultural elements and recognises the reality of each person based on the mix of all the relevant factors affecting the individual.

Multiple discrimination is a long-standing reality associated with negative and deeply-held stereotypes in society. It increases and transforms the damage caused and widens the gap with society in general. However, it has barely been considered in international and national instruments because non-discrimination has been addressed on the basis of one single factor leading to discrimination - gender, disability, age, race, etc.; a combination of two or more has been considered in very few cases and there is a failure to understand the impact of greater oppression which leads inexorably to structural inequality.

The experiences of women with disabilities show us how they can be victims of discrimination in ways that are similar, but also different, to the discrimination faced by women without disabilities and men with disabilities. Women with disabilities may

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<sup>19</sup> United States Agency for International Development (USAID). Data taken from the web site of the National Disability Observatory: <http://www.observatoriodeladisapacidad.es>.

<sup>20</sup> United States Agency for International Development (USAID). Data taken from the web site of the National Disability Observatory: <http://www.observatoriodeladisapacidad.es>.

<sup>21</sup> Communication from the Commission to the Council, the European Parliament, the European Economic and Social committee and the Committee of the Regions - Non-discrimination and equal opportunities for all - A framework strategy, 1st June 2005, published COM 2005/224 - Official Journal C 236, 24th September 2005.

be discriminated in the same way as women without disabilities, or in the same way as men with disabilities, or they may suffer discrimination due to gender and disability, or they may fall victim to discrimination simply because they are women with disabilities, not as a result of adding the gender and disability factors.

Whatever the case and however discrimination occurs, it has particular implications for a woman with disabilities because there are usually a number of factors present, some particularly relevant, which place her in a more vulnerable position. Being an older woman or a girl with disabilities, having a mental disability, being a foreigner, living in a rural setting, or being unemployed, are some of the factors that interact simultaneously to produce a unique and special type of discrimination that deserves to be addressed differently.

#### 4. MAINSTREAMING GENDER IN DISABILITY POLICIES: OBSTACLES

##### 4.1. Rejection of the gender perspective

Undoubtedly we are in the process of modernising discourse regarding certain realities which until recently were largely ignored (woman-disability) or, when addressed, subject to stereotyped and stigmatising structures.

Correcting the traditional terms used to refer to certain social groups is an attempt to avoid the negative and pejorative connotations - often originating in questions of context rather than linguistics itself - surrounding some expressions.

In this respect, and leaving aside the language used by public bodies which is related to political notions and institutions, it cannot be stated categorically that the more up-to-date language regarding women and disability is firmly established in everyday use; although the connotations may have changed slightly, the core meaning-reflecting an ignorance of these realities through the use of overprotecting and offensive language - remains.

Vilifying the legal and social position of women has been a common feature in history and constitutes one of the greatest discriminations perpetrated by the human race. Perhaps the scale and duration of this type of discrimination makes it difficult to question any measures and/or policies undertaken to mitigate this marginalisation. Deepening and determining the scale or raising doubts in the face of this social injustice may seem ironic; however, some so called *gender policies* must be analysed and reviewed to avoid falling into the ambiguity of political correctness.

Although *politically correct* language is basically euphemistic in nature and serves the social function of dignifying or enhancing the image of an individual or group, the fact is that it is not carried through to social behaviour, and in more than a few cases it leads to an open rejection of policies to combat gender-based discrimination because the language chosen by public authorities mainly deals in abstractions and formulae which still consider suitable and adequate what is established by society and thus avoids an analysis of the underlying question.

In addition, as it is almost always women who engage in the discourse or formulation of measures, we are given the impression that this is exclusively an issue for them; men are not used to taking part in gender and equality debates, actions and policies. And even though gender mainstreaming explicitly includes men, in most countries they have not been a target in terms of gender equality.

If the aim is to mainstream gender equality as a general interest topic in disability policies, gender equality must include the need for men to actively take on board these principles also, and this means there is a need to develop a male gender perspective to foster equality.

#### **4.2. Disconnect between the gender approach and disability**

The difficulties in identifying multiple discrimination against women with disabilities are a result of two factors: first of all, the needs and demands of women with disabilities were thought of as those of a vulnerable group within another vulnerable group (people with disabilities) and marginalised by them; secondly, gender and disability have been addressed separately by the women's movement and the disability movement and there has been a considerable gap between the two movements.

The feminist movement, despite talking about *all* women, has followed a dominant pattern for women that does not include women from minorities such as women with disabilities, who tend to be grouped together side by side in subgroups called *women in situations of exclusion*. On the other side, the disability movement has also failed to consider multiple discrimination against women with disabilities as its efforts have generally been focused on a homogeneous group and its fight against the same discrimination suffered by all its members.

At the same time, there has been a disconnect between legal instruments concerning gender-based discrimination and disability-based discrimination, despite significant developments in both fields.

While progress has been made in public policies promoting equal opportunities, they have been formulated on the basis of typologies of policies depending on the target group. So public policies have been introduced for people with disabilities, public policies in the field of equal opportunities for men and women - with or without disabilities - have been put in place, and we have public policies targeting women with disabilities. The approach to gender discrimination and the approach to disability discrimination have evolved in parallel, with insufficient linkages to allow the gender perspective to be mainstreamed in targeted public policies for persons with disabilities.

#### **4.3. Dysfunctionality in administrative arrangements**

For gender to be successfully mainstreamed in disability policies it is not enough merely to adopt measures to promote the mainstreaming process; public structures capable of making it work must be put in place.

Once guidelines for gender and disability have been formulated, there must be no political encroachment on areas reserved for public authorities if we are to avoid making the structure and functioning of authorities dysfunctional. Although there must be liaison between the government and public administration, there should be no functional interference preventing disability and equality policies with the gender perspective from functioning.

Changes at different levels of government should not lead to the elimination of policies which are in place if they are producing positive results; nor should there be changeable arrangements leading to duplication in activities, contradictions and disconnect between the different policies being implemented.

If the techniques used to define public arrangements are not permanent and independent of the ruling party this may cause the governed to become mistrustful and lead to an undermining of the goals of policies adopted.

#### **4.4. Cost reduction**

Although a number of steps have been taken both in gender equality and equality for persons with disabilities, planning and programming are probably the techniques most commonly-used by public authorities to provide permanence and coherence.

While planning and programming are instruments to arrange rationally and in a co-ordinated fashion public action in areas where public authorities intervene, it must

be understood that mainstreaming the gender perspective in disability policies need not involve any additional cost as it would be sufficient to include the gender perspective in disability policy plans and programmes.

In this respect the model for plans in the field of disability must be all-embracing and cover both current measures and actions and those planned for the future. This mainstreaming and interdependent approach should be used because it is known that partial approaches are unworkable and have brought about only limited solutions to the problems women with disabilities experience.

If overall planning and programming in disability policies is performed in line with this model, most of the changes needed to ensure the gender perspective is mainstreamed in disability policies could be carried out at no additional cost for the plan or programme.

## 5. MAINSTREAMING GENDER IN DISABILITY POLICIES: ADVANTAGES

### 5.1. Quality of life for women with disabilities

For women with disabilities vulnerability is composed of a number of factors. Being a woman and having a disability, which by themselves are perceived by society stereotypically and in a stigmatising manner, mean they are in a clearly disadvantageous position when it comes to realising their life projects. In addition, however, within the population of women with disabilities there are a number of particularly vulnerable groups due to the confluence of certain variables which may lead to a multiplication of the discrimination they suffer - living in a rural area, being a girl or immigrant with disabilities, or being unemployed.

All of these circumstances are unknown as in practise gender policies have systematically ignored several groups, including women with disabilities. Ignorance prevents understanding of the reality the group experiences and has led to unbalanced public action and exclusion.

Consequently, gender and disability indicators which enable us to gather real and accurate data regarding the living conditions of women with disabilities must be part of the formulation process for both gender policies and disability policies prior to undertaking and implementing actions to further equality. This information will provide a greater understanding of the inclusion and exclusion processes affecting the population and the keys to addressing the discrimination women with disabilities suffer in different ways.

## **5.2. Social sustainability**

Social sustainability, taken to mean maintaining social cohesion with a view to reaching common goals, cannot be considered without mainstreaming the gender and disability perspectives. In our modern day society and adopting a holistic approach, all systems and dimensions making up society must be consistent with each other because components are interdependent. Sustainability enables one to consider the human being as a whole and help the individual to secure a wide range of human rights, which are the foundation for a cohesive society.

In this context, mainstreaming the gender perspective in disability policies provides the opportunity to rebuild balance between the needs people with disabilities have and social justice demands; it enables society to evolve and show solidarity based on justice and the common good; it prevents situations where women with disabilities are victims of direct or indirect discrimination from occurring; and it generates added value by integrating diversity as a prerequisite for co-existence.

## **5.3. Economic development**

Mainstreaming gender in disability policies is advantageous not merely in terms of social profit; social profit needs to be combined with economic profit.

Overcoming barriers and creating propitious conditions for women with disabilities to be included should also be seen as advantageous from an economic point of view, both for women with disabilities themselves and for general economic and social growth.

Making it possible for women with disabilities to be part of the social fabric involves allowing them to earn income independently in order to make a financial contribution to their homes and communities. Principally, however, it gives them heightened self-esteem, respect and skills for decision-making and to change their lives. Access to remunerated activities strengthens the position women with disabilities hold in the home and surrounding environment as their contribution to the family or community through economic resources adds value to their opinions and enables them to influence family and social structures.

Furthermore, when the economic capacity of a woman with disabilities is developed the capacity of the family increases as it has been shown that women are more likely to spend their income on the needs of the family, thus creating a multiplier effect which enhances the impact of including women with disabilities in the economic fabric.

In macro-economic terms, evidence suggests that discriminatory societies hinder economic growth and development because they must assume the costs incurred by those excluded. Economically, the difference between the total cost of resources assigned to a socially excluded person and the income that person may earn were he or she to be included in the economic fabric represents, in the former, a major expense for the public purse and, in the latter scenario, savings and economic profit.

## 6. IMPLEMENTING A JOINT ACTION STRATEGY TO MAINSTREAM THE GENDER PERSPECTIVE IN DISABILITY AND EQUALITY POLICIES

Discriminatory acts against women with disabilities and their perception occur in all spheres of life. However, no legal action is taken to counter them due to invisibility, misconceptions and stereotypes surrounding women with disabilities, a lack of acknowledgement of their rights and freedoms, or ignorance of the available legal instruments at hand to fight discrimination.

Nevertheless, we can discern an opportunity to change this thanks to the growing number of anti-discrimination legislative initiatives being undertaken with the backing, above all, of the 2006 International Convention on the Rights of Persons with Disabilities, which has triggered major shifts in mindsets, philosophical structures, public intervention and legislation. We believe the Convention, an invaluable political, social and legal instrument, must be linked to a three-pronged approach: firstly, engagement by society as a transformational body politic with co-responsibility for overall wellbeing; secondly, the implementation of active policies aimed at combating discrimination and promoting equal opportunities for women with disabilities through a range of varied activities; and, thirdly, a renewed approach by the third sector to ensure women with disabilities are fully included and can participate freely in its organisational and operational structure<sup>22</sup>.

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<sup>22</sup> Achieving equal treatment for persons with disabilities has become a priority area in policy and public action programming. In this respect, see '*COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS - European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*', published in the Official Journal of the European Union on November 15th 2010, and '*Spanish Disability Strategy 2012-2020*', Spanish Ministry for Health, Social Policy and Equality, published by the Royal Board on Disability, Madrid, 2011.

## **6.1. Freedom from disability-based discrimination for women in the UN Convention on the Rights of Persons with Disabilities**

### *6.1.1. The concept of material equality on the basis of disability.*

The Convention on the Rights of Persons with Disabilities (CRPD), adopted on 13th December 2006, is a major step forward in the fight against discrimination on the grounds of disability. The Convention places people with disabilities firmly within the scope of human rights in the international community. Disability is considered to be the result of excluding a group of people who are at the very core of human diversity.

The paradigm shift introduced by the Convention towards a social model for human rights places the individual in context in his or her environment to assess equality and imposes an obligation to act when *de facto* inequality exists.

The Convention on the Rights of Persons with Disabilities includes the right to non-discrimination based on equal opportunities and, consequently, the need to achieve material equality. This involves putting in place instruments to combat discrimination such as accessibility measures, positive action programmes, inverse discrimination and reasonable accommodations, which are now an integral part of the right to non-discrimination.

This is recognised in the Convention, which explicitly states that the denial of reasonable accommodation is discrimination on the basis of disability (article 2) and establishes the need for specific measures to achieve *de facto* equality of people with disabilities (articles 5.4 and 9).

### *6.1.2. Gender mainstreaming in the Convention*

As mentioned previously, women have traditionally been invisible in the fight against disability-based discrimination. The Convention has largely resolved this problem through article 6<sup>23</sup>, which acknowledges that women with disabilities are victims of multiple discrimination and introduces an obligation to take all appropriate measures to ensure the full enjoyment of all human rights and fundamental freedoms on an equal footing with others.

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<sup>23</sup> Direct engagement by women with disabilities during the negotiation phase of the treaty was vital to having this article included. This merely highlights the need to involve and recognise women when formulating policies affecting them.

It is precisely the obligation to go beyond formal recognition of the right to equality that is strengthened by seeking responses and targeted actions for women with disabilities which should ensure full development as individuals.

In this respect, mainstreaming the article horizontally in all policies designed to promote and protect people with disabilities should be sufficient to cover the specific needs of women. In addition, however, the Convention explicitly introduces this horizontal aspect in some of the other rights enshrined in the international treaty, and it is precisely the fact that it is only included in 'some' rights which indicates persisting shortfalls in the presence of gender questions in disability policies; more so when mainstreaming does not extend to cover essential issues for women's development such as respect for the home and family, or areas where gender-based discrimination clearly exists such as the right to employment.

Article 7 of the Convention adds age to the gender-disability pairing by explicitly mentioning girls with disabilities and placing an obligation on states to adopt specific measures to protect them in the exercise of their fundamental rights.

#### *Non-discrimination of women on the grounds of disability*

Both the *Convention on the Elimination of all Forms of Discrimination against Women* (CEDAW) and the *Convention on the Rights of Persons with Disabilities* (CRPD) base non-discrimination on the concept of equal opportunities.

Direct discrimination, that is to say any provision or action that treats a woman with disabilities less favourably or disadvantageously in respect of another person without disabilities in the same situation, either because she is a woman or because she has a disability, or both, is a violation of her human rights<sup>24</sup>.

It is worthwhile mentioning indirect discrimination, which may be caused by provisions and actions affecting women and which, if they fail to take the disability

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<sup>24</sup> CEDAW, article 1: "...discrimination against women" shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field."

CRPD, article 2: "'Discrimination on the basis of disability' means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;"

perspective into account, may discriminate against her because of her disability. One flagrant and repeated example is the lack of access for women with disabilities to gender violence programmes, which often overlook the need to ensure accessibility for people with disabilities (lack of accessible information, information in languages and means of communication, inaccessible emergency shelter services, etc.).

On the other hand, if a provision or action favouring persons with disabilities leaves out the gender perspective it will lack the measures needed and will fail to include people with disabilities due to their being women. This could be the reason why educational attainment and employment rates are considerably lower for women with disabilities than in the case of men with disabilities.

While CEDAW does not cover both aspects<sup>25</sup>, the CRPD takes into account the double gender and disability factor and includes frequent references to the particular situation of women in disability policies.

The Convention reinforces gender mainstreaming by including equality between men and women in article three as one of the general principles. Consequently, government policies to combat discrimination implemented as a result of the Convention must consider the gender dimension.

One dimension of disability discrimination is particularly important for women. The traditional role played by a woman in the family - as mother, daughter or wife - means she is very often a carer or 'informal assistant' to the persons with disabilities if there are insufficient effective measures to enable independent living. In some cases this relationship between the dependent person and the woman, whether she has a disability or not, may constitute a violation of her rights - for example in access to employment - as she is forced to take on care provision for a person with disabilities<sup>26</sup>. This human rights violation is also foreseen by the CRPD, which prohibits any discriminatory act motivated by disability, regardless of who has the disability (article 2). Implementation at national level of anti-discrimination protection based on the CRPD must cover such cases, which mostly affect women.

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<sup>25</sup> We could perhaps say the same about the *Convention on the Rights of the Child* in relation to girls with disabilities, while bearing in mind that in this case there are three conditions to be considered; age, gender and disability. In this respect age and gender are explicitly dealt with in article 7 of the *Convention on the Rights of Persons with Disabilities*.

<sup>26</sup> This is a similar situation to the obstacles women face in terms of accessing employment and being promoted when they are also mothers, etc.

*Civil dialogue and participation in political and public life*

To ensure people with disabilities are free from discrimination, it is necessary to ensure they take part in decision-making processes on those questions directly affecting them, thus taking into consideration their demands and largely avoiding social exclusion.

A lack of representativeness and participation renders people invisible and is the root cause of discrimination. CEDAW protects women's right to participate in article 7, and the CRPD, in article 29, obliges states to guarantee full participation in political life and other public affairs, and especially participation in non-governmental organisations involved in political issues nationally and internationally.

Given that women with disabilities are underrepresented in the disability movement in positions of power and decision-making, it may have been good to complement the general principle of equality by including in article 4, *General Obligations*, a specific reference to the need to ensure women with disabilities take part in drawing up and implementing legislation and policies. However, this article fails to mention organisations of women with disabilities explicitly when addressing civil dialogue, although it does mention girls with disabilities.

*6.1.3. Implementing the Convention in policies combating discrimination to favour women with disabilities*

The CRPD provides a level of protection for the rights of persons with disabilities which must be implemented in national legislation in those countries that ratify it.

The Convention includes anti-discrimination measures for women with disabilities in some of the main areas in their lives, although not in as many as would have been desirable.

*Social image*

Stereotypes and prejudices that hold women and people with disabilities to be inferior are specifically referenced in article 8 of the CRPD, which mentions those based on age and gender explicitly.

*Freedom and security, freedom from inhuman or degrading treatment, exploitation and abuse*

*“Violence against women takes many different forms, including violence in the home; rape; trafficking in women and girls; forced prostitution; violence in situations of armed conflict, such as murders, systematic rape, sexual slavery and forced pregnancy; honour-based killings; dowry-related violence; feminine infanticide and prenatal selection of the sex of the foetus in favour of male babies; female genital mutilation and other harmful practises and traditions”<sup>27</sup>*

According to a report published by UN Women in 2011 on the prevalence of physical and sexual violence against women in 86 countries, violence against women and girls is a problem of pandemic proportions<sup>28</sup> which affects around 70% of all women worldwide.

The disability a woman has may make her a particularly vulnerable victim who, as we have shown, may enjoy access to fewer resources to fight attacks that threaten her physical and moral integrity when prevention and protection systems are inaccessible and other measures fail to provide equal opportunities. The scale of violence is so alarming in the case of women with disabilities that legislation even in countries which are strongly committed to combating discrimination may not penalise physical mutilation such as forced sterilisation due to disability<sup>29</sup>. Precisely due to this fact, and the fact that it demonstrates a higher risk of rights violation, it is vital to enhance protection for women with disabilities in anti-violence policies.

The CRPD does not provide specific protection in this respect as the gender perspective is missing from the articles on liberty and security of the person (article 14), freedom from torture or cruel, inhuman or degrading treatment or punishment (article 15) and protecting the integrity of the person (article 17).

However, article 16 of the CRPD, on freedom from exploitation, violence and abuse, does make reference to the need to include a suitable gender perspective in policies aimed at the recovery and reintegration of victims of violence (paragraph 4),

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<sup>27</sup> Briefing Note number 4, United Nations, 2000, ‘*Review and appraisal of the implementation of the Beijing Platform for Action: report from the Secretary General*’, E/CN.6/2000/PC/2.

<sup>28</sup> [http://www.unifem.org/gender\\_issues/violence\\_against\\_women/facts\\_figures.php](http://www.unifem.org/gender_issues/violence_against_women/facts_figures.php).

<sup>29</sup> CRPD Committee, 2011, *Concluding Observations of the Committee on the Rights of Persons with Disabilities: Spain*, 6th period of sessions, 19th-23rd September 2011:

[http://www.ohchr.org/Documents/HRBodies/CRPD/6thsession/CRPD.C.ESP.CO.1\\_en.doc](http://www.ohchr.org/Documents/HRBodies/CRPD/6thsession/CRPD.C.ESP.CO.1_en.doc)

CEDAW Committee (2010) *Concluding observations of the Committee on the Elimination of Discrimination Against Women: Australia*. CEDAW Forty-sixth session, 12 - 30 July 2010, CEDAW/C/AUS/CO/7. See <http://www2.ohchr.org/english/bodies/cedaw/cedaws46.htm>

although this is insufficient considering the widespread violation of rights women with disabilities face in this area.

*Equal recognition before the law and access to justice*

As we have seen, having a disability may mean a woman is in a particularly vulnerable situation which is often even exacerbated by laws that limit her rights on two counts. In addition, economic dependence, which is common in these cases, and a lack of qualifications are major obstacles to accessing justice. If we add the fact that available resources are often inaccessible, these obstacles can become insurmountable barriers to legal protection.

The defencelessness women with disabilities suffer in these cases merits strong protection which is not provided either in the CRPD or CEDAW. While CRPD article 12 establishes equality before the law for all people with disabilities and provides additional protection in the face of violations of their rights to possess or inherit goods, control their own financial affairs and other property rights, it fails to highlight the gender perspective, which must nevertheless be considered in national implementation.

*Access to education, information and employment*

The gender perspective for women with disabilities in relation to training and information is of particular significance due to low participation and employment rates in the labour market leading to reduced independence and greater risk of poverty.

Current low qualifications and low employment rates among women with disabilities leads one to conclude that neither policies to protect women nor disability policies have been successful in delivering effective measures to combat discrimination against women with disabilities. There is unquestionably a need therefore to include the double gender and disability perspective if we are to achieve equal opportunities in these areas.

CEDAW explicitly protects women's rights in this respect - in education (article 10), suitably informed consent (article 10, paragraph h)<sup>30</sup>, and equal opportunities in access to employment (article 11); however, once again the disability dimension is

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<sup>30</sup> The consequences of not having access to information are particularly serious when granting informed consent to medical treatment such as sterilisation, abortions and other similar practises which mainly affect women and often do not provide the necessary safeguards in terms of communication so that a woman with disabilities can give her consent freely and voluntarily.

missing, and this may lead to the Convention becoming ineffective for women with disabilities. In the CRPD, however, the problem remains unresolved as the gender perspective is lacking in the rights to access to information (article 21), education (article 24) and employment (article 27).

The current situation faced by women with disabilities in these fields demonstrates the need for protection and targeted actions to raise their level of qualifications and training and boost employment rates.

### *Respect for the family and autonomy to live independently*

Being integrated in society means having the means to participate autonomously and enjoying the same options as other members of the community.

From an exclusively gender perspective, CEDAW enhances women's independence to enter into marriage, choose their spouse, plan the number of children they wish to have and share responsibilities, thus breaking down the stereotypical image of women. And it is precisely that role as carers, providers of food and cleaners which is almost exclusively assigned to women but denied to people with disabilities, who are viewed as lacking physical and mental capacities to perform it. This affects precisely women when, for instance, they see how their rights to marriage, to bear children and to have custody of those children after divorce are limited as a result of their having a disability.

The CEDAW preamble mentions how society's obligation extends to the provision of social services to allow parents to participate actively in the community through work and public life, while at the same time undertaking their family responsibilities.

As a result, it is vital that the facilities and community-based support services enabling independent living and set out in article 19 of the CRPD emphasise the gender perspective, thus allowing women to achieve the same standard of inclusion in the community while protecting their right to form a family. In this case neither CEDAW nor the CRPD have included the double condition of the woman with disabilities in protecting the right to non-discrimination, which must rely on the general mandate given in article 6 of the CRPD.

### *Health and social protection*

In the medical/rehabilitation model of disability, health policies and programmes place the impairment - be it physical, sensory, mental or intellectual - at the heart of

health care for the individual with disabilities. Other horizontal aspects were addressed (inadequately, if at all) which turned the individual - regardless of his or her impairment - into a health care receiver based on other factors such as age (paediatrics or geriatrics) gender (gynaecology or urology) or others which may be of relevance in providing suitable health care.

In this respect, pigeonholing the patient with disabilities in this way has meant women with disabilities have been left out of health care provision and programmes when these were not directly related to their disability, for example from sexual and reproductive health campaigns. Furthermore, general health services lack sufficient means to ensure proper health care due to their disability.

Mainstreaming disability and gender in the right to health should involve enhanced co-ordination by health services in order to achieve higher access levels and better quality based on the principle of equal opportunities.

Although this twin-track approach is lacking in both the CRPD and CEDAW, it is present in the provisions for social protection for persons with disabilities in article 28, paragraph 2 (b) of the former, which includes women and girls with disabilities as a priority group.

## **6.2. Social participation**

The way disability is treated socially shows that despite having formally abolished outdated and exclusive conceptions and treatment towards people with disabilities, public opinion, often unconsciously, still bears prejudices that go along with acts that exclude and reject disability.

This perception is further aggravated when gender and disability come together because the hegemonistic ideological and symbolic representations of a woman with disabilities in our society are based on misconceptions about her skills and limitations as she is often thought of as asexual, intellectually challenged and dependent, among others. As a result of these beliefs, society acts in ways that marginalise women with disabilities: overprotection, assigning roles traditionally given to women; segregation and institutionalisation in their participation in society; or providing unfriendly products, services and environments that prevent women with disabilities from developing and taking part in society on equal terms with other members of the community.

Marginalisation of this kind has serious consequences for women with disabilities; in addition to suffering the same or similar problems as their male counterparts, their dignity as a person is undermined and they are therefore deprived of full citizenship.

Having to face up not only to numerous social disadvantages, but also to a public perception which devalues them, means the dignity of women with disabilities goes unacknowledged both socially and individually.

Indifference towards the dignity of a woman with disabilities in the social sphere manifests itself in the obstacles she is faced with, on the one hand when her condition is stigmatised and her opportunities for inclusion in social groups are reduced, and on the other when her right to realise her own life projects fully and effectively is not guaranteed in the same way as it is for others.

Society as a whole cannot and should not be excluded from decisions on creating, consolidating and planning the social welfare structure. Its engagement is important quantitatively and especially qualitatively as it gives support to solidarity and the common interest, the sign of a true welfare state<sup>31</sup>. In this respect, measures are needed to raise awareness in society and in families about the rights women with disabilities enjoy<sup>32</sup>.

On the other hand, the damage done to the image of women with disabilities, which fails to meet the standard prototype for beauty created by society, leads to reduced self-esteem and makes them particularly vulnerable, especially when other factors such as social isolation, lack of education or mobility problems are also present. This humiliation poses a threat to dignity as a quality which is inherent in their individuality and has a direct effect on personhood development. Low self-esteem causes serious problems as they attempt to integrate in society and has negative consequences for their quality of life.

Empowering women with disabilities by raising their self-confidence and enhancing power and authority would lead them to perceive of themselves as capable and legitimised to gain access to resources and occupy spaces in decision-making on the issues that directly affect them<sup>33</sup>.

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<sup>31</sup> Ana Sastre Campo has carried out a study on the right of people with disabilities to live in the community, *The right of people with disabilities to inclusion in the community in the UN Convention*, which can be found in *Disability, Third Sector and Social Inclusion*, pages 67-82, first edition, Madrid, CERMI, Fundación Derecho y Discapacidad, Ediciones Cinca, 2010.

<sup>32</sup> See the recommendation included in the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers, adopted by the General Assembly of the European Disability Forum following a proposal by the EDF Women's Committee, Budapest, 2011. Chapter 1 (Equality and non-discrimination), paragraph 1.3.

<sup>33</sup> See the recommendation included in the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers, adopted by the General Assembly of the European Disability Forum following a proposal by the EDF Women's Committee, Budapest, 2011. Chapter 1 (Equality and non-discrimination), paragraph 1.2.

In order to overcome inequality and the obstacles preventing women with disabilities reaching a position of status in society and taking part in it fully and actively, society in general must engage in this social responsibility and women with disabilities must be personally empowered.

### *Civil society actions*

Civil society is duty bound to assist in this social responsibility through actions such as the following:

- Create and disseminate campaigns to promote an attitudinal shift towards women with disabilities, breaking the link between disability and incorrect social and cultural connotations;
- Portray women with disabilities in the media as part of the general public, not just when their story is the main focus;
- Raise awareness in families to enable women with disabilities to break free of overprotection;
- Encourage society to report cases of discrimination against women with disabilities if the women themselves are unable to do so, and to support those who can and do.

### *Steps towards empowerment*

- Integrate empowerment strategies in programmes targeting women with disabilities, including raising self-confidence and autonomy to take decisions on one's own life;
- Offer training in conflict management, transformational leadership, acquiring social skills, communication skills and self-determination;
- Create mechanisms and structures to enable women with disabilities to participate actively as agents for change in both organisations of persons with disabilities and general women's organisations;
- Support organisations, groups and networks of women with disabilities as they advocate for their own collective interests, while respecting their management processes;
- Promote the collective dimension to empowerment among women with disabilities to join forces, participate and fight for their rights.

### 6.3. Public action: more and different

The traditional approach employed to date in gender and disability strategies failed to consider adequately the interaction between the two factors. As a result, real inclusion of *all* members was unsuccessful. The gender and disability models promoted until now were formulated on the basis of an analysis of one single factor causing discrimination: gender or disability. This single-track perspective has thwarted suitable policies to tackle inequalities and led therefore to restricted and ineffective anti-discrimination efforts.

Consequently, public action in disability and gender needs to be thoroughly reviewed and the gender perspective must be mainstreamed. This will not come about merely by formally including the content of the multiple discrimination perspective; it will require a wide range of public action measures:

#### *Introduction of a data gathering, analysis and monitoring system*

Furthering equality and boosting the fight to combat discrimination against women with disabilities is unfeasible if we are not aware of the real situation women with disabilities are in and their specific needs beforehand.

Having mechanisms in place to gather data not only enables us to get to know the living conditions and discriminatory situations suffered by women with disabilities; it also provides an opportunity to assess discrimination spread and monitor progress in anti-discriminations measures<sup>34</sup>.

#### *Regulatory reform to safeguard the rights of women with disabilities*

Laws, regulations, customs and habits in disability matters and gender issues must be reviewed, reformed and implemented to guarantee freedom from discrimination and equal opportunities for women with disabilities<sup>35</sup>.

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<sup>34</sup> Cf. Recommendation 1.9, chapter 1 (Equality and non-discrimination) of the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers, adopted by the General Assembly of the European Disability Forum following a proposal by the EDF Women's Committee, Budapest, 2011: "Sex and disability indicators should be included in all research and reports on non-discrimination and equal opportunities."

<sup>35</sup> See recommendation 1.5, Chapter 1 (Equality and non-discrimination), 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers, adopted by the General Assembly of the European Disability Forum following a proposal

*Monitor and demand compliance in public actions*

Public interventions in the fields of disability or gender must be subject to monitoring and control to ensure they are effectively implemented.

*Create effective sanctioning mechanisms*

A dynamic system for infringements and sanctions must be put in place and agencies to combat discrimination set up or improved. These should ensure all steps taken to protect the rights of women with disabilities are implemented and effective.

*Information on rights and instruments in the fight against discrimination*

Women with disabilities are generally unaware of their rights and the legal instruments at their disposal to combat discrimination. Campaigns are needed which use various communication methods - leaflets, posters, mass media, etc. - to inform them of their rights and anti-discrimination mechanisms. These campaigns should target women with disabilities and public authorities, the media and organisations representing people with disabilities and their families<sup>36</sup>.

*Promote studies on discrimination against women with disabilities*

Supporting and funding research that includes indicators for social exclusion among women with disabilities would facilitate a deeper understanding of discrimination against them and efforts to combat it<sup>37</sup>.

#### **6.4. A new approach by the Third Sector**

In the same way as institutional feminism and institutional disability, where public agencies have put in place equality plans and strategies for persons with disabilities

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by the EDF Women's Committee, Budapest, 2011: "All legislation, policies and initiatives in the field of disability or gender should take the specific situation of women with disabilities into account."

<sup>36</sup> See recommendation 1.2, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers: "Women and girls with disabilities should be informed of their rights in order to be able to make their own decisions."

<sup>37</sup> See recommendation 1.10, Chapter 1 (Equality and non-discrimination), 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers.

respectively, without mutual consideration, the third sector has operated with its back to the intersection between the identities of women and disability.

Although efforts by third sector organisations, and particularly those involved in disability issues, are praiseworthy as they have raised awareness of citizens' rights and promoted social cohesion, it must be said that insufficient attention has been paid to a part of the population of persons with disabilities, and this has led to failure to include *all* members of the group. This is understandable as generalising in respect of the groups with and for whom the third sector works is due to the pragmatic need to put forward their demands in a united fashion which differs from the demands of others, thus helping to forge unity and differentiate themselves from others. This methodology has left women with disabilities in a clearly disadvantageous position within society because, as we have seen, they are in a worse position not only in relation to women without disabilities, but also in comparison with their male peers.

Although the disability movement has gradually introduced the principle of equality between men and women in its organisational culture, much remains to be done before gender mainstreaming becomes a fully-integrated part of the organisational and operational structures in organisations representing people with disabilities and their families. With the exception of certain isolated examples, the gender mainstreaming which is said to exist in the third sector is mainly limited to paid work by women, who outnumber men in the sector. This fact would initially appear to indicate progress in implementing equality between men and women, but it merely masks a reality which does little to overcome inequalities between the two genders and, on the contrary, helps to sustain stereotyped divisions of tasks based on sex because positions of responsibility continue to belong to men while women act. Furthermore, and as a result of ignoring the fact that gender influences working conditions (flexibility through reduced working hours, fixed-term contracts, etc.), women's employment conditions are still poorer than those of their male workmates.

To introduce equality once and for all, disability organisations must mainstream gender in their organisational structures and operational structures. The organisational structure of a disability organisation has a direct impact on how the organisation is viewed by society, as well as on working conditions and performance in the workplace. Furthermore, by optimising operational structures disability organisations can make significant progress as there will be a knock-on improvement in how resources are managed in the projects, plans, programmes and actions the organisation undertakes and, through this inclusive perspective, efforts will be made to ensure both men and women benefit<sup>38</sup>.

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<sup>38</sup> See recommendation 1.4, Chapter 1 (Equality and non-discrimination), 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists

### *Organisational structure*

- Review and, if necessary, amend constitutions, rules and by-laws to make sure the inclusion of equality and non-discrimination is clearly formulated and stated in the mission, vision, tactics, goals and values of disability organisations;
- Include an explicit commitment to equality by putting in place protocols and joining key national and international efforts to promote equal opportunities;
- Break down stereotypes that divide tasks according to sex and ensure women hold positions of responsibility and men are involved in intervention roles;
- Promote gender equality from the very highest positions;
- Treat all men and women equitably in the workplace, respecting and advocating for their rights, and ban discrimination;
- Further education, training and career development for women;
- Introduce organisational development practises that strengthen women's position and encourage them to take part in decision-making;
- Promote equality through community-based initiatives and meetings;
- Assess and disseminate progress made towards gender equality.

### *Operational structures*

- Boost diversity-management, arbitrage and equality policies;
- Ensure the organisation's financial resources are fairly distributed to cover the needs and interests of both men and women;
- Design a targeted strategy for women with disabilities in areas that require separate intervention from those involving men and women equally;
- Include gender in communication outcomes and processes;
- Disseminate information on issues specifically affecting women with disabilities;

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and policymakers: "Organisations representing persons with disabilities and their families should include the principle of equality of men and women in their organisational culture, rules and regulations and work programmes."

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## Chapter II

# **AWARENESS, THE MEDIA AND SOCIAL IMAGE**

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## Chapter II

### AWARENESS, THE MEDIA AND SOCIAL IMAGE

#### 1. INTRODUCTION

The aim of this chapter is to outline the situation regarding women with disabilities and the social media, and the role they play or could play within the media, either as the focus of information and content or working in the sector. We shall try, therefore, to find out if women with disabilities face more difficulties than others in accessing or interacting with the mass media, and then to determine how the so called *mass media* portray, if they do, the reality of girls and women who live with a physical, sensory, intellectual or mental disability.

At the end of the chapter, we would have liked to take a closer look at the positions women with disabilities hold in the radio, television and written press in order to study the role they play individually and socially; however, a lack of data and prior research on the subject makes this impossible, so we will make do with remarks on the role these women would play if room were to be found for them in the media.

#### 2. THE INFORMATION SOCIETY: A REALITY FOR WOMEN WITH DISABILITIES?

In this section we shall attempt to find out if the so called *information society* in which the whole world is said to live is truly a reality for everyone, and in particular for women with disabilities.

To start off, it has to be said that today's world is characterised by globalisation and the constant flow of information. This means that what is happening in one part of the world right now can reach the rest of the planet immediately and people can find out what's happening on the other side of the world almost in real time thanks to the traditional media and new social networks.

## 2.1. Women with disabilities as a disadvantaged group in accessing the media

So, can we be sure everyone in society is able to access the media for information whenever he or she wants? The answer is obvious as there are many groups in society which, for different reasons, are at a disadvantage in relation to others and, as a result, find it more difficult to obtain information and approach the media.

One of these groups is undoubtedly people with disabilities. Although in some respects internet has introduced great improvements in access to information provided by traditional media outlets (for deaf citizens, to give one example), in other cases there has been a need to warn authorities of the danger of exclusion some people with disabilities face if networks are not designed according to universal accessibility criteria (people with visual impairment or intellectual disability, for instance)<sup>1</sup>.

If, in general terms, people with disabilities face more obstacles than the rest of the population in accessing media content, within this group women are at a disadvantage in relation to men, as we shall now attempt to show.

The *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - a toolkit for activists and policymakers*, adopted in Budapest on the 28-29th of May 2011 by the General Assembly of the European Disability Forum, recognises that,

*“Women with disabilities, therefore, are still to be found on the fringes of all human rights movements and remain bogged down in a clearly disadvantageous position within society.”*

The manifesto goes on to say that,

*“The status of women with disabilities is not only worse than that of women without disabilities, but also worse than that of their male peers; this is especially so in rural areas, where matriarchal and primary economic systems, with fewer services and opportunities for this group than in urban environments, are still predominant.”*

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<sup>1</sup> Universal accessibility is based on the concept of universal design. According to the UN Convention on the Rights of Persons with Disabilities, universal design is, “the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design”. However, the CRPD points out that universal design, “shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.”

The “*clear disadvantage*” referred to in the text occurs from childhood. As the manifesto states, “*Girls and women with disabilities have high rates of illiteracy, school failure, absenteeism and drop-outs, all of which have major consequences as regards cohesion, involvement and social behaviour.*”

From this perspective and according to the manifesto, “*There is a need to promote inclusion in education for girls and teenagers with disabilities in order to mitigate the clear disadvantage they suffer in education, which in turn hinders the subsequent inclusion in the labour market and community of women with disabilities.*” Paragraph 12.2 of the manifesto points out that among women with disabilities there are “*high unemployment and labour market inactivity rates.*”

While, as we have seen, girls and women with disabilities face major obstacles in education and employment, they also clearly have an underdeveloped understanding of the need to be critical and put forward their demands, leading to them failing to advocate for their rights and push for social improvement. At times they are even unaware of their rights.

In terms of access to the media, advancement must involve greater use of closed captioning and audio description on television and public web sites. As the 2010 European Disability Strategy highlights (drawing on a 2007 European Commission working paper<sup>2</sup>):

“*...on average in the EU-27, only 5% of public websites comply fully with web accessibility standards, though more are partially accessible.*”

With regard to television channels, the strategy points out that:

“*Many television broadcasters still provide few subtitled and audio-described programmes.*”

In Spain, for instance, the need to provide audio description and closed captioning for viewers with disabilities has been acknowledged. The most recent regulations in the field, the 2010 General Audiovisual Communications Act, includes a range of specific services which broadcasters must introduce gradually in order to improve access for people with visual and hearing impairments<sup>3</sup>.

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<sup>2</sup> European Commission working paper (2007) 1469, page 7.

<sup>3</sup> Article eight, section 1, of the law states that, “*persons with visual and hearing disabilities enjoy the right to universal accessibility to audiovisual communication in line with the possibilities technologies offer*”, while in the fifth transitional arrangement the obligations placed on broadcasters to ensure access for people with disabilities are set out:

The fact is that, according to the 2008 *Survey on Disabilities, Personal Autonomy and Dependence* (EDAD), in Spain there are a total of 608 500 women with hearing disabilities and 600 770 women who are blind or severely partially sighted.

Recognising the fact that citizens with disabilities still face barriers in accessing information, article 21 of the 2006 Convention on the Rights of Persons with Disabilities urges States Parties to provide “*information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost.*”

Of course delivering audio description and subtitling on television will benefit all people with visual and hearing disabilities, be they men or women. What we are attempting to highlight is that women generally face greater difficulties than men in terms of knowing that this support is available to them and, as a result, demanding it, above all if they live in rural areas, as already explained.

This being the case, authorities must heighten their awareness of the situation and take steps to improve it. This obligation is established in article 14 of the 1979 *Convention on the Elimination of all Forms of Discrimination against Women*:

*“States Parties shall take into account the particular problems faced by rural women and the significant roles which rural women play in the economic survival of their families, including their work in the non-monetized sectors of the economy, and shall take all appropriate measures to ensure the application of the provisions of the present Convention to women in rural areas.”*

The European Union Charter of Fundamental Rights (2000) takes the same view; article 26 states that the EU “*recognises and respects the right of persons with*

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1 Accessibility levels for persons with disabilities in broadcast programmes, as referred to in article 8, will have reached the following percentages and levels by December 31st of each year:

	2010	2011	2012	2013
Subtitling	25%	45%	65%	75%
Sign language (number of hours)	0.5	1	1.5	2
Audio description (number of hours)	0.5	1	1.5	2

2 Accessibility levels for persons with disabilities in broadcast programmes on public channels will have reached the following percentages and levels by December 31st of each year:

	2010	2011	2012	2013
Subtitling	25%	50%	70%	90%
Sign language (number of hours)	1	3	7	10
Audio description (number of hours)	1	3	7	1

*disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community”.*

Section 1 of article 21 goes even further and prohibits all types of discrimination:

*“Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.”*

## **2.2. Social networks**

If, as we have seen, women with disabilities have fewer tools at their disposal than their male counterparts to demand improvements in access to traditional media, the same is true of internet and social networks<sup>4</sup>, which are becoming universal tools for communicating and relations but which unfortunately, as we will see below, are generally not accessible.

These so called social networks on internet are becoming mass tools as they are used by hundreds of millions of people worldwide, more specifically 940 million people according to the report ‘Social networks on internet’ (December 2011), drawn up by the National Telecommunications and Information Society Observatory.

It is estimated that Facebook and Twitter, two of the most popular social networks, currently have around 750 and 200 million users respectively worldwide<sup>5</sup>; this means that many people interact on them on a daily basis. They do so multi-directionally and as both content consumers and producers.

These networks are bringing in new ways for people and groups to relate as they make it possible to engage in mass and multi-directional communication from almost anywhere and, of course, at all times of the day. They are used in personal and professional lives, as forums for discussion and almost as mass media, so they are present in many homes and businesses. They are becoming more widespread in

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<sup>4</sup> There are many approaches to defining social networks on internet but little consensus, although most experts agree a social network is “*a place on the net whose purpose is to enable users to relate to one another, communicate, share content and create communities*”, or a tool for “*democratising information and turning people into content receivers and producers*”. This is the conclusion reached in the report *Social networks on internet, December 2011*, published by the National Telecommunications and Information Society Observatory (ONTSI in Spanish).

<sup>5</sup> [www.facebook.com](http://www.facebook.com) and Wikipedia.

tablet PCs and mobile telephones, thus extending their reach to public transport, coffee-shops, parks and other places.

Whether we like it or not, internet-based social networks are fast becoming vital tools for communication and relations and are impossible to avoid unless one consciously decides to do so.

To prove these points we will provide just one more figure: according to the 2011 ONTSI report (page 64), 80.20% of all people in charge of staff recruitment use them to complement other tools when assessing and hiring employees.

Everyone should have the opportunity to access social networks on an equal basis with others and decide freely if they wish to join them. However, reality shows they are not accessible, or at least usable, for persons with disabilities, and especially for those who are blind or partially sighted. Despite this, there is evidence that some people do use them despite being blind and due mainly to the fact that they have made an effort to request or devise methods by themselves to improve access.

This situation highlights once again the risk women and girls with disabilities, who have less training and are less likely to voice their demands than their male peers, face of being excluded from these new communication tools even more than their male counterparts, and above all if they live in rural areas.

What is now a reality and not an idle threat is that many of the social networks we are discussing are currently inaccessible. To illustrate this point, we will base our case on a study carried out in Spain, one of the countries where these new means of communication have been most warmly welcomed: the most up-to-date statistics indicate that Spain is in third place and only behind Brazil and Italy worldwide in the number of social network users<sup>6</sup>.

The report, prepared by *Discapnet's* Observatory on ICT Accessibility in 2010, states that accessibility still remains "*unfinished business*" in terms of social network web sites which, in many cases, '*pose obstacles for users with certain types of disability even to register with them*'. Other platforms, the report goes on to say, "*are accessible in this respect*", but include other subsequent obstacles for users in accessing information and using applications and functionalities.

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<sup>6</sup> The aforementioned report by the National Telecommunications and Information Society Observatory points out that, "*according to data published by Nielsen, Brazil heads the world table for active social network users with 86%, followed by Italy on 78%*". Spain, the report goes on to say, "*is in a clear third position and only one percentage point behind the second-placed country (77%)*".

The report - *Social Network Platforms and Accessibility* - looked in detail at the eight most widespread platforms in Spain at the time according to number of users and media profile: Facebook, Tuenti, MySpace, Xing, LinkedIn, Flickr and Windows Live Spaces.

The observatory performed a technical assessment of each of the platforms and gathered user feedback. A star system was used to rank the results. Following analysis of the results, the report concluded that LinkedIn was the most accessible platform from a technical point of view (three stars out of a maximum five - moderate accessibility). Flickr and Xing were next, although some way behind, with two stars (poor accessibility), while the other platforms were given just one or no stars.

As regards users' experiences, Flickr was the most accessible (three stars), followed by Xing, Twitter, Facebook and LinkedIn with two stars. The worst were MySpace, Windows Live Spaces and Tuenti with one star apiece (extremely poor accessibility).

The average of all the social network platforms chosen for the research was therefore one star for accessibility from a technical viewpoint (extremely poor accessibility) and two stars (poor accessibility) from the perspective of users with different types of disability.

Based on these results, the study concluded that the accessibility level of the most popular and widely-used social network platforms in Spain was, at that time, "*quite low*", despite the fact that, as the report pointed out, "*potentially, anyone with access to internet and basic notions of how to use these tools could become a user of these social network platforms*". As a result, the report suggested it was the duty of those responsible to make sure the social media and the information generated was accessible "*to all users under equivalent conditions, including those with disabilities*".

The *Discapnet* study is in agreement, in this respect, with the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union (2011); paragraph 3.9 of the manifesto states that, "*Equal access to various components of the information society should be ensured for women and girls with disabilities.*" It goes on to say that, "*When developing information and communication technologies, economic factors, the need for training and equal opportunities regardless of age should be taken into account to allow girls and women with disabilities at risk of social exclusion or poverty access to them.*"

### 3. THE SOCIAL IMAGE OF WOMEN AND GIRLS WITH DISABILITIES

Having reviewed the difficulties women and girls with disabilities face in exercising their right to information through the media, we shall now consider and reflect upon how these same women are portrayed to society in the media.

### 3.1. Women and girls with disabilities: media invisibility

Although no studies have been carried out, by observing the media we can see that they do not generally set apart women with disabilities because they are women and, at the same time, have some type of physical, sensory, intellectual or mental disability. When disability is addressed in the media it is discussed in general terms and by referring to people with disabilities as a whole, without bearing in mind that women with disabilities often face greater difficulties due to their gender. The media ignores their existence as a result and as the 2nd Manifesto points out:

*“... [women with disabilities] are practically completely ignored by the media and when they do appear, the approach is to treat women with disabilities from an asexual medical perspective and ignore their capabilities and contribution to the surrounding environment.”*

The media, therefore, has failed to grasp the double problem or discrimination this group is subjected to, despite the fact that it appears to be gaining an awareness that women with disabilities form a group which requires particular focus.

This in spite of the fact that these same media outlets act as a shop window for part of the reality in which we live and as a conduit for some of the aspects that make up that reality; as a result, they have a key role to play in visibilising women and girls with disabilities and they should make an effort to perform this role. It is a key role, in our opinion, because they could portray and give voice to women with disabilities, but also because in their everyday work they could also help to promote a positive and considerate use of language when discussing women with disabilities as people with disabilities who face additional and specific problems in comparison to men who also live with a disability.

This is in line with the 2011 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union, which has the following to say about the important role the media can play in bringing forth a *“positive shift in public attitudes”* regarding this group:

*“The media plays an important role in disseminating information on women with disabilities and should contribute to a positive change in public attitudes towards them in a manner consistent with the principles and values of the UNCRPD.”*

In the same paragraph (2.6), the manifesto refers to the language the media should use to refer to women and children with disabilities in order to contribute through their daily duties to the *“positive shift”* mentioned above:

*“The use and choice of positive language describing disability and women’s matters should be encouraged among professionals working in the media.”*

In addition to visibilising women and girls with disabilities by finding space for them in media content, the media should also consider playing a positive role in promoting their image. In this respect, article 8 of the General Audiovisual Communications Act, adopted in April 2010, states that the media should attempt to portray a 'reasonable' and 'normalised' image of this group. To be precise, the law stipulates the following:

*“Audiovisual broadcasters shall endeavour to offer a reasonable, normalised, respectful and inclusive portrayal of persons with disabilities as an enriching expression of human diversity. Broadcasters shall refrain from disseminating stereotyped or biased perceptions, or those emanating from lingering social prejudices. In the same way, they shall endeavour to ensure that persons with disabilities appear in programmes in proportion to their importance and participation in society as a whole.”*

The media should therefore offer programmes addressing the needs of women with disabilities and meet their role as educators, as set out in paragraph 2.7 of the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union:

*“Television, radio and newspapers should be encouraged to develop educational programmes which address the needs of women and girls with disabilities, in cooperation with their representative organisations. Special efforts should be made to raise public awareness about the diverse nature of this group of women, paying special attention to women with invisible disabilities.”*

However, as we can see from this quote, programmes addressing women and girls with disabilities should be made in partnership with the organisations that represent them, that is to say disability organisations and, of course, women's organisations also. It is our belief that the latter have overlooked their peers with disabilities somewhat.

For the reasons above, we believe organisations representing and advocating for women's rights could potentially play a very important role in raising the profile of the female population with disabilities; they have managed to gain a foothold in the media and they should take advantage of it to disseminate and set out to society the needs of their counterparts with disabilities and, while on the subject, their virtues.

In this respect, women's organisations should perhaps begin by realising that their colleagues with disabilities form a different group from men with physical, sensory, intellectual or mental impairments and, consequently, need to be addressed specifically.

Having said this, it is no less true that the task of awareness raising needs to begin, in many cases, among women with disabilities themselves, as many refuse to admit that they experience greater problems and are at a disadvantage in comparison to their male peers because they are women.

Many place more importance on a personal circumstance - their disability - than on what they are in essence - women - with all that that implies, and they fail to recognise that the fact they are of the female sex means they experience different problems and are at a disadvantage in relation to their male peers who, from their side, have also failed to appreciate this fact and consider contributions made from this differentiated viewpoint.

And, as we saw above, if one is unaware of a reality one cannot condemn it and fight to modify it. It is no surprise then that the media does not cover the specific situation faced by women with disabilities, above all as it is now beginning to realise that the disability movement itself is part of modern day society and, as a result, needs to be covered in the information it offers and, in general, in its programmes, including advertising.

Although advertising, and especially television advertising, features many women in adverts, they are almost never, or never, women with disabilities, despite the fact that this group is also part of the target audience at which the ads are aimed.

We suspect the creative world of publicity thinks disability 'isn't beautiful', and is therefore incompatible with the air of youth and perfection given off by the women in their adverts. However, they do not mirror all females as not all women can identify with them.

The advertising world then, as a powerful tool for building socio-cultural identity among people, as the aforementioned manifesto points out, must act boldly and engage in constructing a fairer world. It must cast aside its fears and include women and girls in its adverts, thus contributing to spreading a normalised portrayal.

*"Advertising is a useful tool for creating socio-cultural images of people. Nevertheless, the image of women with disabilities has not been addressed",* states the manifesto.

As a result of this, *'Women and Disability: access to employment and training'*, a European Council Conference held in León in February 2009, suggested *"organising campaigns aimed at increasing the presence and improving the portrayal of women and girls with disabilities in the media and in advertising in general."*

### 3.2. Improving the social image of women and girls with disabilities: recommendations

It seems clear that the social image of women and girls with disabilities needs to be improved, and to do this major efforts in awareness raising are required. In our opinion, this should not be done just in the media - important though this sector is - but in society in general through information campaigns and, of course, through education in schools and families to teach the principles of equality and respect for diversity.

If we start in schools and the home, where the foundations of a person are laid, the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union argues that,

*“An attitude of respect for the rights of women and girls with disabilities should be fostered at all levels of the education system, including in all children from an early age.”*

And it goes on to say,

*“It is necessary to ensure that formal curricula in primary, secondary and tertiary education include teaching material on equality between women and men, on disability and understanding diversity, non-stereotyped sex roles, mutual respect, non-violent conflict resolution in inter-personal relationships and concepts of honour and individual self-determination, adapted to the evolving capacity of learners.”*

In terms of social media and as we suggested above, the needs and characteristics of women with disabilities need to be afforded time in educational programmes to raise awareness in society. Women with disabilities should, of course, be given the opportunity to express their opinions themselves.

*“The media should consult and involve women with disabilities, preferably nominated by their organisations, who should also take part in presentations and monitor programmes. In view of the practice of exchanging radio and TV productions at regional and international level, those programmes should be widely disseminated.”*

In short and as the 2nd manifesto recognises,

*“Through adequate training and drawing up basic tools for dealing with women and girls with disabilities in information and publicity, it is vital to project an image of them as being more involved socially and mainstreamed which does not rely on taboos and irrational arguments about them.”*

Finally and to conclude this section, we now put forward a number of recommendations - aimed at policy makers and the third sector - to improve the social image of women and girls with disabilities which, as we have seen, does not reflect reality.

Although the recommendations reiterate some of the points made above, we believe the reader will find it helpful to have them grouped together under one single heading.

### 3.2.1. *Recommendations for policy makers*

We shall begin by reminding policymakers how important it is to provide women and girls with suitable education as they are, *a priori* and due to their sex, part of a disadvantaged group in training and employment within the larger group of persons with physical, sensory, intellectual and mental disabilities.

We believe education is the gateway to employment and, through employment, to mainstreaming in all areas of life, in addition to making people free and critical, qualities which are vital to accessing information.

However, the government's duties in terms of education do not end there. Governments must ensure schools at all levels offer an education rich in values and capable of teaching students that all people, by virtue of being people, enjoy a number of rights which, in the case of groups such as women and girls with disabilities, are not always respected.

One of the most important responsibilities of politicians is to ensure education highlights equality between women and men, breaks down stereotyped gender-based roles and raises awareness and understanding surrounding disability through the use of suitable material at all stages of education.

In addition, public authorities should make sure women and girls with disabilities are portrayed realistically in the media through programmes and information that reflect their situation, needs and capabilities and, of course, are put together with guidance and participation from the organisations representing them, as the manifesto setting out their rights points out:

*"...greater engagement of women and girls with disabilities in the fields of information and communication should be promoted, not only in relation to their needs, but also as active members within everyday society."*

It is also the task of governments to harness the potential of the media to further awareness-raising campaigns on the rights of girls and women with disabilities to improve their social image, as the manifesto indicates:

*"Effective public awareness campaigns should be initiated and maintained on the rights and fundamental freedoms of women and girls with disabilities, in society in*

*general and in specific areas (work, trades unions, business, law, health, and so on) in order to enhance their social perception and enable them to exercise such rights and freedoms, eliminating harmful stereotypes, prejudices and practises which are still deeply held in society, including those based on sex and disability.”*

### 3.3.2. Recommendations for the third sector

First and foremost, organisations from the disability and feminist movements must be aware that girls and women with physical, sensory, intellectual and mental disabilities face different obstacles to those faced by men who live in the same situation and women without disabilities; as a result, they should make the obstacles visible and fight to break them down.

This is in line with paragraph 2.2 of the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union, which says:

*“Women and girls with disabilities must enjoy greater visibility at all levels of society. The disability and feminist movements must provide positive role models for other women and girls with disabilities and work with their families to break down the mistaken roles and habits traditionally assigned to women and girls with disabilities due to their condition.”*

...because if women with disabilities change the perception they have of themselves it will be easier for them to project it within their families and in society through the media, among other outlets.

As the manifesto makes clear, organisations representing women and girls with disabilities should also ensure content in new technologies does not violate the integrity of this group of citizens:

*“New information and communication technologies and systems, such as internet, social networks and websites, should not contain information that in any way violates the integrity of women and girls with disabilities.”*

And it goes on to say:

*“The representative organisations of women and girls with disabilities should work to ensure this at national and European level in cooperation with their respective national disability council and national women’s lobby, and with the European Disability Forum and the European Women’s Lobby. Exchanges of good practises among these organisations should be encouraged, with the engagement also of local organisations.”*

In short, then, it is about women's organisations and organisations from the disability sector learning, in their respective fields, to appreciate the singularity of girls and women with physical, sensory, intellectual and mental disabilities and work with them to raise their profile and make them more visible in society by harnessing the power of the media, as they do when they put forward their general interests, and taking on board contributions from all in a plural and diverse society.

#### 4. WOMEN JOURNALISTS WITH DISABILITIES: DO THEY EXIST?

In this section we would have liked to study in detail women journalists with disabilities and compare them with their male counterparts and female journalist without disabilities. However, as we have not found any information the only thing we can do is offer some reflections on how important it is for the media to help promote a realistic and positive image of women with disabilities in society and recommend research is conducted in this field.

While we believe all media outlets can do their bit to portray an accurate and normal image of women with disabilities, television would appear to be best placed to visibilise the work done by journalists with disabilities. In our opinion, as a mass media based mainly on image and with an everyday presence in homes, television is an appropriate media to demonstrate to the world that a woman with disabilities is also capable of working as a journalist and, therefore, delivering information.

This, however, does not mean we believe news agencies, newspapers or radio stations are not ideal media for a woman journalist with disabilities to work in; the difference between these media outlets and television lies, in our opinion, in the fact that the small screen is to be found almost everywhere and, as we said above, reaches all homes on a daily basis.

The fact is that if a woman with disabilities is working in radio, for instance, listeners will most likely not realise she is blind or a wheelchair user, while if she is seen on television it will almost certainly be noticed.

We do not mean to underestimate in any way the work done by women journalists with disabilities on the radio. This should be seen as progress in the modern day world and will, of course, also help to make people aware of women with disabilities' capabilities, although it may only be in that field of employment.

The same, we believe, can be said of a female journalist working in the printed press or a news agency; both environments are positive for her as they enable her to perform the task for which she was trained over the years through hard work and

demonstrate to her workmates that disability is not always an insurmountable obstacle.

It would have been ideal, as we said, to have had data on how many women with disabilities are currently employed in the media, and also what jobs they perform, because although every position is important and necessary they do not all have the same power in projecting a positive and realistic image of women with disabilities.

From this perspective, we respectfully recommend that public authorities and the disability movement instigate studies on women with disabilities in the media and on journalism courses. This is the only way to find out how many women qualified in communication are working in the area of studies they chose and how many have not been given that opportunity by the media.

Similarly, it would be interesting to find out in detail what work those who are employed are performing in their jobs as journalists in order to be able to draw conclusions to help improve the profession and, of course, portray a positive and realistic image of this population group.

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# Chapter III

## GENDER-SENSITIVE ACCESSIBILITY

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## Chapter III

# GENDER-SENSITIVE ACCESSIBILITY

### 1. INTRODUCTION

According to Yannis Vardakastanis, President of the European Disability Forum, lack of accessibility is the most subtle form of discrimination. It affects people who have some type of limitation in their functional capacities which, when this interacts with badly-designed environments, products or services, creates serious difficulties and, in many cases, makes it impossible to use them safely and comfortably. These difficulties are overcome when design for all criteria are applied in all design processes from the very outset. The result of including design for all is universal accessibility, where each and every citizen, be they man or woman and regardless of functional capacities, can exercise his or her rights on an equal basis with others.

The challenge we face in this chapter is to find out if girls and women with disabilities would suffer discrimination if the gender perspective were left out of design for all criteria.

Upon first reflection, we may think accessibility is gender neutral by its own conception and benefits men and women equally. However, a deeper analysis of the terminology used reveals that the term 'design for all' itself uses sexist language, which is not the case with the expression 'universal design', based on the concept developed by the American architect Ron Mace and on the following guiding principles:

- **Equitable Use:** the design is useful and marketable to people with diverse abilities;
- **Flexibility in Use:** the design accommodates a wide range of individual preferences and abilities;

- **Simple and Intuitive Use:** use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level;
- **Perceptible Information:** the design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities;
- **Tolerance for Error:** the design minimizes hazards and the adverse consequences of accidental or unintended actions;
- **Low Physical Effort:** the design can be used efficiently and comfortably and with a minimum of fatigue;
- **Size and Space for Approach and Use:** appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

By applying these principles in design processes it would appear, a priori, that there is no discrimination on the grounds of gender and that both men and women are being allowed to exercise their rights, regardless of their abilities, when using environments, products and services. Nevertheless, to find out if this is indeed the case, through CERMI, the Spanish Committee of Representatives of Persons with Disabilities, a survey was carried out among girls and women with disabilities. The questionnaire aimed to:

- Gather feedback from a small sample of women and girls with disabilities on whether they felt discriminated against due to their gender in accessibility and design for all issues in various areas (among others urban settings, public buildings, access to information and communication, ICTs, product and service design);
- Within each area, identify the specific needs and problems faced by women and girls with disabilities which remain unaddressed in terms of accessibility.

Using a self-assessment questionnaire, girls and women with disabilities were invited to give their opinions on the potential difficulties and problems in accessibility as a result of their gender in different environments and circumstances in their daily lives.

Sixty-nine girls and women with disabilities took part:

<b>Age:</b>	
Under 18	<b>8.7 %</b>
Between 18 and 45 years old	<b>60.9 %</b>
Over 45	<b>15.9 %</b>
Did not reply	<b>14.5 %</b>
<b>Type of disability:</b>	
Physical	<b>33.3%</b>
Intellectual	<b>2.9%</b>
Visual impairment	<b>36.2%</b>
Hearing impairment	<b>29.0%</b>
Mental	<b>1.4%</b>
Organic	<b>4.3%</b>
<b>Employment:</b>	
Currently employed	<b>47.8 %</b>
Currently unemployed	<b>20.3 %</b>
Student	<b>17.4 %</b>
Incapacitated for employment	<b>7.2 %</b>
Mainly housework	<b>2.9 %</b>
Others	<b>4.3 %</b>

### Results of the survey

Most responses were given from a universal accessibility approach rather than a gender-based perspective. This may be because the intention of the questions was not fully understood, even though throughout the questionnaire it was reiterated that the goal of the survey was to gather the perspective of women and girls (with disabilities).

However, presumably it is the case that when girls and women face discrimination in relation to accessibility, the disability variable is considered to be more significant than the gender variable, both in 'real terms' (from an objective perspective a pavement without a ramp affects a woman in a wheelchair in the same way as it does a man in a wheelchair) and in 'subjective terms', in other words how these situations are perceived and interpreted by women.

This means that in some cases a discriminatory situation may be viewed simply as a lack of accessibility, when there may be additional hidden discrimination against women. Many respondents stated that “the problems are the same for men and women”, “I don’t think there’s gender discrimination, but there is disability discrimination”, or “urban environments aren’t discriminatory on the grounds of gender, they are discriminatory because of disability”.

For these reasons, the figures quoted at the beginning of each section for the percentage of women and girls with disabilities who feel they have suffered discrimination must be viewed with caution. Due to the global approach in many questionnaires which do not appear to contain a gender perspective, it is difficult to gauge how many of the women who replied that they felt discriminated against did so due to gender, due to disability or because of both.

Gender-based discrimination may be difficult to perceive in certain apparently neutral areas, such as for example in a city or public building, when there is a more ‘limiting and manifest’ variable present such as disability.

The questionnaire attempted to identify those areas related to accessibility and design for all where double discrimination (gender and disability) is discerned. This was partially achieved by highlighting the gender perspective in many responses which, although of a general nature, offered some hints as to what specific needs women and girls with disabilities may have and the types of problems they may face.

In this respect there are two related ideas which should be considered if we are to reach an understanding of the gender perspective in accessibility:

1. Some spaces, products and services are used more often by women and girls, and accessibility in these spaces, products and services needs to be improved to avoid discriminatory situations. One example is children’s playgrounds.
2. There are some spaces, products and services that, although they have become more accessible, have not addressed the specific needs of girls and women with disabilities during the design phase.

A study of universal accessibility from a gender perspective would, therefore, imply a realisation that there are spaces, products and services that are frequented, purchased and used more often by women. As a result it is essential to take into account the specific needs of girls and women with disabilities to include them in the overall universal accessibility concept.

This means that approaching accessibility from a gender perspective does not involve amending the concept of universal accessibility, but rather studying the

specific needs being a woman entails and including them in the concept. By doing so, the universality of the concept is further enhanced. At present these needs remain unvoiced and invisible due to the disadvantageous position in which women and girls with disabilities find themselves in many aspects in society.

Lower attainment levels in training, higher unemployment rates, great difficulties in accessing new technologies, violence, lack of work-family balance, excessive 'responsibilities', lower purchasing power, lower political and social participation levels, etc., are all social factors independent from accessibility but which nevertheless have a negative impact on it. This is, in short, because the disadvantageous position of women in society means they are less visible (and even more so in the case of women with disabilities), so their demands, specific needs and problems remain in the background. Persons with disabilities in Spain —almost 9% of the total population— constitute a heterogeneous group, and within this heterogeneity we have the gender variable.

Awareness in all sectors of society is the key to turning this situation around. In addition there is a need to promote the gender perspective in accessibility among women with disabilities themselves; because they know better than anyone else their current situation, they must voice their own needs and need to be heard.

## 2. SERVICE DESIGN

The importance of accommodating products and services to the real characteristics of men and women may be, in many cases, sufficient to bolster independent living. If *accommodation* does not take place, environments will be disabling and excluding if any of their everyday use factors are, and this creates a serious problem which requires addressing. However, when applying targeted equality principles in constructing spaces that are universally accessible for men and women alike, on the one hand, and integrating persons with reduced personal autonomy, on the other hand, it is often forgotten that men's and women's life spaces have still not reached a true state of equivalence, so principles facilitating integration such as universal accessibility are applied to the population in general.

To resolve this dilemma, which would in itself be a turning point, fourteen years after the first manifesto we now have the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - a toolkit for activists and policymakers* (May 2011). The second manifesto is divided in 18 thematic areas, each of which makes reference to different articles in the UN Convention and seeks to address five key questions: outline the situation faced by women and girls with disabilities in the

field in question; put forward their demands for direct attention; suggest areas for improvement in the community; propose studies and research to gain an understanding of the specific situation in which this group finds itself; and briefly outline the key legislative questions in each area.

In terms of accessibility, the *Manifesto* seeks to draw out gender questions in urban and build environments, transport, access to information and communication and goods and services.

In relation to violence against women, it considers prevention, care and recovery for victims, legislative measures required and studies and research that should be undertaken.

Health is approached by examining primary health care, sexual and reproductive health, health care for women who are victims of violence and mental health.

In order to mainstream gender properly, the *Manifesto* calls for safeguards to ensure women with disabilities play a full part in relevant bodies or authorities, preferably in the role of consultants, advisers or experts, to make sure that when environments, goods and services are designed, the specific needs and demands of the female population with disabilities are taken into consideration.

## **Safeguarding rights**

Universal accessibility, design for all and the gender perspective must be mainstreamed in all products, objects, instruments, tools and devices, in order to ensure that those used regularly by women and girls are also accessible for women and girls with disabilities, and can be used safely and comfortably and as independently and naturally as possible. Particular attention should be paid to those related to the sexual health of women with disabilities (contraceptives, gynaecologist's examination bed, mammography equipment, and so on), and to motherhood (babies' bottles with handles, prams designed to be clipped on to wheelchairs or pushed with one hand, wheelchair-accessible nappy changers, and so on), and they should be included in publicly-available catalogues at affordable cost.

Manufacturers should be encouraged to design commonly-used objects not only for use by men but by both sexes (such as watches, wheelchairs, cars, and so on); these items should also be available in versions designed for women. Accessible toys should also be produced. All care services for women (and especially those related to health, motherhood, violence against women and childcare) must be fully accessible for women and girls with disabilities.

We mustn't forget that a service is accessible when receptiveness goes hand in hand with non-discrimination; in other words a quality service delivered equally to everyone regardless of their capacity or ability.

A wide range of personal and environmental factors come into play to enable a person to cope without limitations in a specific context or environment. While each person has different capabilities, it is understood that a sector of the population has functional diversity which places limits on its activities and restrictions on its participation. This means people with functional diversity have specific requirements that must be met if they are to perform to their fullest capacity in environments, places and services unadapted to their capabilities. By meeting these accessibility requirements or needs, any person, regardless of their capacity, can perform independently and enjoy the same opportunities as others.

Women with disabilities form a heterogeneous and varied group, and the differences among women with disabilities is reflected also in the type of needs to be met. Just as there are no two identical people, there are no two identical disabilities. Two women with the same disability do not necessarily have the same accessibility requirements, perhaps due to different dysfunctions or simply because they interact with the environment in different ways (Rapoport and Alonso, 2005).

To give one example, let's take the strategic planning model set out in the *1<sup>st</sup> Comprehensive Action Plan for Women with Disabilities in Andalusia (2008-2013)*<sup>1</sup>. The plan highlights how women with disabilities, as a result of their gender roles, face inequality in access to and control over resources, enjoyment of their rights, and their social situation and position in relation to employment, formal education, affective relationships, self-perception and the way they are portrayed by the media and in society as a whole, enjoyment of fundamental rights such as sexual and reproductive rights, justice and social protection, access to social participation environments and decision-making, and access to public goods and services.

As a result the situation and position is one of double discrimination; gender and disability intersect and place women with disabilities in an unequal position compared to women and men without disabilities and in relation to men with disabilities. In addition to discrimination caused by their being women and having a disability, other types of discrimination may come into play due to their social class, ethnic background, and so on, with gender discrimination cutting across the whole series of types of discrimination.

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<sup>1</sup> 1<sup>st</sup> Comprehensive Action Plan for Women with Disabilities in Andalusia (2008-2013): [http://www.juntadeandalucia.es/igualdadybienestarsocialigualdadybienestarsocial/export/Personas\\_Discapacidad/HTML/plan\\_mujer/download/Plan\\_Mujeres\\_con\\_Discapacidad.pdf](http://www.juntadeandalucia.es/igualdadybienestarsocialigualdadybienestarsocial/export/Personas_Discapacidad/HTML/plan_mujer/download/Plan_Mujeres_con_Discapacidad.pdf).

The multiple discrimination faced by women with disabilities has an impact on their independence and a bearing on the specificities in terms of their practical needs and strategic interests.

Access is not an act or a state but refers to freedom of choice in entering, approaching, communicating with or making use of a situation. The environment is either the entirety or parts of the situation that is being accessed. Equal participation would be available if equalisation of opportunities to participate were provided through measures to enhance accessibility. The elements of accessibility are attributes of environmental availability but are not environmental characteristics.

One of the advantages of assessing environments based on the universal dimensions related to the interaction between people and their environments is that we are able to analyse and evaluate accessibility variables and identify ways to reduce social exclusion and thus safeguard everyone's rights. Accessibility does not just interest a specific social group; it is necessary and a prerequisite to bring about progress for all<sup>2</sup>.

A lack of accessibility to environments and services affects women in very particular ways, and not just women with disabilities; as we know, many of the people who care for older people or people with some type of support needs are women. The built environment, building design, transport networks and telecommunication design make life even more difficult for many women, who are traditionally confined to domestic life but, nevertheless, are obliged to make use of public spaces which are often not designed for them.

### **Reality and action items**

From the point of view of women with disabilities and in other people's minds, this problem is viewed as an obstacle affecting people with disabilities regardless of their sex; however, inequalities in access continue to restrict their rights.

In Spain, for instance, many women use public transport, and women with disabilities are no exception. Limited financial resources make it more difficult for women to have access to their own adapted vehicle, so consequently a lack of accessibility in public transport has a serious impact on women with disabilities.

Regarding design, it is vital that architects and urban planners gradually begin promoting more carefully-constructed designs for public spaces. The fact that women

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<sup>2</sup> For more information (in Spanish): <http://www.un.org/spanish/esa/social/disabled/disacc.htm>

are becoming engaged in architectural design is helping to bring forward projects conceived from a different and much more conciliatory and integrating viewpoint and generate inclusive spaces in urban settings<sup>3</sup>.

Studying women's involvement in universal accessibility principles and transforming the standards by which they are applied would turn products and environments into active driving forces in the quest to further personal autonomy, retain and improve health and, in short, improve women's quality of life.

As a result, the main goal must be to identify women's involvement in the guiding principles in universal accessibility and gauge how their social spaces are represented in support products for personal autonomy.

The aim is to put an end to designs based on a sexist division of the use of space and time, even more pronounced in the case of persons with disabilities. Traditionally, men have occupied the public, urban and social spheres while women have been confined to the private, domestic spheres. By breaking down this premise we must move towards a new type of design addressing the true social reality, which is far wider-ranging and complex, divested of old-fashioned roles.

Efforts must be made to encourage self-determination leading to a shift from the concept of people who plead for care and attention to full citizenship, constructing a democratic and integrating society that does not exclude people who are unable to develop their basic rights as a result of their disability<sup>4</sup>.

The ongoing process of empowering women in all areas of life must be reflected in the entire system. There is no standard citizen around which public spaces should be designed; there is a plurality of citizens who must be consulted and engaged in creating shared spaces.

Comprehensive accessibility requires analysing proposals to determine if the space and services are designed to generate life, coexistence and security, and to achieve it we must conceive accessibility as something which is far more wide-ranging than eliminating architectural barriers. It must correspond to a reality<sup>5</sup>.

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<sup>3</sup> For more information (in Spanish): <http://laciudadaccesible.ideal.es/2011/03/accesibilidad-y-mujer/>

<sup>4</sup> Conclusions of the 1st International Congress on Women and Disability: <http://centreantigona.uab.cat/docs/articulos/1%20Congrés%20internacional%20sobre%20Dona%20i%20discapacitat.%20Conclusions.pdf>.

<sup>5</sup> For more information: [http://www.ekitenthinking.org/documents/67\\_hiria\\_kolektiboa.pdf](http://www.ekitenthinking.org/documents/67_hiria_kolektiboa.pdf).

## Conclusions

The fact that women have made great strides over the past decades in taking control of social spaces and positions is now noticeable, as shown in access to education and the workforce and participation in democratic institutions. This process has taken place at high cost and the result is a scenario in which there is occupational segregation in the labour market, women with disabilities face different types of discrimination, and a new challenge has arisen due to new areas created as a result of the information society revolution, and in particular virtual communities. The new infrastructures needed to access these networks and the prerequisites to enjoying them have created new divisions. Once again access to knowledge arises as an added complexity in the already stormy passage marked by polarities in the different social realities worldwide.

This thought leads us to pose a number of questions: is access to new areas in our social and, in particular, market structure possible without creating a certain level of chaos in those areas which women have traditionally occupied? Is the incorporation of women to knowledge on an equal footing with men an ongoing reality? Or, on the contrary, have social changes in recent years brought about the appearance of new scenarios in participation involving growing fragmentation that makes equal annexation impossible?

Consequently, engagement in new spaces designed in the information society is a prerequisite for an equal distribution of power. The question is if these new models based on accessibility principles create new types of exclusions or if exclusion is merely the result of introducing new models in a fragmented society (Sotomayor, 2007).

In short, the concept of *gender accessibility* or gender-sensitive universal accessibility has an impact mainly on two fundamental parts of social life: access to information and technologies and access to built environments. Both, however, converge towards the same field in accessibility: the social, the public, information, freedom, knowledge, wisdom. We could, therefore, use the synergy created by the gender perspective to merge the concept of *accessibility in information and technologies* and *accessibility to the built environment* in one single space which is accessible for men and women alike and contains no physical or virtual barriers. (De la Fuente and Sotomayor, 2010)

As Chicano points out, men and women must reach a consensus on a new model for society and citizenship, built around a redefinition of what is public and what is private and introducing a different rationality for our times.

The mass media must also play their part in transforming in clichés based on concerted efforts to make things continue as they are in terms of women's image and the roles men and women are to perform. (Chicano, 2002)

In short, according to the 2003 study '*Disability and social exclusion in the European Union: time for change, tools for change*', the key factors leading to persons with disabilities falling victim to social exclusion, in order of importance, are the following: lack of access or limited access to goods and services, stigmatisation of persons with disabilities, lack of suitable training, lack of specialised services, shortfalls in education systems, lack of economic policies to compensate for the additional cost of disability, the structure of allowances and, finally, institutionalisation.

All the new strategies put forward in the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - a toolkit for activists and policymakers* mainstream the gender perspective and may be powerful tools in compensating for inequalities as they generate new opportunities in education, employment, leisure and communication for women with disabilities and, consequently, enable them to achieve a normalised life and improvements in their life quality on an equal basis with other citizens (de la Fuente and Sotomayor, 2009. Page 373).

### 3. URBAN, BUILDING AND TRANSPORT DESIGN

In this section we aim, from a theoretical point of view, to suggest ways to move towards full equality between men and women in building cities. Women with disabilities form part of the wider group of women; unlike the others, women with disabilities face a double dimension in terms of difficulties in using built spaces: problems related to being a woman and those associated with their disability. In this respect, the challenge in this chapter on 'accessibility' is somewhat more complex than merely addressing urban planning from a gender perspective, which in itself is a complex task.

Building a city and its environments according to the philosophy of 'gender mainstreaming' entails organising citizens' space and time based on an understanding of the different needs men and women have. As a result, the first question that requires addressing is to identify what needs the two groups have in this context, regardless of the individuals' personal situation. In other chapters in this book many of the keys to women with disabilities developing their daily lives through the use of cities and their activities are outlined, so we can develop a 'needs

checklist' in order to improve their quality of life and, moreover, the life quality of all other citizens.

In this context, active engagement by women in the design and construction process is a key tool, so this chapter will offer practical solutions —called 'measures' here— to make this engagement a reality in the short and medium term. In order for such engagement to be truly active, women must be present in at least three areas of daily life: citizenship, politics and technical aspects.

Despite the fact that women with disabilities do not perceive quantitative differences —in terms of discrimination and in relation to men with disabilities— in an inaccessible city, there are some spaces where there is clearly a higher level of discrimination. These are spaces which they use more often because they are women: parks and gardens, collective garages and underpasses in urban environments; health and education centres, where there is a lack of equipment and the bathrooms and information available are the key problems.

Equality between men and women is enshrined in article 14 of the Spanish Constitution, which proclaims, "*the equality of all citizens before the law, without any discrimination on the grounds of sex*". Moreover, article 9.2 of our Magna Carta places an obligation on public powers to promote the conditions whereby freedom and equality for the individual and the groups which that individual forms part of are real and effective. Over the past years standards and international treaties establishing rights and freedoms have become part of the Spanish legal system. In addition and based upon the transfer of powers to autonomous communities in Spain, these regional authorities have developed their own regulations in this field, although they do not always deal specifically with the rights and freedoms of women with disabilities, despite the fact that the conditions in which they access and utilise spaces in their towns, cities and environments are poorer in terms of meeting their needs than in the case of other women.

This chapter puts forward action measures to help bring about effective equality for women with disabilities in their daily lives. The sections below will address separately aspects related to urban design and the built environment, with the understanding that collective transport is included as it is a fundamental part of urban infrastructure if a city is to function smoothly: For this reason there is no separate section for transport.

Each section proposes tools for working to facilitate the inclusion of the gender perspective in daily practises in building cities and city environments, with a view to making both accessible.

### 3.1. Urban design

#### 3.1.1. Overview

In terms of urban and land use planning, full equality between men and women is a response to a new strategy in approaching how a city and its environments are constructed; this new strategy involves new concepts and methods for urban planning in practise. The key pillar in these new concepts and methods is the active engagement of women in the process to make gender equality truly effective. This poses a major challenge as implementation creates difficulties due to its cross-cutting nature and the impact it has on all aspects of municipal public administration.

National and regional regulations promulgated in the past ten years in the fields of accessibility, gender equality and urban and land use planning help to meet this challenge. In order to do so, it is necessary to:

- a) Map the real situation in current municipal urban planning;
- b) Draw up proposals with measures to mainstream the gender perspective in such practises;
- c) Implement these measures and monitor the situation to check results and the impact the measures have from the point of view of equality between women and men.

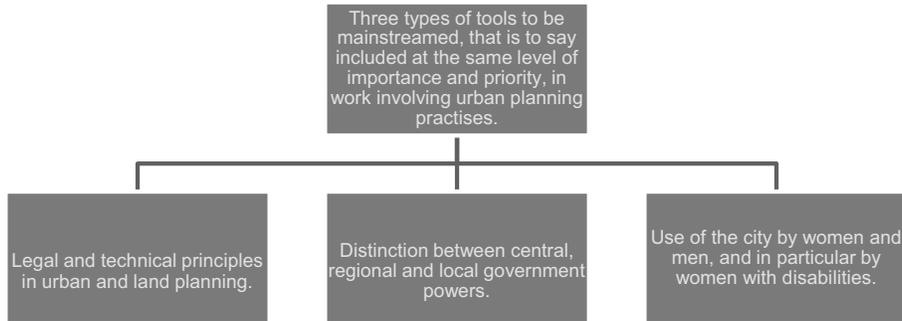
Mapping the real situation involves considering the complexity arising from legal principles and the powers held by the various public authorities which intervene in the process. There are at least three levels of public authorities involved: central government, regional or autonomic government and local government. Furthermore, mapping the reality involves ascertaining a situation which is often difficult to understand, which is that men and women, and in particular women with disabilities, use spaces and time in urban settings and their environments in different ways.

In the first stage —the planning stage— urban planning seeks to reflect the needs of citizens in a particular area (normally a city or town) in a model for their town or city and its environments, based on collecting data on the starting point prior to planning. Data collection is based on the different types of activities traditionally associated with the urban environment: economic activities, social activities and, within this type of activities, reproductive activities, which have not always been properly considered.

It is not difficult to understand that the better citizens' needs are identified in terms of the use of spaces and their activities, the better planning solutions to the problems

FIGURE 1

*Tools for implementation in urban planning practises in relation to the gender perspective*



the citizens' needs pose will be. In this respect a system to assess inhabitants' requirements that takes into account the entire population is vital. Figure 1 contains a theoretical model which could serve as a baseline for new development in a town or city.

### 3.1.2. *Gender mainstreaming in urban planning*

#### 3.1.2.1. Overview of starting point

Mapping the reality in current municipal urban planning practises means determining in detail the situation which, up to the present, has prevented in some way the inclusion of the gender perspective in urban design by means of taking into consideration accessibility from the very beginning of the process. This situation has its roots in three different areas:

- a) Ignorance regarding the concepts of gender and equal opportunities in relation to accessibility, urbanism and land use planning among both political and technical policymakers.
- b) The methodology employed in the process of building a city lacks flexibility because of the need to adhere to legal constraints in regulations related to urban and land use planning. These regulations have an impact not only on document content in the process, but also on the process execution itself.

- c) Stereotypes held up to the present time which manifest themselves in different ways and levels. For instance, we can see there is little engagement by women in the process execution stage —citizen participation, policy development and technical areas. Household activities, normally performed by women, are rendered invisible because they are not part of the macro economy, used as the basis for building towns and cities and improving their environments. Furthermore, we can observe serious difficulties in taking on board recent significant changes and new lifestyles and family lifestyles, alongside the fact that women now play a full role in macroeconomic activities.

Based on the above, we can draw out three areas for consideration in suggesting measure to bring about change:

- There is a proven need to focus on gender and equal opportunities training and awareness in the area in question. This is true both in the case of those responsible for interventions in the city and its environments and those in charge of local development. It is an indisputable reality; to date and at no stage has there existed training on gender equality and accessibility.
- The second proven fact —a result of the first— is that in urban planning, land use planning and management there is a lack of real awareness that public policies affect women and men differently. One significant fact in this respect is that in day-to-day activities there is no perception of the need to take into account the different needs women and men have, as mentioned in section 1.1, in order to design an urban area and its environments successfully.

While we are conscious of the fact that implementing gender equality in urban design processes is still not real and effective, it is necessary to attempt to approach this problem unequivocally at the level which holds practically all powers in the field: local authorities. For this reason the measures we put forward are aimed at this level of government.

### 3.1.2.2. Gender and design in urban spaces

The concept of gender, in principle, is not associated with the features of the built environment. Nevertheless, the sexual division in employment has influenced the thought, planning and management processes for services in our towns and cities. It has been shown that gender has been a more significant factor even than social class in arranging town and city development.

Most people perform their daily living activities in urban settings, regardless of the population of the town, city or village. That is why it is vital that the needs of the entire population, that is to say the needs of all the people who make up the population, are considered in the spaces where these activities take place. The needs of women and men in urban areas are different in accordance with the differing traditional roles of each, and these needs must be known and understood to be able to act in regard to these spaces and related elements.

Until recently, the needs of women in general, and women with disabilities in particular, were not included when designing urban areas; only the following socioeconomic activities that form part of the macroeconomy were considered:

- Primary sectors: agriculture, livestock, hunting, forestry and fishing;
- Secondary sectors: mining, manufacturing, energy and construction;
- Third sectors: trade, catering, transport, storage and communications, financial intermediation, education and services.

Meanwhile, responsibilities which have formed part of the daily life of women, such as homekeeping, childcare and caring for older people...in short activities that take place within the home, have not been taken into account when designing and constructing the city because they are not included in GDP calculations as they traditionally do not produce profit. Therefore there is a need to reconsider the criteria used to determine day-to-day activities in conceiving urban areas and their environments to include those activities that, although not part of the macroeconomy, also make use of the spaces they contain.

In this regard, it is vital to reflect on the role these spaces play as dynamic and active physical environments which can contribute to increasing inequalities by creating barriers or, on the contrary, to facilitating social integration by removing them. The transformation we have experienced in our country over the last decade, with new family models and women taking on remunerated work, has led to the use of new working methodologies which differ from those in the past and are characterised by the ability to incorporate these new uses for urban environments and, consequently, fresh ways to design urban environments prior to building them. A well-structured, ordered and balanced urban setting meets the personal needs of all groups involved and better safeguards quality. To achieve this, urban environments must be equipped with the necessary structuring elements<sup>6</sup> that enable coexistence of residential areas, facilities

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<sup>6</sup> Structuring elements in a town or city are understood to be the urban environments where most daily living activities are performed. Most structuring elements are set out in regional planning laws adopted by regional governments. Among others, they are:

and free spaces for communal use and provisions for suitable public transport based on the quantitative and qualitative levels of activity neighbourhood by neighbourhood.

We can cite a number of examples where spatial intervention and urban design alter the habitat, coexistence, perception of security and the landscape itself.

#### Case study 1

A lack of suitable play areas for girls and boys close to home and the workplace necessitates an 'excessive use of time' which women, persons with disabilities and older people can not always afford.

#### Case study 2

Placing a bench or seat in a public thoroughfare or park, or simply making a suitable place available for a wheelchair user, can contribute to transforming the urban habitat as it allows people to use open spaces in urban settings. The street will be used and it will be more comfortable and safer, thus encouraging socialisation by inhabitants as groups of people can get together.

#### Case study 3

Providing proper lighting in linking elements —routes— between spaces in urban areas, whether they are used by pedestrians or vehicles, ensures that they can be utilised safely because they are understood better. This also helps to enhance convenience and autonomy.

#### Case study 4

Including tactile markings in pedestrian areas in urban settings, and in routes linking pedestrian areas, makes it possible for people with visual impairment to use

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- Classification of all land in the municipality;
  - Provisions to ensure the construction of social housing and other similar types of housing;
  - Systems of a general nature, including parks, gardens and free spaces and infrastructures, services, provisions and facilities;
  - Densities, uses and potential for construction.

them safely, conveniently and independently, thus facilitating social inclusion by different groups of citizens.

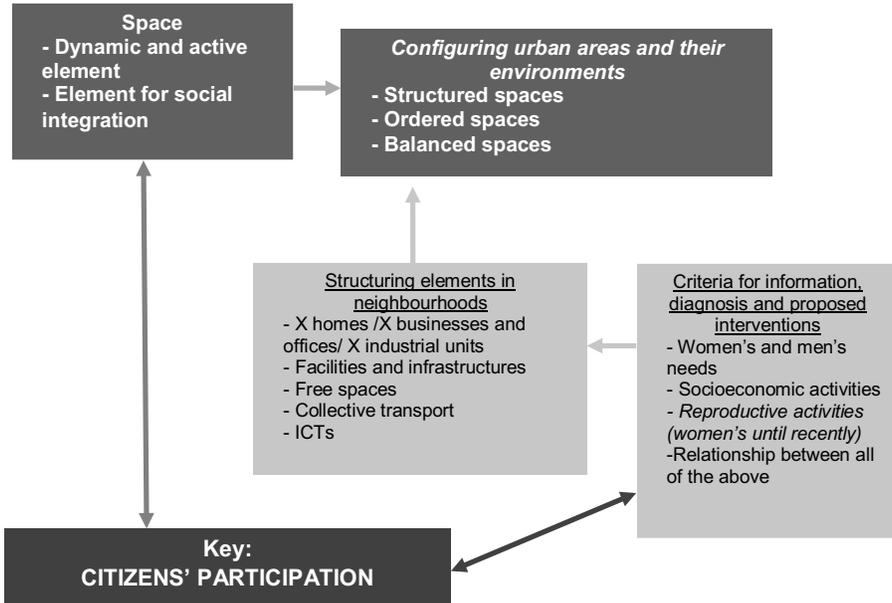
For spaces —the means for all daily living activities— to become real tools for equality and act beneficially for all citizens without discrimination, we propose including in their design at least the following:

- a) Consideration of the needs of women —the different ways they inhabit and use urban spaces— based on the activities they perform in them. This intervention entails a need to co-operate with the different groups that make up the female population (over half the total population) with a view to gathering information about their needs.
- b) Promote women’s engagement by ensuring their participation in all social and political spheres, and work to make sure their voices are heard and views taken into account.
- c) Make those activities traditionally performed by women visible, such as tasks associated with housekeeping, caring for people with support needs, childcare, etc., by appraising them and providing content. In this regard, transforming the design of urban spaces will help to ensure these activities are shared by women and men as they will become known to all citizens.
- d) Include people’s new needs in a plural society as a public duty, such as the need to reconcile family and professional life and the needs of women with disabilities, who require suitable services for their daily lives. These then become public affairs instead of private matters for each family, woman or man to deal with. The fact that women now work outside the home and there is a need to reach a common solution to daily living activities forces us to modify the criteria upon which urban spaces are designed. Activities, content, times and the relationship among all these aspects will be the driving force for urban design.

The essence of the interventions outlined above is a single key element: citizens’ engagement. Social, economic and institutional organisations must have their own place/space in the urban design and construction process. This is stated in Royal Legislative Decree 2/2008, dated June 20th, adopting the revised text of the land act. This decree has introduced significant changes in land use planning processes in terms of citizens’ participation and the environment in comparison to the previous legislation.

Figure 2 shows a scheme by which built spaces can be thought of as recipients of women’s and men’s needs. The scheme includes the key elements in defining urban design and construction policies.

FIGURE 2  
*Built spaces and social integration*



Verifying universal accessibility in the design of urban spaces must involve a structure that seeks a balance between people's needs and the functionality such spaces require, taking into consideration the way women and men use them.

In the case of buildings —facilities and residential areas— the proposed scheme is shown below in Table 1.

For urban spaces —free spaces (parks and gardens), urban thoroughfares, public transport stops and hubs, pathways— the proposed scheme is shown below in Table 2.

TABLE 1

*Scheme for verifying universal accessibility in buildings*

<b>VERIFYING UNIVERSAL ACCESSIBILITY IN BUILDINGS: FACILITIES AND RESIDENTIAL AREAS</b>	
<b>Indoor and outdoor spaces (new build or re-use)<sup>7</sup></b>	Parking areas
	Entrances and exits
	Spaces for horizontal and vertical transit
	Spaces for collective activities, especially toilets
	Interactive and non-interactive information
<b>Communication elements</b>	Communication systems

TABLE 2

*Scheme for verifying universal accessibility in urban spaces*

<b>VERIFYING UNIVERSAL ACCESSIBILITY IN URBAN SPACES: FREE SPACES, URBAN THOROUGHFARES, PUBLIC TRANSPORT STOPS AND HUBS, PATHWAYS</b>	
<b>Spaces included (new build or reuse)<sup>8</sup></b>	Parking areas
	Entrances and exits
	Spaces for horizontal and vertical transit
	Spaces for collective activities, especially toilets
	Collective or individual transport systems
	— routes, timetables, relationship between systems
<b>Communication elements</b>	Interactive and non-interactive information
	Communication systems

<sup>7</sup> 'New build' refers to any newly-constructed building. 'Re-use' refers to any intervention in an existing building.

<sup>8</sup> 'New build' refers to any newly-constructed building. 'Re-use' refers to any intervention in an existing building.

### 3.1.2.3. Space and time together as a tool for equality

For built spaces to become real tools for equality and benefit women, they must be designed on the basis of time management, a new dimension which is linked closely and directly with the configuration of urban settings and their environments and can be used to enhance life quality for all citizens.

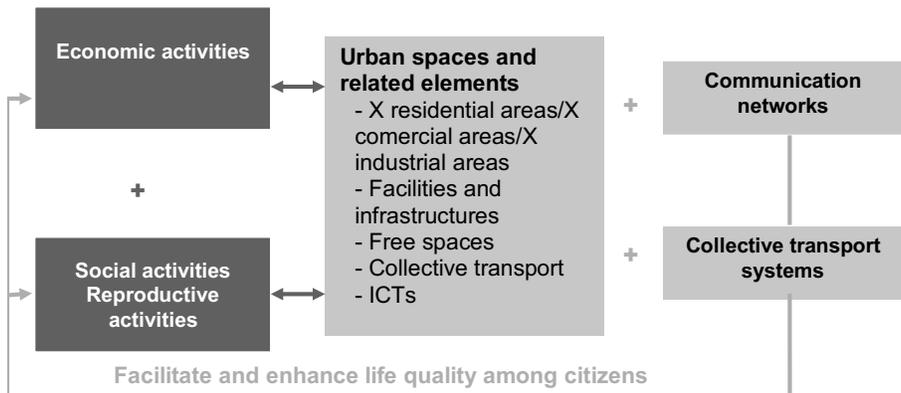
Economic and social activities in urban environments involve many trips by women and men, not merely because of the size of the spaces in which they take place but also due to the nature and functionality of communication networks and transport systems. This means one is obliged to study in detail the reality faced by women and men in relation to the trips they make. Linked to this is the need to find out how Information and Communication Technologies (from hereon in ICTs) are used by these two population groups to be able to intervene and improve how time is managed. Figure 3 shows how the time dimension has an impact on improvements in life quality among citizens.

For time, an element facilitating management of all daily living activities, to become a real tool for equality and benefit women, we propose including the following interventions in urban design and construction:

- a) Neighbourhood structuring elements must facilitate the lowest possible number of daily trips.

FIGURE 3

*The time dimension in urban design*



- b) Different types of traffic –pedestrian, vehicular and mixed– must be allowed to co-exist through improvements in communication networks.
- c) Suitable facilities must be made available to provide quality services in ICTs.

### 3.1.3. *Measures for adoption*

The action measures we propose to bring about the mainstreaming of the gender perspective in urban design can be divided in three groups:

- Awareness raising;
- Corrective measures to mainstream the gender perspective in the Survey on Local Infrastructures and Facilities;
- Gender impact assessment report.

We will now go into more detail in separate sections.

#### 3.1.3.1. Awareness raising

Awareness is raised by organising targeted training in two specific fields:

- a) Accessibility, gender, urban and land use planning.
- b) Accessibility, gender, investment and development.

Our proposal is based on the nature of implementing gender equality and equal opportunities, that is to say its cross-cutting nature.

Targeted training on accessibility, gender, urban and land use planning and development should be aimed at policy-making and technical personnel responsible for these matters in municipalities. Its objectives are:

- a) Transfer of knowledge on accessibility and gender equality and their connection with urban and land use planning practises. Those in charge of designing and constructing urban spaces and managing and implementing local development programmes will be trained to use tools which meet the needs of their citizens and the areas where they perform their daily living activities.
- b) To improve co-ordination between different departments in local authorities. In general terms this aim may seem logical and something which should occur

naturally every day, but in terms of accessibility and gender equality, as there is no prior experience training is needed in good collaborative practises in everyday activities. This is the only way to ensure the measures adopted are implemented effectively when rolling out local development programmes.

As an example of how to draw up a training programme in this area, Table 3 outlines a basic training course in urban design, improving environments and local development. The course includes sessions with theoretical and practical content that will support any further and wider-ranging training programme undertaken.

The training course is based on the philosophy of reutilising content and methodologies in subsequent courses until practitioners are fully trained.

Although this training course can be given jointly to policymakers and technical staff, we recommend it is offered separately and based on the individual's responsibilities. The reason for this is related to the legal principles in urban and land use planning practises, whereby the two groups have different civil, administrative and criminal liabilities.

TABLE 3  
*Course Schedule*

<b>TRAINING COURSE ON ACCESSIBILITY, GENDER, URBAN AND LAND USE PLANNING</b>	
<b>Objectives</b>	1 Adapt knowledge in urban and land use planning activities to municipalities, studying their impact and connections affecting women and men.
	2 Learn, study and use experiences in the field from Spain, Europe and the rest of the world.
	3 Learn, study and propose new management methods for services in urban areas and adapt them to take into account ICTs and their use by women.
	4 Adapt local management tools to fresh needs in the urban area based on knowledge of the reality in the areas to which they belong.

TABLE 3 (Cont.)  
Course Schedule

<b>TRAINING COURSE ON ACCESSIBILITY, GENDER, URBAN AND LAND USE PLANNING</b>		
<b>Content and schedule</b>	Activities: theoretical and practical training (15 hours blended training/on-line)	
	<ol style="list-style-type: none"> <li>1 General concepts:                             <ol style="list-style-type: none"> <li>1.1 Introduction and general course concepts: the gender perspective and urban and land use planning.</li> <li>1.2 Mandatory regulations: the gender perspective, equal treatment, urban planning, land use planning.</li> </ol> </li> </ol>	Time: – Theory: 2 hours. – Practise: 1 hour.
	<ol style="list-style-type: none"> <li>2 Urban and land use planning:                             <ol style="list-style-type: none"> <li>2.1 Intermunicipality and supramunicipality in urban and land use planning.</li> <li>2.2 Rural areas, urban and land use planning at provincial level.</li> </ol> </li> </ol>	Time: – Theory: 4 hours. – Practise: 3 hours.
	<ol style="list-style-type: none"> <li>3 Managing urban and land use planning:                             <ol style="list-style-type: none"> <li>3.1 Public management in gender equality in municipalities.</li> <li>3.2 Research and action in the gender perspective in urban areas:                                     <ul style="list-style-type: none"> <li>– social housing.</li> <li>– facilities and infrastructures.</li> <li>– services.</li> <li>– collective and individual transport and landscaping in rural environments.</li> </ul> </li> </ol> </li> </ol>	Time: – Theory: 3 hours. – Practise: 2 hours.
<b>Suggested methodology</b>	Activities	
	1 Presentations outlining the specific content in each section at the beginning of each day of the course.	
	2 Reflection groups at the end of each day.	
	3 Presentation of the material coming out of the reflection groups. The material is then used to draw up manuals to promote the work carried out in the groups.	

### 3.1.3.2. Corrective measures to mainstream the gender perspective in the Survey on Local Infrastructures and Facilities

The Survey on Local Infrastructures and Facilities (from hereon in SLIF) is a valuable conceptual and practical instrument of relevance in activities directly related to the urban construction process as it has a direct impact at two key moments in the process:

- a) Urban and land use planning stage.
- b) Time of delivery of the works approved during the planning stage.

For this reason, data compilation for the SLIF must include the gender perspective as a prerequisite for effective equality between women and men in any town or city.

Urban and land use planning takes place through a process involving three main working areas:

1. Information and assessment of the situation.
2. Proposals for intervention based on a planning structure in each municipality.
3. Citizen participation throughout the process.

One of the key instruments in the process is the SLIF. The SLIF is a national survey that employs the same methodology nationwide, feeds into a data base and is conducted in co-operation with the Ministry for Public Administration. It is, therefore, the core objective instrument for studying and assessing local needs and determining the following:

- a) Economic co-operation between authorities.
- b) Urban and land use planning.

The data bases created through the SLIF are used in all urban and land use planning procedures as they reflect the current status regarding facilities and infrastructures in municipalities. Consequently, the structure of the survey itself is vital if we wish to respond to citizens' needs. SLIF data is broken down in the areas set out in the following table.

TABLE 4  
*SLIF breakdown by areas*

AREA	
1 Demographic data	13 Cultural and leisure time centres
2 Housing and height in built-up areas. Number of hotel rooms	14 Parks, gardens and natural areas
3 Urban planning	15 Markets and fairgrounds
4 Road network	16 Slaughterhouses
5 Road access to built-up areas difficult to reach	17 Cemeteries and morgues
6 Road infrastructure	18 Health centres
7 Water supply	
7.1 Collection 7.2 Conveyance 7.3 Storage 7.4 Treatment 7.5 Distribution network 7.6 Independent supply	19 Care centres
8 Sewage and waste treatment	
8.1 Sewage network 8.2 Collection 8.3 Outlets 8.4 Waste treatment 8.5 Independent sewage systems	20 Centres for education
9 Rubbish collection and management	21 Fire stations and civil protection facilities
10 Lighting in public thoroughfares	22 Town halls and other facilities used for municipal purposes
11 Communications and energy supply	23 Unused public buildings
12 Public sports facilities	

A reading of the results of this survey allows us to gain an understanding of the real situation in towns and cities in relation to their basic infrastructure and facilities, thus enabling the process to be improved. The results can be broken down into three elements for analysis:

- 1 Real insight into the starting point in terms of facilities and infrastructure with a view to municipal planning.

- 2 Planning can be carried out within an appropriate framework in order to be able to take the best possible decisions on municipal works.
- 3 Resources can be assigned to local bodies objectively, rationally and in a balanced fashion.

### 3.1.3.3. Gender impact assessment report

Regulations on equality between men and women state that the policies which require attention, especially by public authorities, are those related to local development and access to housing. More specifically, article 31 of Organic Law 3/2007, dated 22nd March, for effective equality between men and women, in the section dealing with urban policies, land use planning and housing, stipulates that public authorities must adopt measures to make effective equality between men and women, and in particular measures to boost access to housing by women in situations of need or risk of exclusion, and women who are victims of gender-based violence. In addition, the article states that the needs of the various social groups and types of families must be considered in order to improve equal access to all urban infrastructures.

To ensure compliance with the provisions of the law, urban and land use planning and management processes must be obliged to include a 'standard report' assessing gender impact. The goal of the Gender Impact Report is to make sure that women's concerns and experiences form an integral part of the following process stages:

- a) Development stage in urban and land use planning policies.
- b) Management and monitoring stage in urban and land use planning.
- c) Planning policies assessment phase in relation to gender.

More specifically, article 31 of Organic Law 3/2007, dated 22nd March, for effective equality between men and women, dealing with urban policies, land use planning and housing, stipulates that public authorities must adopt measures to make effective equality between men and women, and in particular measures to boost access to housing by women in situations of need or risk of exclusion, and women who are victims of gender violence. In addition, the article states that the needs of the various social groups and types of families must be considered in order to improve equal access to all urban infrastructures.

The Gender Impact Report on urban design must be based on assessment indicators drawn up in accordance with the provisions set out in articles 19 and 20.

We recommend assessment and monitoring is performed on the basis of previously-established indicators allowing the following:

- a) An assessment of how land use planning is designed (ex ante assessment) using an instrument called a 'check list' which is applicable to all documents in this stage. The indicators in the check list seek to verify that the principle of equal opportunities has been included as a central focus area.
- b) An assessment of how each project is executed, that is to say how it is delivered, the results obtained and its impact. This assessment is based on execution indicators (delivery and outcome) and impact indicators which determine what impact in terms of equality the work carried out and delivered has, and if progress has been made towards the goal of equality between men and women.
- c) An assessment of project management, that is to say internal organisation. Indicators allow us to evaluate whether project management in each case and urban and land use planning overall have led to greater gender equality or not.

In short, the goal of the indicators is to 'quantify' qualitative data and information through different measurements (indexes, percentages, average value and others).

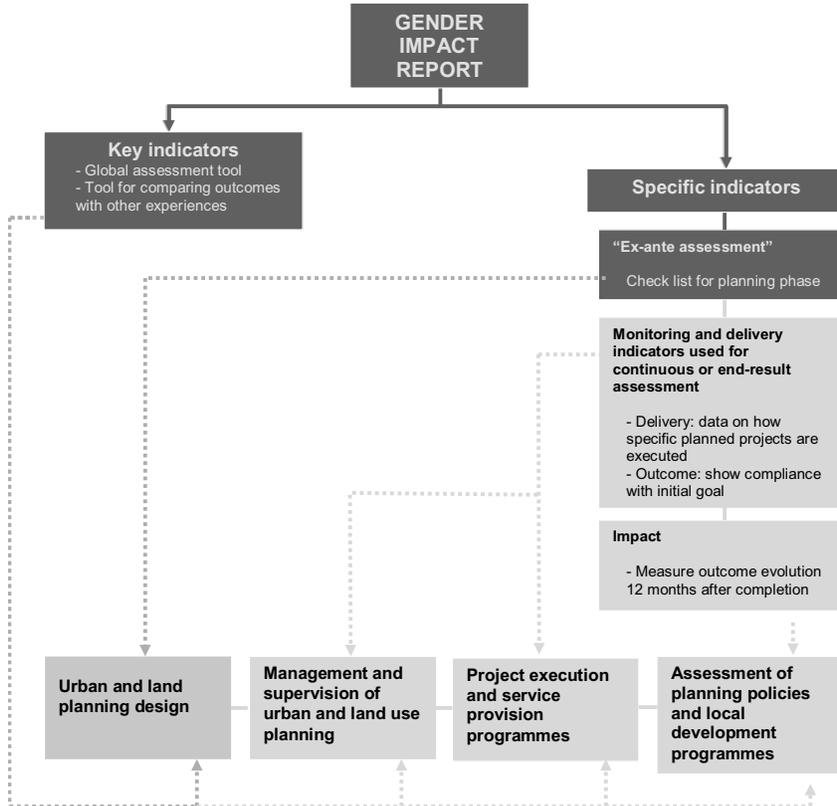
It is important to point out here that drawing up a set of indicators does not merely involve gathering and handling data; each indicator to be used *must be selected in relation to the key theoretic variable*. The introduction of the gender perspective in drawing up social indicators and, in general terms, in producing statistics is essential and critical in bringing to light gender inequalities (Beijing Declaration and Platform for Action, adopted at the 4<sup>th</sup> World Conference on Women, Beijing, 1995).

Consequently, the set of indicators we put forward here addresses two different issues: first of all the indicators serve a descriptive purpose, by which we mean measurement can show us the current status in urban design and construction processes and offer 'hints' for improvement in future activities; and, secondly, they enable evaluation, allowing us to gauge what progress has been made by measuring the final outcome against previously-identified situations where inequality is present.

We have, therefore, the following two types of indicators:

- a) Key indicators: these are the tools used for overall assessment of the implementation of the gender perspective and for comparison with similar experiences.
- b) Specific indicators: tools used to assess each project at different stages.

FIGURE 4  
*The Gender Impact Report in designing and constructing urban areas - design stage.*



\* NB: indicators and the corresponding stage in urban construction are shown in grey.

There are three types:

- ‘Check list’ indicators: a list of items used by technical personnel to carry out a quick check on the mainstreaming of the gender perspective during the planning stage;
- Delivery and outcome indicators: used for an ongoing assessment during delivery and upon conclusion of each project;

- Impact indicators: used to measure the evolution of the outcome over time (for instance a twelve-month period) and enabling verification of points which are difficult to determine when a project has just been finalised.

Figure four above should give a clearer idea of the indicators we recommend for the urban design stage.

## **3.2. Built environment**

### *3.2.1. Gender and building urban spaces*

As shown in section 1 above, there are various rules and regulations that impose obligations on public authorities to implement effectively the principle of equal treatment and equal opportunities for men and women. The following measures are used to seek to achieve these goals:

- a) Rules and regulations are approved and implemented.
- b) Public policies in all areas are drawn up and assessed.
- c) All related activities are performed.

When developing an urban area there are a number of specific regulations —both technical and legal— that must be observed. The economic and social development of a built-up area and, as a result, of the citizens who inhabit it, relies on these regulations. In this respect it is vital to deliver exactly what was scheduled in the design phase, and in this stage of the process everyone involved must adhere to accessibility and gender equality policies on which design has been based.

Given their importance, the list below includes the spaces that make up an urban area. Each of these should be assessed to ensure construction was carried out in line with the policies mentioned above:

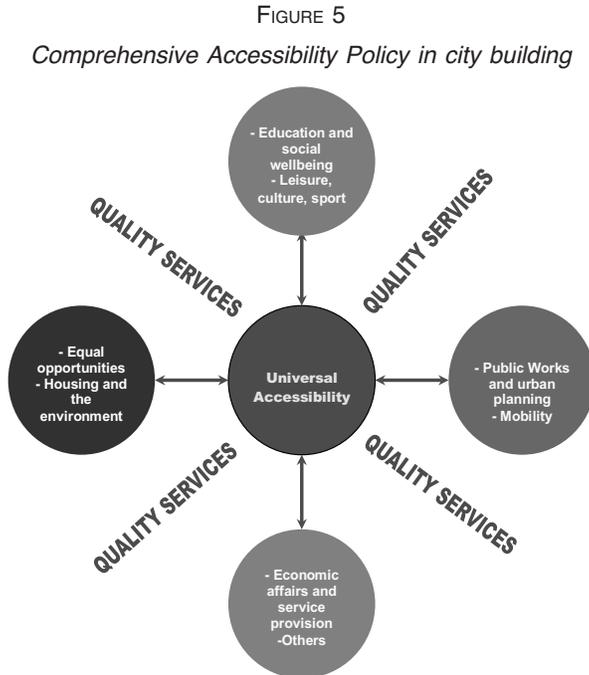
- a) Residential zones: houses and collective housing.
- b) Commercial, administrative and industrial zones.
- c) Facilities for collective activities allowing service delivery to citizens.
- d) Urban infrastructure allowing the urban area to function.
- e) Free spaces (parks, public gardens, etc.).
- f) Collective transport systems.
- g) Information and Communication Technologies.

Accessibility and the gender perspective must therefore be mainstreamed in the construction stage for gender equality to be truly effective. To make this possible specific regulations currently in place governing universal accessibility must be applied, and it is also necessary to make it mandatory to apply a Comprehensive Accessibility Policy in the area. All local authority departments should be engaged in implementing this policy; this, despite the attendant difficulties, is a key factor.

The different local authority departments should be located in accessible built environments since the ultimate aim is to offer citizens quality services through the use of the contributions in levies and taxes made by citizens themselves.

Evidently, co-ordination between the different public authorities in charge of offering or contracting such services through public or private companies for delivery is absolutely essential. It is also important to point out that in Spain the overall administrative model involving the different levels of government does require improvement in terms of co-participation and co-responsibility.

Figure 5 shows a proposed scheme for developing such a comprehensive policy.



Public works, urban planning, mobility and environmental affairs departments are responsible for delivering and monitoring activities related to the physical environment; these may be private or public in nature, so it is vital they are controlled from the outset if the outcome is to be satisfactory and meet the needs of persons with disabilities.

Departments in charge of equal opportunities, housing, education, social wellbeing, leisure, culture and sport are responsible for actions and services that take place in the physical environment, and the department for economic affairs and service provision is in charge of managing revenues and expenditure related to the areas previously mentioned, with the aim of ensuring municipal services are accessible for all.

Close co-ordination among the various departments at municipal level is needed and must be carried out efficiently; to achieve this it is crucial that each department clearly identifies its roles and responsibilities. Once identified, the task is to determine which accessibility accommodations are required and sufficient to make sure that activities are designed and constructed in such a way that they satisfy the different needs men and women have.

### *3.2.2. Measures to be adopted in local development programmes*

Mainstreaming the gender perspective in local development programmes involves incorporating it into three different areas: administration processes, works delivery and service provision:

- a) Administering local development programmes involves implementing all projects related to the works to be carried out and services to be offered in a municipality. These actions will have been planned previously based on the social and financial requirements set out in urban planning and land use programmes in the municipality.
- b) Delivery programmes for works and services involve managing the time and space required to carry out the projects mentioned in a) above.
- c) Drawing up the Gender Impact Assessment Report.

Each area is developed further in the following sections:

### 3.2.2.1. Mainstreaming the gender perspective in urban and land use planning management

When managing urban planning and land use, measures must be taken to include the gender perspective as the works and services delivery programmes depend on this management.

One useful methodology in this regard could be the implementation of cross-cutting gender plans at municipal level. These plans consist of a set of measures geared towards furthering equality in all areas of local development. The measures must be co-ordinated and scheduled in the medium term. The plans, therefore, require teamwork involving all municipal departments in each village, town or city.

In the area we are currently addressing —administration— the following objectives are needed for the purpose of improving the life quality of citizens:

- a) Consideration of the needs and interests of all social groups, including women, when building a city and its environments.
- b) Delivery of quality services.
- c) Use of Town Planning Management Regulations and municipal ordinances as rules for standard practise and driving forces for change.

There are effective tools that can be used in land use planning instruments to achieve these goals<sup>9</sup>. Table 5 offers a description of the tools we suggest. These can be very helpful for local bodies as they can be used as action guides in their area and in accordance with their day-to-day activities.

Finally, in terms of project management, local bodies are responsible for leading, inspecting and overseeing all actions towards project delivery, with engagement by individuals. This responsibility is set out in legislation governing urban planning and, in particular, in the current national land law. For this reason, local authorities must be equipped with mechanisms to facilitate this task, which is neither simple nor easy to perform.

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<sup>9</sup> Urban planning regulations used by regional governments state that planning instruments are divided into general planning, development plans and catalogues (or a similar instrument).

TABLE 5

*Tools for addressing planning and land use from the gender perspective*

<b>DEVELOPMENT OF GENDER-SENSITIVE URBAN PLANNING TOOLS</b>	<b>CHECK-LIST DELIVERY INDICATORS</b>
1 The authority concerned decides if the project is public- or private-sector led, and selects management method.	a) Women's organisations (social and economic) are included in the process. b) Criteria for selecting infrastructures which meet the needs of women and men are included*. c) Criteria for selecting facilities which meet the needs of women and men are included**. d) A proportion of social housing is set aside for marginalised groups, among others women***.
2 Timelines for delivery and order of execution set.	
3 Areas affected by the development planning are identified, the delivery method is selected and the execution stages and procedures are established.	
4 Urbanisation works in the area affected by the project are carried out if the method selected is co-operation or expropriation.	
5 Urbanisation and building works are due, inspected and monitored if other methods are used.	
6 Gender equality and equal opportunities ordinances drawn up for the municipality.	

\* Taken from the findings of the SLIF.

\*\* Taken from the findings of the SLIF.

\*\*\* Taken from the citizens' participation process.

Table 6 below sets forth a suggested set of tools for local authorities to improve their day-to-day actions and mainstream accessibility and gender equality in their daily administration.

TABLE 6

*Gender-sensitive administration (management, inspection and supervision):  
tools for improvement*

<b>MANAGEMENT, INSPECTION AND SUPERVISION TOOLS FOR GENDER-SENSITIVE ADMINISTRATION</b>		
<b>Actions</b>	<b>Delivery indicators</b>	<b>Outcome indicators</b>
1 Co-ordinating administrative and supervision activities in urban management.	<ul style="list-style-type: none"> <li>– Legal instruments used: study of how these are implemented differently for men and women.</li> <li>– Women’s engagement in urban consortia.</li> <li>– Women’s engagement in neighbourhood organisations.</li> </ul>	Relationship between: <ul style="list-style-type: none"> <li>– Instruments used.</li> <li>– Time taken.</li> <li>– Suitable adjustments in line with plans.</li> </ul>
2 Constructing social housing: most marginalised groups.	<ul style="list-style-type: none"> <li>– Location of the area chosen.</li> <li>– Suitable typology for new family models.</li> <li>– Selection criteria for the target public.</li> <li>– Percentage of the total number of homes set aside for this purpose.</li> <li>– Type of tenure and sex of owner or tenant.</li> </ul>	<ul style="list-style-type: none"> <li>– Number of houses for this purpose.</li> <li>– Time taken to go through the process.</li> <li>– Selection of next programme: time and location.</li> </ul>
3 Constructing facilities and infrastructures.	<ul style="list-style-type: none"> <li>– Location of the area chosen.</li> <li>– Suitable typology for new family models.</li> <li>– Selection criteria for the target public.</li> <li>– Spatiotemporal relationship with other zones in the municipality.</li> </ul>	<ul style="list-style-type: none"> <li>– Time taken to travel from residential zones or workplace.</li> <li>– Selection of next programme: time and location.</li> </ul>

TABLE 6 (Cont.)

*Gender-sensitive administration (management, inspection and supervision):  
tools for improvement*

<b>MANAGEMENT, INSPECTION AND SUPERVISION TOOLS FOR GENDER-SENSITIVE ADMINISTRATION</b>		
<b>Actions</b>	<b>Delivery indicators</b>	<b>Outcome indicators</b>
4 Implementing municipal and supramunicipal mechanisms for engagement in the land market.	<ul style="list-style-type: none"> <li>– Legal instruments used: study of how these are implemented differently for men and women.</li> <li>– Establishing a management protocol for municipal land.</li> <li>– Establishing end uses for municipal land: study of how implementation differs for men and women.</li> </ul>	<ul style="list-style-type: none"> <li>– Impact of the outcomes on men and women.</li> <li>– Comparison of different uses of municipal land by men and women.</li> </ul>
5 Urban supervision and order.	<ul style="list-style-type: none"> <li>– Safeguards and dissemination on urban planning and land use.</li> <li>– Effectiveness of co-ordination among the different departments.</li> <li>– Effectiveness of supervision mechanisms: study of how implementation differs for men and women.</li> </ul>	<ul style="list-style-type: none"> <li>– Data on transparency and public dissemination regarding projects.</li> <li>– Supervision of co-ordination among different departments: citizens' participation.</li> </ul>

### 3.2.2.2. Mainstreaming the gender perspective in scheduling the delivery of works and service provision

Our proposal for scheduling the delivery of works and service provision is based on the municipal Works and Services Co-operation Plan. This plan differs from other possible solutions in three ways:

- 1 It is an economic co-operation programme based on investments made through local co-operation.

TABLE 7

*Proposed methodology for gender-sensitive municipal investment scheduling*

GENDER-SENSITIVE MUNICIPAL INVESTMENT SCHEDULING		
Aspects of scheduling and content	Gender assessment indicators	
<p>1 Goal: to enhance rationalisation in administration.</p> <p>a) Deliver fully-completed works.</p> <p>b) Make services available to users in the shortest possible time.</p> <p>c) Improve municipal investment planning and enable greater co-ordination with projects undertaken by other authorities.</p> <p>d) Reduce the number of projects drawn up.</p> <p>e) Execute investments in a maximum timeframe of two years.</p>	<p>Delivery indicators</p> <ul style="list-style-type: none"> <li>– Works to be delivered: study of how these are implemented differently for men and women.</li> <li>– Time taken for works to be delivered: study of how they are implemented differently for men and women.</li> <li>– Citizens’ participation in supervising works to be delivered: data disaggregated by sex.</li> </ul>	<p>Outcome indicators</p> <p>Relationship between:</p> <ul style="list-style-type: none"> <li>– Instruments used.</li> <li>– Time taken.</li> <li>– Suitable adjustments in line with plans.</li> <li>– Study of how they are implemented differently for men and women.</li> </ul>
<p>2 Method: distribute funds judiciously.</p> <p>a) Urgent works to be scheduled first.</p> <p>b) Reasonable balance between all areas in the same province.</p> <p>c) No municipality to concentrate its investment in one fiscal period.</p> <p>d) Use indicators to measure fund distribution based on the following elements:</p> <ul style="list-style-type: none"> <li>– Infrastructure shortages.</li> <li>– Population.</li> <li>– Number of centres in the municipality.</li> <li>– Service spread among population centres.</li> <li>– Property tax collected (inverse relationship).</li> <li>– Business tax collected (inverse relationship).</li> <li>– Per capita income (inverse relationship).</li> </ul>		

2 Its goal is to meet the needs identified in basic infrastructures and municipal facilities.

3 It is developed through the Survey on Local Infrastructures and Facilities.

According to the needs identified at municipality level, projects are developed for delivery over two different time scales: annually or biannually. Scheduling projects is

vital as the most significant municipal investments in the social and economic sphere are dependent upon it. The decisions taken during the scheduling stage will, therefore, have a direct impact on citizens as a whole.

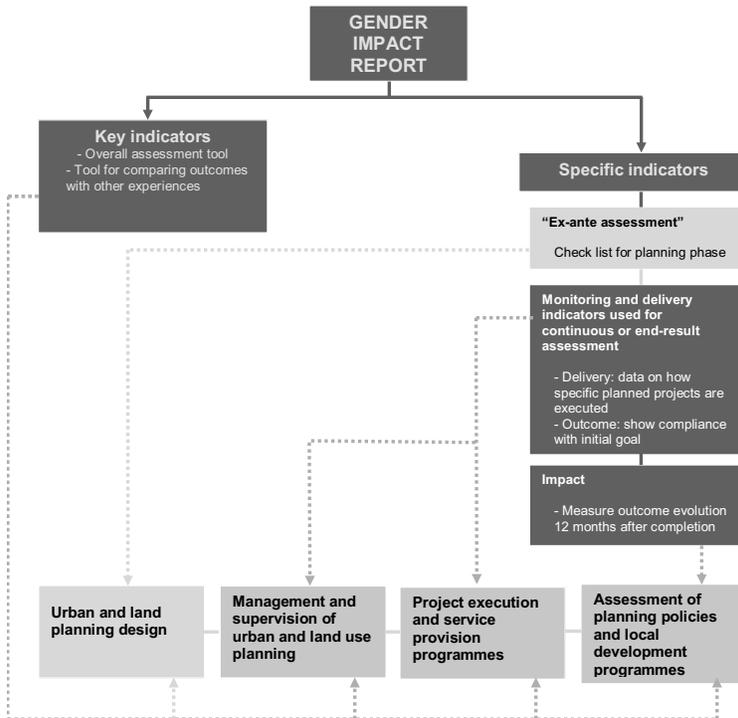
In consideration of the above, Table 7 contains a proposed methodology to ensure project scheduling for works and services is performed in a gender-sensitive fashion.

### 3.2.2.3. Gender impact assessment report

Following the same methodology as in the section on urban design, once a legal obligation exists to assess impact on gender when managing urban and land use

FIGURE 6

*Relationship between the gender impact assessment report on urban design and construction - built environment phase*



\* NB: indicators and the corresponding stage in urban design are shown in grey.

planning, the aim of the gender impact assessment report in the built environment should be to check whether the concerns and experiences of women and men are integral parts of the following stages in the process:

- a) Administering and supervising urban and land use planning.
- b) Programmes for work and service provision delivery.
- c) The assessment of local development programmes in respect of gender.

Figure 6 offers a summarised and clearer view of the indicators we recommend for the built environment stage.

## 4. INFORMATION AND COMMUNICATION TECHNOLOGIES

### 4.1. Introduction

Technology has advanced at a remarkable rate over the past twenty years. Among all technologies, those which are changing our lives most are information and communication technologies (ICTs). They have brought about a shift in how we receive information, take decisions on what we buy, interact with authorities, receive training, access leisure activities and even do our jobs. Due to the phenomenal rise in the use of 'social networks', ICTs are also changing the way we make contact with others, socialise, and even engage as citizens.

Nevertheless, are gender and disability issues considered in these new processes? By using ICTs, do specific opportunities exist for women with disabilities? Could ICTs be key tools in achieving gender equality? Can accessibility problems related to ICTs cause women with disabilities to be doubly discriminated?

It seems evident that ICTs in themselves do not cause discrimination towards women, but the use we make of them can. In this section we shall attempt to address the questions above.

### 4.2. Access to the knowledge society

ICTs further access to the Information Society. Having the right information helps to make the right choices in decision-making processes and, therefore, people who access the information society hold an advantage over those who do not.

Although there is no reliable data on internet access rates by women with disabilities, there is information that shows that this group within the population uses internet less. However, the gap between internet use by men and by women is becoming less significant; in 2004 it was 10%, while by 2010 it had been reduced to almost half that figure.

The factors leading to this difference in use are principally age, purchasing power, occupation and level of education. Access to ICTs among people over 40 is lower, and women with disabilities fall into this group in a higher proportion. Women's purchasing power is lower due to the notorious salary gap and a lower employment rate. Women with disabilities have a lower activity rate than men with disabilities. Housework, traditionally a task for women, is related to lower ICT use, and finally women's level of educational attainment is lower than men, although in further education women now outnumber men and achieve higher marks. It is safe to presume the digital gap affects women with disabilities even more given the concurrence of these factors.

Women and men do use technologies differently: while women use social networks more frequently than men, men are more likely to use internet to visit web sites containing information, e-administration sites and sites offering employment opportunities<sup>10</sup>. Other sources<sup>11</sup> underline how men make greater use of internet for consumption and play, areas where technology products are also more prevalent, while women tend to opt for services with more practical and social contents. In general, women use internet as a tool to perform specific activities (keep in touch with friends and family, take part in group dialogue, obtain information and perform practical tasks). Rarely do women who use internet have a deep technical knowledge of the subject, use the network and applications for advanced purposes or exercise authority.

This isolation with respect to access to technologies has an impact on communications, information and knowledge, and therefore has a bearing on discrimination and equal opportunities. Accessibility problems in ICTs may involve two dimensions: lower ICT use by women and difficulties in accessibility for persons with disabilities.

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<sup>10</sup> According to the event '*More women in ICTs: a source of opportunities for society, the economy and business*' held at the University of Alicante in September 2011.

<sup>11</sup> Amelia Rodríguez Contreras ([www.potaldelacomunicacion.es](http://www.potaldelacomunicacion.es)), Autonomous University of Barcelona.

### **4.3. Girls, women and ICTs: visibility**

There is a generally-held belief that women are technophobes and men are more skilled at using digital tools<sup>12</sup>. These traditional roles also affect girls because adverts, children's series and films continue to show boys using skill and strategies, whereas new technologies for girls are shown as ornaments (pink mobile phones, social networks to post photos and gossip, etc.). The traditional role of the mother performing household tasks determines the digital isolation faced by women, limiting access to training and to job opportunities.

Women and girls with disabilities are invisible to the knowledge society and their limited engagement is influenced by the permanence of cultural prejudices and established patterns restricting independent living for women. Another factor is the lack of on-line content and services designed for this large group. If we carry out a simple test, we see that a Google search for 'women with disabilities' returns 1.6 million hits, but if we look for 'men with disabilities' we find 6.2 million results, that is to say five times as many.

It is necessary, therefore, to provide content and services to 'attract' women with disabilities to internet and promote their technological literacy, develop methods to strengthen lifelong learning, facilitate access to technologies and develop computer-based services that meet the needs and demands of persons with disabilities.

### **4.4. ICTs as allies in the fight against gender-based violence**

ICTs can help to combat gender-based violence by promoting awareness-raising campaigns, providing relevant information on-line and shaping opinions on networks based on the participation 2.0 concepts.

However, internet contains pornographic content and the net can be used as a tool for harassment and to engage people in networks involved in human trafficking. Measures are needed to strengthen ICT use in order to combat violence against women and girls, and in particular against those belonging to vulnerable groups, such as women with disabilities.

On the other side, we do have examples where ICTs are used as instruments to protect people from violence, such as GPS-based tagging devices used to monitor assailants and RFID wristbands, but these devices are completely inaccessible, fail

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<sup>12</sup> Dr. Martin Hilbert, in *Economic and Social Sciences*, Cepal Newsletter, 9/2012.

to take disability into account and, in many cases, use warning systems that cannot be picked up by women with sensory disabilities. Accessibility to ICTs solutions in the fight to combat abuse and gender-based violence remains an unresolved issue.

#### **4.5. Channelling women with disabilities' talent, creativity and vision through ICTs**

*“ICTs may be the most tangible tool we have in the fight against discrimination on gender grounds”*<sup>13</sup>. ICTs enable women in particularly vulnerable positions, such as those who have a disability, to play an active role in networks engaged in development, support, dissemination, and also access to new jobs and on-line training. Evidently women need to be empowered to use ICTs, but in the case of women with disabilities this is not enough because accessibility is a prerequisite; if platforms are not fully accessible we will widen the digital gap for a particularly vulnerable group within the population. For women with disabilities, accessibility becomes a determining factor in achieving inclusion.

Women can also contribute to the knowledge society by adding their talent and creativity. A diversity of opinions, experiences and approaches to problem-solving makes society a richer, more competitive and more tolerant place. As a society we cannot afford to do without the talent women with disabilities possess, so we must implement active policies and introduce measures to avoid exclusion.

#### **4.6. Recommendations**

Although more and more people now relate gender to ICT usage, there are no accurate statistics on internet access rates among women with disabilities. As a starting point, it is crucial to have information and an overview of the needs of women with disabilities with regard to ICTs. Through ICT use opportunities do exist, however, for women with disabilities; opportunities for enhanced visibility, to access information, to fight against the scourge of gender-based violence, for social participation and engagement in the labour market. Accessibility is a key variable in safeguarding these opportunities.

As a starting point, we put forward the following recommendations:

- Develop empowerment programmes and actions enabling women with disabilities to access information and increase participation;

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<sup>13</sup> Quote from an article by Martin Hilbert.

- Strengthen the use of ICTs as tools to combat violence against women and girls with disabilities;
- Promote networks aimed at development, support dissemination and access to new jobs and on-line training;
- Treat accessibility as a cross-cutting issue in technological development and, in particular, in technologies designed specifically for women;
- Encourage women with disabilities to contribute to the knowledge society;
- Enable women with disabilities to engage in designing and developing technology-based solutions that meet their needs;
- Make the needs and preferences of girls and women with disabilities more visible on-line.

## 5. INFORMATION AND COMMUNICATION

### 5.1. Introduction

Despite progress towards gender equality over the past decades, being a woman and having a disability still means suffering multiple disability and a situation of greater isolation and vulnerability in comparison both with the population in general and the two ‘minority’ groups to which they belong: women and persons with disabilities.

Is there discrimination or a gap in access to information and communication? What does ‘gender perspective’ imply in terms of accessibility to these channels? This section will attempt to clarify these questions and identify action items to ensure gender relationships are considered in information and communication as we move towards accessibility.

In the previous chapter we saw how distorted and negative images of women with disabilities persist, in particular in the media (television, radio, printed press, new ICTs, etc.). These images reinforce values that lead to greater vulnerability among women with disabilities. As women have taken on a more active role in society some stereotypes have been broken down, and the media itself can contribute to making women with disabilities more visible and presenting them positively and in a normal fashion.

As stated in the European Commission 2020 Strategy, “*accessibility is a prerequisite for participation in society and in the economy.*” To understand the accessibility challenges in the field of information and communication from a gender point of view,

we must begin by considering some socio-demographic aspects and studying the very nature of communication. This will help us as we seek to put forward proposals for action towards full participation and independent living for women with disabilities.

## **5.2. Information and communication as privileged leverage for change: an advantageous starting point.**

If we consider disability to be the result of a process of interaction with the environment<sup>14</sup>, the gender variable is a determining factor alongside other related socio-demographic factors, for instance age, and social factors such as education, employment and access to relations<sup>15</sup>. The situation women face in comparison with other variables —and in particular age— has improved in several areas, while in others it continues to lag.

Education is closely linked to access to information and communication in our 'knowledge society'. Persons with disabilities tend to have lower educational attainments than those without disabilities. In general terms, women with disabilities have lower levels of education than men with disabilities. However, when the statistics are controlled for age we can see that this is in fact true only for those over 45 years old; under this age, educational attainment achieved by women is equal to or superior to that of men (National Disability Observatory 2010, A. Huete, 2011). Consequently, it is in the field of education where most progress in eliminating inequalities has been achieved and where women with disabilities, and particularly younger women with disabilities, are achieving success in equalising opportunities. Nevertheless, we do still need to address the greater disadvantage faced by older women.

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<sup>14</sup> Disability is viewed nowadays as a question of interaction between the individual, with his or her particular functionality, which may include differences with respect to the median, and environments (WHO, 2001). Disability exists because, in relation to the functional difference with respect to the median, activities and participation are restricted. The environment may present architectural barriers, communication barriers, attitudinal barriers, as well as aspects facilitating inclusion. In this respect, the goal is to conceive accessible spaces, products and services and eliminate potential barriers; in this case, in information and communication.

<sup>15</sup> Consolidated findings from the *Disability, Independence and Dependency Situations Survey* (National Institute for Statistics, 2008) allow us to estimate that in 2008 there were 4.1 million people with disabilities in Spain living in private homes or residences, that is to say 9% of the population. Almost 2.5 million are women, compared to 1.6 million men, so women with disabilities make up 60% compared to men (40%). The prevalence of disability rises with age. The numbers of men and women with disabilities are similar until around 40 years of age —from then on women outnumber men considerably until, in later years, there is more than double the number of women with disabilities than men.

We do not have data on the digital gap, the difference between men and women with disabilities in access and use of information and communication technologies. According to the findings of the Survey on Equipment and Use of Information and Communication Technologies in the Home (National Institute for Statistics, 2011), the trend towards breaching the digital gap between genders in recent years is confirmed<sup>16</sup>.

Age, income, educational attainment and occupation are the most influential social factors in access to and use of ICTs. We can extrapolate to say that despite the added difficulties women with disabilities face —above all fewer economic resources and limited access to paid work— the trend towards equality in access to ICTs is occurring also in the case of women with disabilities, making access to information and communication a potentially huge tool for leverage in terms of access to participation.

In other areas, as will be seen as they are addressed in more detail in other chapters of this book, the situation faced by women with disabilities is one of greater inequalities and disadvantages, both in comparison with men with disabilities and other women without disabilities:

- Lower levels of economic activity and higher unemployment rates than among men with disabilities, resulting in reduced financial independence;
- Greater dependence on the family and, in the case of older women, higher numbers living in institutions;
- Higher prevalence of negative stereotypes linked to being a women and, in addition, having a disability. This results in public stigmatisation and, through introjection of such prejudices, lower self-esteem and greater devaluation;
- Greater exposure to forms of mistreatment, violence and abuse.

Given this situation, information and communication channels, including ICTs, are fundamental tools —and perhaps the most practical and direct ones— in overcoming gender-based discrimination against women with disabilities.

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<sup>16</sup> While in 2004 the figures showed that men led women by 9.9 percentage points in computer use, and in 9 points in internet use and frequent use of internet, the gap closed considerably to half this figure throughout the decade. In 2011 the difference in computer use, internet use and frequent use of internet had been reduced to 5.5 percentage points.

### 5.3. Mainstreamed in all policies, interdependent with the different fields in accessibility and participation

The human rights approach - the future in terms of achieving equality in diversity - in addition to being universal and inalienable, incorporates two additional principles which are particularly enlightening in terms of accessibility and communication:

- **Indivisibility:** the furtherance of one human right does not justify violation of another. Exercising a right regularly depends, in overall terms or in part, on the realisation of other rights.
- **Interdependency or interrelation:** furthering one specific human right must be part of comprehensive efforts to achieve human rights holistically.

Information and communication are an integral part of policies and measures that enable people to realise their human rights and participate in society. Achieving the right to health, or education, or social protection, for instance, may depend on the realisation of the right to information.

Information and communication form part of policies, but also of spaces, objects (for instance technology design or the design of support products incorporates values and meanings) and any product we can think of. The goal, therefore, is to conceive and put in place these communicative dimensions in suitable and accessible terms in relation to the specific needs women with disabilities have.

### 5.4. Aspects in communication, barriers and pivotal solutions

It is worth considering the different areas and types of communication and information, as well as bearing in mind different accommodations in terms of accessibility, in order to act accordingly. In a simple statement, the CRPD sets out the different aspects and alternatives in communication: “*languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.*” Language is defined as, “*spoken and signed languages and other forms of non-spoken languages.*”

Languages, whether they are spoken or non-spoken, expressed face to face or through technologies, with support from a human mediator (interpreter, personal assistant, and so on) or not, are used in different situations and activities. Built environments (public buildings, transport, streets) also contain communicative aspects

in their layout and to facilitate intuitive and independent orientation, signage and pictograms to facilitate comprehension, as emerging aspects of accessibility. Street furniture and equipment can also become barriers to or facilitators for access to information. Non-verbal language includes adjusting the way we deal with others in face-to-face interactions.

Persons with disabilities are heterogeneous and have different needs when it comes to communicating; the reality of women with disabilities is also heterogeneous and subject to differing situations involving co-existence and social support, age, and access to services and resources. Policy design and implementation must take into account common aspects in the use of products, services and environments by women and their different realities, needs and preferences in terms of communication.

Lack of space precludes us from going into detail on requirements related to access to information and communication for each type of disability. However, publications on this topic include the excellent and recommendable “*Communication for all: guidelines for accessible communication*” (CERMI, 2005), the result of co-operation between CERMI and Telefonica.

## 5.5. Recommendations

Information is a component in each policy designed to bring about equality for women with disabilities in every field (health, education, employment, access to justice, etc.). This right must be upheld, and at the same time instruments to exercise it must be provided by means of concrete measures. The 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union suggests a number of measures in this respect (in particular in chapters 2 and 3), and the Manifesto is the basis for the following recommendations we put forward (some of which are already mentioned in the Manifesto)<sup>17</sup>:

- Provide information using accessible communication methods such as easy-to-read formats and sign language;
- Encourage women to become active drivers in communication when expressing their needs;
- Identify barriers to communication in public spaces, objects and services and apply the principles and methods of design for all in solution design. The gender

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<sup>17</sup> These measures can be adapted for use by both policy-makers and third-sector activists.

perspective must be included if we are to achieve a truly universally accessible environment;

- Train and raise awareness among those in charge and staff at services providing information and guidance to the public (in the health sector, employment, etc.) in gender and disability, thus enabling them to become aware of the specific needs women with disabilities will have in their area;
- Focus on and facilitate access to communication in those areas where women make different use of services and content, such as health, sexuality and reproductive rights, or gender-based violence (prevention and support, including monitoring potential abuses involving institutionalisation, etc.), and also areas such as employment where the gap is greater and exclusion is particularly noticeable;
- As an additional and complementary measure, but also related to information and access to information and as part of the same gender mainstreaming approach, research, statistics and other data-gathering processes should include and disaggregate the disability variable by sex;
- Break down isolation in communication by addressing the issue, discussing it and including it in policies, including both disability policies (without addressing gender) and gender policies (without considering disability). Strengthen spaces for intersectionality and communication between policy-makers and activists in each area. For instance, public authorities may facilitate communication fora to address issues they are responsible for in citizens' participation and representation organisations or through other channels.

## 6. PERSONAL ASSISTANCE: HUMAN SUPPORT TO ACHIEVE INDEPENDENT LIVING

Whenever universal accessibility and support products fail to make up for women with disabilities' functional limitations, personal assistance becomes a pivotal resource in achieving independent living. Personal assistance is the human support women with disabilities and/or in situations of dependence may need to ensure equal inclusion in the community and social participation. Despite the long history of personal care services in the USA and other European countries and the fact that it is legally recognised<sup>18</sup>, implementing personal assistance in Spain is still in its infancy, although

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<sup>18</sup> Personal assistance is recognised in international legal instruments such as the CRPD (article 19, *Living independently and being included in the community*). In Spain, *Act 51/2003*,

it is beginning to take root in several parts of the country and in a number of programmes<sup>19</sup>. Personal assistance involves a new and different approach to social services and is attracting growing interest as it meets the needs of women with disabilities and women with higher support needs and helps to empower them. For this reason it has been given its own section in this book, precisely here in this chapter on accessibility<sup>20</sup>.

No matter how severe a disability or situation of dependence is, personal assistance can provide the support needed to reach the highest possible level of control over one's own life. As Lobato (Vasey, S., 2004: 8) says, "*personal assistance has turned out to be a tremendously effective tool both for persons with disabilities themselves and for authorities responsible for dispensing public funds. Personal assistance and independent living ensure the wishes of the person with disabilities are respected at all times and, as a result, he or she can decide on all aspects of life, just as persons without disabilities have the ability to do this guaranteed.*"

This is about giving women with disabilities the option to live like other citizens...work, study, go on holiday, socialise, become a mother, enjoy her free time, access culture, engage in politics, etc... Personal assistance is particularly beneficial for women with disabilities as they are more likely to suffer from isolation, less likely to be involved in employment, have lower incomes and are more exposed to risks such as abuse.

The *1<sup>st</sup> Comprehensive Action Plan for Women with Disabilities (2005 -2008)*, drawn up by CERMI, includes a section on independent living and defines as a key element, "*the right of women with disabilities to take control over their own existence*". The plan

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*dated December 2nd, on equal opportunities, non-discrimination and universal accessibility for persons with disabilities* includes independent living as a guiding principle and defines it as "a situation in which the person with disabilities exercises decision-making over their own life and engages actively in the life of the community, in accordance with the right to freely develop personality." Article 9, *Positive action measures*, includes personal assistance as a type of complementary support (along with technical aids, financial support, specialised services and auxiliary services for communication) in the area of universal accessibility.

Personal assistance and personal assistants are included in Act 39/2006, *dated December 14th, to promote personal autonomy and care for persons in situations of dependence*, which provides financial support to fund personal assistance.

<sup>19</sup> See X. Urmeneta (2011) for more information on experiences in personal assistance in Spain.

<sup>20</sup> In this respect personal assistance can be thought of as a component of accessibility, as an accommodation in the human and social environment and as a facilitator to enable people to take part in activities and participate in different areas, while taking into account their functional differences.

refers to personal assistance as, *“formalised personal support, self-managed by the women herself provided this is possible, and sufficiently flexible in terms of tasks and working hours to achieve the goal that constitutes the cornerstone of this philosophy of life: to enable women with disabilities to lead the life they want in line with their personal interests and in the environment they consider most appropriate, without their disability being an obstacle to making this goal a reality”* (CERMI, 2005: 201).

There are a number of situations that call for such support. Women with reduced mobility, for instance, with limited manual dexterity or control over their arms, legs or balance, but who are capable of deciding how they want to live. They may need support to get dressed, wash, go to the bathroom, go out to work or study, drive or go on holidays. A blind woman may need to be accompanied to learn new routes in urban areas, to use a vending machine or go shopping. In the case of a woman with a hearing disability who uses sign language, support comes in the shape of a sign language interpreter. For a deafblind woman, a communication interpreter is needed. Women with intellectual disabilities can receive personal assistance to better understand their surroundings or organise their 'to do' list. Furthermore, personal assistance can directly facilitate the option to become a mother or enjoy sexuality, fundamental human rights which every woman with disabilities should be able to enjoy if she wishes to (CERMI, 2005).

As this is an individual, personalised and self-managed service, personal assistance can be a highly effective solution to meeting real needs and enabling women with disabilities to have a balanced and more independent relationship with their families, in addition to participating socially in different activities.

Support is provided by a personal assistant (PA) in a relationship set out in a contract to which the person with disabilities or his or her legal representative is normally a signatory. On occasions formal contract handling can be performed by an Independent Living Office (ILO) which is part of a public body, perhaps a town council or provincial authority, or an association. Nevertheless, it is the woman with disabilities who manages all aspects of the direct relationship with the PA, from recruiting to monitoring his or her performance and, if the need arises, terminating the contract.

Personal assistance services may be considered a type of direct financial allowance for hiring a PA (direct payment), or may be delivered by a local or regional authority in the framework of an Independent Living Support Programme, with an assigned budget to cover the number of hours required weekly or annually (or using other methods, including direct payment) depending on the needs of the women with disabilities, her life project and her Individual Independent Living Plan.

## 6.1. Recommendations

The keys are ensuring this right is delivered to all, making sure there is sufficient funding available to meet its purpose, and self-management, with whatever support is required, by the women with disabilities. Support may take the shape of administrative assistance (to arrange contracts, holidays, recruitment and termination, etc.), training in the independent living philosophy and training to manage the PA service. Training and ongoing support to solve any difficulties which may arise may be provided through a ‘peer support’ scheme, that is to say sharing experiences and thoughts, with the required guidance, with other personal assistance users.

### **Recommendations for policy-makers: future measures**

- In partnership with women with disabilities and their associations, ensure access to personal assistance as an option available to women with disabilities in their area of competence (local, regional, etc.) and as a legally-recognised right under current legislation;
- Learn from existing experiences and programmes;
- Include users in the design, administration and assessment of PA programmes;
- Channel the resources and coverage necessary, either directly or through other organisations. These may be managed by Independent Living Offices (ILOs);
- Ensure that female users are able to select the gender of their PA as part of the PA selection process;
- Adopt enabling regulations at regional level in the corresponding regulations on personal assistance provision and the labour regulations covering PAs.

### **Recommendations for third-sector activists: future measures**

- Lead from the front in your sphere of action and learn from other existing experiences in order to promote access to personal assistance by women with disabilities and high support needs and/or women in situations of dependence;
- Provide and channel the experiences and opinions of women with disabilities as stakeholders in the process of designing and developing PA services;
- Promote further training in independent living and PA management.

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## Chapter IV

# EQUAL RECOGNITION BEFORE THE LAW AND EFFECTIVE ACCESS TO JUSTICE

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1. EQUAL RECOGNITION BEFORE THE LAW
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## Chapter IV

# EQUAL RECOGNITION BEFORE THE LAW AND EFFECTIVE ACCESS TO JUSTICE

### 1. EQUAL RECOGNITION BEFORE THE LAW

*“Just as feminists in the 60s and 70s uncovered how women are excluded from history, showed how women experience poverty and discrimination, and insisted on the need to recognise and put an end to violence against women, we are driven by a sense of outrage and injustice. We are offended by the fact our voices are silenced, so the oppression we suffer remains unacknowledged, and we consider unjust the exclusion of women with disabilities from the heart of society.”*

**JENNY MORRIS**

#### **1.1. Women with disabilities as rights holders: legal personality and capacity**

The International Convention on the Rights of Persons with Disabilities (hereafter CRPD) represents a paradigm shift in how legal capacity is recognised, enjoyed and exercised. Since entering into force, this instrument imposes an obligation to respect equality in legal capacity and guarantees support in situations where people require assistance in decision making. The ‘substitution model in decision making’ is replaced by the ‘support model in decision making’<sup>1</sup>.

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<sup>1</sup> See BARRIFFI, F. and PALACIOS, A. (Editors), *Legal capacity, disability and human rights. A renewed approach in the light of the International Convention on the Rights of Persons with Disabilities*, Buenos Aires, EDIAR, 2011.

This has important consequences for how women with disabilities enjoy and exercise all their rights. Policies, laws and society in general often seem to be oblivious to the fact that women with disabilities are rights holders (of *all* rights), and prior recognition of their legal personality and legal capacity is the first step.

The meaning and scope of these terms can have differing implications in different legal and social contexts<sup>2</sup>. However, internationally the Convention on the Elimination of all Forms of Discrimination against Women (hereafter CEDAW) and the CRPD define the terms in the same way: the impossibility of restricting and/or violating the recognition of legal personality or the exercise of legal capacity on the basis of gender or disability<sup>3</sup>.

To this end, the CRPD lays down a number of safeguards and obligations for States Parties to follow; these must be read, interpreted and implemented from the social model of disability and including the gender perspective. Article 12 of the Convention includes the supported decision making model which, along with the principles of autonomy, dignity and equality, and the article setting out the right to independent living, bring to reality the social model of disability in a very important area in the lives of women with disabilities: participating on equal terms as the rest of humanity in the decisions that affect their own destiny.

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<sup>2</sup> The difference between French law and Spanish law is just one example. In French law, *personnalité juridique* is a precondition for acquiring legal capacity. Two separate concepts can be identified in legal capacity. The capacity to enjoy belongs to all people and cannot be restricted or removed. The capacity to act, however, presupposes certain additional elements are in place and may be removed or limited under certain circumstances. Nevertheless, the meaning of the term 'legal capacity' includes both capacity to enjoy and capacity to exercise. It must be said that French law is particularly important in this respect as the regulation of legal capacity in many Ibero-American countries takes its inspiration from it - amongst others, the Uruguayan and Argentinean Civil Codes. In Spanish law, however, legal capacity can be defined as *aptitude and suitability to be a rights and duties holder and, in general terms, to legal relations*. Here the concept of legal capacity presupposes an unchanging attitude towards the individual, who is granted wide-ranging legal capacity by the legal system both in personal affairs and in family and property matters. However, legal capacity should not be confused with the capacity to act, which refers to the aptitude of the individual to perform legal acts directly and validly; this quality is respected in the individual when he or she is adept at exercising, by himself or herself, his or her own rights and, in general, at functioning independently in legal settings. In Spanish law, therefore, the connotations of the term 'legal capacity' seem to apply in a restricted fashion merely to the capacity to enjoy or, in other words, the *de jure* capacity. See *Background conference document about legal capacity*, prepared by the Office of the United Nations High Commissioner for Human Rights (6th period of sessions), paragraph 30. For an analysis of preparatory work leading up to the Convention on the Elimination of all Forms of Discrimination against Women, see Rehof, L., *Guide to the Travaux Préparatoires of the United Nations Convention on the Elimination of All Forms of Discrimination against Women*, Martinus Nijhoff, 1993.

<sup>3</sup> Article 15, International Convention on the Elimination of all Forms of Discrimination against Women, and article 12, International Convention on the Rights of Persons with Disabilities.

The ‘supported decision making’ model also includes an important principle which forms the basis for the social model of disability and can be summarised in the slogan ‘*nothing about people with disabilities without people with disabilities*’. This principle was brought forth with democratic participation by people with disabilities and public life in mind and in an attempt to prevent decisions on policies to be formulated and implemented being taken without the engagement of those affected by them. At the same time, however, the principle encompasses, perhaps to an even greater extent, private life and decisions by these people themselves. As it was developed without considering the gender perspective, it is normally expressed as ‘nothing about us without us’, and this is why it was necessary to visibilise the *invisibilised* through calls to take up the slogan ‘nothing about women with disabilities without women with disabilities’<sup>4</sup>.

As a result of the major shift in philosophy involved and the repercussions in different areas of life, article 12 is probably the precept bearing the most innovative provision in the Convention, above all for people who are in situations of particular vulnerability and suffer most from discrimination in taking their own decisions, such as women with different intellectual and psychosocial disabilities.

The question now arises as to exactly what tools article 12 offers, what it means for the lives of women with disabilities and the exercise of their rights, and above all what demands it places on states and society.

## Reaffirming recognition of legal personality

The first section of the article reaffirms recognition of legal personality for men and women with disabilities by establishing that:

*“1 States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.”*<sup>5</sup>

The right to recognition of legal personality means recognition as persons before the law and is, therefore, a prerequisite for all other rights<sup>6</sup>. It is a condition inherent

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<sup>4</sup> See Peláez Narváez, A., prologue to the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers, adopted in Budapest on 28-29th May 2011 by the General Assembly of the European Disability Forum following a proposal by the EDF Women’s Committee, and endorsed by the European Women’s Lobby, revision carried out in light of the United Nations *Convention on the Rights of Persons with Disabilities*. Available at: <http://www.edf-feph.org/Page.asp?docid=26614&langue=EN>.

<sup>5</sup> Article 12, paragraph 1, International Convention on the Rights of Persons with Disabilities.

<sup>6</sup> See BARRIFFI, F., ‘*Legal capacity and the capacity to act of persons with disabilities in the light of the UN Convention*’, in *Towards the right to disability - studies in tribute to Rafael de Lorenzo*, Pérez Bueno, L.C. and Sastre, A., editors), Aranzadi, Spain, 2009, page 359.

in the person and the basis for that individual's enjoyment and exercise of all other rights. It could be said that both men and women are 'moral beings' and personhood is an attribute of that moral being, as opposed to legal capacity, which is an aptitude.

It is important not to lose sight of the fact that one acquires legal personality simply by being a person; it is not subject to any other restriction or limitation. On this point the Convention merely 'reaffirms' this acknowledgement, thus implying a prior recognition which can be found in article 16 of the International Covenant on Civil and Political Rights for all persons, which states that, "*Everyone shall have the right to recognition everywhere as a person before the law.*"<sup>7</sup>

### **Recognition of equality in legal capacity**

Paragraph 2 of the article introduces a paradigm shift and stipulates recognition of an important safeguard: equality in terms of legal capacity. The paragraph states that:

*"2 States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."*<sup>8</sup>

This groundbreaking rule, based on a recognition of people's legal capacity on equal terms (men and women, with and without disability) and in all areas of life, introduces a momentous shift in human rights due to the importance of legal capacity as a means to enjoy and exercise one's human rights. Among other major and significant questions, it means recognition and respect for the right to one's identity, the right to choose with whom one wishes to live, where one wishes to live, how one wishes to live, with whom one wishes to interact on a personal level - including the right to form a family -, citizen participation in democracy, and a long list of additional rights including aspects which are essential if one is to be able to develop one's own and unique life projects.

The legal capacity safeguard applies both to the capacity to enjoy and *de jure* capacity as well as the capacity to act and exercise. This is so if we consider the preparatory work for article 12 (previous discussions and how the discussions evolved during the drafting stage) and the interpretation given in the Convention on the Elimination of all Forms of Discrimination against Women, an instrument with a similar purpose, and especially if we bear in mind the philosophical model which underpins the Convention<sup>9</sup> and its purpose, which is none other than to "*promote, protect and*

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<sup>7</sup> Article 16, International Covenant on Civil and Political Rights.

<sup>8</sup> Article 12, paragraph 2, International Convention on the Rights of Persons with Disabilities.

<sup>9</sup> PALACIOS, A., *The social model of disability - origins, description and expression in the International Convention on the Rights of Persons with Disabilities*, Madrid, Cinca, 2008.

*ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”<sup>10</sup>*

It is important to underline that the article acknowledges legal capacity “*on an equal basis with others*”. CEDAW affords the same meaning to gender by establishing, in article 15, identical legal capacity to that of men. This means that certain circumstances, such as for instance the age of the person, which may lead to restrictions in the exercise of legal capacity, may also be applied to persons with disabilities. On the other hand, legal capacity can never be limited or restricted “on the grounds of disability and/or gender” (by means of a directly discriminatory measure) or ‘only’ in the case of persons with disabilities or women (by means of an indirectly discriminatory measure)<sup>11</sup>, because this would violate the equality and non-discrimination safeguards the article explicitly sets out.

Consequently, legislation and/or practises containing grounds for incapacitation based, either directly or indirectly, on disability and/or gender, clearly constitute violations of this obligation and are indubitably discriminatory<sup>12</sup>. This refers to both laws and/or practises which base incapacitation on disability and/or the gender of the individual (directly) and those which are based on other grounds in addition to disability and/or the gender of the individual (indirectly).

This is clearly set out in the ‘Thematic study of the High Commissioner for Human Rights on key legal measures for the ratification and implementation of the Convention on the Rights of Persons with Disabilities’, which states that, “*Whether the existence of a disability is a direct or indirect ground for a declaration of legal incapacity, legislation of this kind conflicts with the recognition of legal capacity of persons with disabilities enshrined in article 12, paragraph 2.*” As a result, States Parties must amend or repeal legislation that violates the duty of States to respect the human right to legal capacity of persons with disabilities.<sup>13</sup>

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<sup>10</sup> Article 1, International Convention on the Rights of Persons with Disabilities.

<sup>11</sup> This would be the case of an ostensibly neutral rule, provision, criteria or practise which placed people with disabilities in a disadvantaged position in relation to others, unless that rule, provision, criteria or practise can be objectively justified in the pursuit of a legitimate goal and the means to achieve that goal are necessary and appropriate. See Council Directive 2000/78/EC, 27th November 2000, establishing a general framework for equal treatment in employment and occupation.

<sup>12</sup> See BARIFFI, F., ‘*Legal capacity and the capacity to act of persons with disabilities in the light of the UN Convention*’, in *Towards the right to disability - studies in tribute to Rafael de Lorenzo*”, Pérez Bueno, L.C. and Sastre, A., editors), Aranzadi, Spain, 2009. The author postulates an interesting theory based on different models of attributing incapacity.

<sup>13</sup> A/HRC/10/48, dated 26th January 2009.

In the Inter-American Human Rights System, of major interest is the recently-released 'General observation of the Committee on the Elimination of All Forms of Discrimination Against Persons With Disabilities on the need to interpret Article 1.2 (b) *in fine* of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities in the context of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities'<sup>14</sup>.

The article in the Inter-American Convention to which the observation refers stipulates that a declaration of incapacitation is not discriminatory if it is necessary and appropriate and national law permits it<sup>15</sup>. This article is clearly incompatible with the International Convention on the Rights of Persons with Disabilities<sup>16</sup>, and for this reason the Inter-American Convention Committee drew up the general observation to adopt an interpretive criteria in the light of this situation, realising as it did that the Inter-American Convention, "*seriously contradicts the provisions of Articles 2 and 12 of the United Nations Convention, and the Committee therefore construes that the aforementioned criterion must be reinterpreted in light of the latter document currently in force.*"<sup>17</sup>

Furthermore, the observation points out that, "*most Civil Codes, especially in Latin America, still retain in their legal provisions institutions such as declaration of insanity and protection as a way to afford legal representation to persons with disabilities, particularly persons with hearing or mental disabilities, and that said institutions need to be revised in light of the provisions of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, as mandated in Article 4.1(a) and (b) of said Convention.*"

As regards legal remedies, the Committee agreed to, "*urge the States Parties to conduct a comparative study of their domestic laws and the domestic laws of the other States Parties to the Inter-American Convention, with regard to the provisions on the legal capacity of persons with disabilities, in order to ensure that they maintain regulations based on their needs in all their social strata and on their country's*

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<sup>14</sup> Adopted at the First Extraordinary Meeting of the Committee on the Elimination of All Forms of Discrimination Against Persons With Disabilities, OAS/Ser.L/XXIV.3.1 CEDDIS/doc.12 (I-E/11), Rev.1, May 4th-5th 2011.

<sup>15</sup> Article 1.2.b., Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons With Disabilities: "If, under a state's internal law, a person can be declared legally incompetent, when necessary and appropriate for his or her well-being, such declaration does not constitute discrimination."

<sup>16</sup> PALACIOS, A., *Legal capacity - a new approach from the social model and disability and human rights perspective*, in *Current challenges for human rights*, Slavín, P. and Bariffi, F., Suarez, Mar del Plata, 2009, page 139.

<sup>17</sup> Observation of the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities, OAS/ Ser.L/XXIV.3.1 CEDDIS/doc.12 (I-E/11) op.cit.

*institutional capacity, but within the framework of Article 12 of the United Nations Convention.*<sup>18</sup>

In terms of practical mandates, the Committee shall, “*request the OAS Secretary General to order a revision, by the appropriate legal bodies, of Article 1.2(b) in fine of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, with a view to aligning it with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and recommending whichever is best: its non-application in practice or its repeal.*”<sup>19</sup>

Finally, it was decided to, “*urge the States Parties to the Inter-American Convention to adopt measures, in keeping with Article 12 of the United Nations Convention, to guarantee recognition of universal legal capacity, including that of all persons with disabilities, regardless of the type or extent of disability, and, consequently, to initiate without delay a process for replacing the practice of declaring legal incompetence, guardianship, or any other form of representation that impairs the legal capacity of persons with disabilities, with a practice based on decision-making with support.*”<sup>20</sup>

The OAS Committee observation leaves no doubt that the substituted decision making model is discriminatory, and it calls for a new system to be built that guarantees supported decision making as part of safeguards for equality.

According to the social model of disability, the definition of legal capacity does not depend on the individual attributes or limitations of the individual, but rather on the social, economic and legal barriers placed in the way of the individual when he or she takes or acts upon personal decisions, and the support or accommodations that must be delivered to facilitate decision making<sup>21</sup>. Accordingly, support to exercise legal capacity takes on a similar dimension to that of a ramp in guaranteeing the right to mobility. Let us now look at how article 12, paragraph 3, addresses this issue.

### **Safeguards in the exercise of legal capacity**

Article 12, paragraph 3, acknowledges that in certain situations some people may require support to exercise their legal capacity. In those cases, States Parties are obliged to provide this support:

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<sup>18</sup> Ibid., item 1.

<sup>19</sup> Ibid., item 2.

<sup>20</sup> Ibid., item 3.

<sup>21</sup> BACH, M. and KERZNER, L., *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, prepared for the Law Commission of Ontario, October 2010, page 18.

*“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.”<sup>22</sup>*

Having established the obligation to guarantee that people (men and women) with disabilities enjoy legal capacity on an equal footing as others, here there is provision for the state to deliver a system to safeguard access when there is a need for support. Of course, such support shall be proportional to the needs of the woman and should be individualised in each case to take into account her specific needs according to her situation<sup>23</sup>.

What this means, if we were to compare this with any other right, is that this paragraph recognises the principle, for instance, of equality in employment. Women with disabilities have the right to work on an equal basis as others (which means they should not be discriminated against “on the grounds of gender or disability”). Now, to deliver that right in the same way as it is delivered to others, and to ensure they do not suffer discrimination due to their gender or disability, women must have the gender perspective guaranteed, universal accessibility and reasonable accommodations, etc.

In the case of legal capacity, acknowledgement of the right on an equal basis with others implies that the exercise of the right cannot be limited or restricted due to gender or disability. And in this case, to ensure non-discrimination for women on the grounds of gender and/or disability in exercising legal capacity, the gender perspective must be mainstreamed and there must be provision for universal accessibility and reasonable accommodation. This is where the support system comes into play; as an element of universal accessibility if needs can be predicted beforehand<sup>24</sup>.

The question, therefore, is not now *if a woman with disabilities has the capacity* to exercise her legal capacity, but rather *what a women with disabilities needs* to exercise her legal capacity<sup>25</sup>.

This involves a major effort by states; most do not currently have these support systems in place for women with disabilities precisely because the old systems were designed based on the substituted decision making model and did not take the gender perspective into account. What this means is not only the need to undertake domestic legislative reform but the provision of a system to support and accompany new

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<sup>22</sup> Article 12, paragraph 3, International Convention on the Rights of Persons with Disabilities.

<sup>23</sup> GARCIA LLERENA, V., *Best interest in the personal sphere of the incapacitated person*, La Coruña, Paideia, 2002.

<sup>24</sup> A thorough study of the difference between universal accessibility and reasonable accommodations can be found in DE ASIS ROIG, R., *Universal accessibility in law*, Cuadernos Bartolomé de las Casas, number 42, Dykinson, Madrid, 2007.

<sup>25</sup> BACH, m. and KERZNER, L., *op. cit.*, page 58.

legislation in order to implement the measures required to ensure that those women with disabilities who need it have access to support in order to exercise their legal capacity.

In this respect, in its observation on the topic, the OAS Committee on the Elimination of All Forms of Discrimination against Persons with Disabilities stresses the need to *“Train the general public, and justice system operators in particular, regarding the new paradigm in effect with respect to the legal capacity of all people with disabilities, including those with severe impairments, through recourse to decision-making support systems; Adopt urgent measures of a regulatory nature to ensure that the judicial system disallows the approval of new declarations of legal incompetence and to foster the gradual development of decision-making support systems, as well as the regulation and implementation of institutions and mechanisms to safeguard against abuse...”*<sup>26</sup>

### **Accompaniment through safeguards in implementing support systems**

The CRPD places an obligation on states to guarantee there is a support system in place for decision making. In line with this obligation, paragraph 4 in article 12 sets out another obligation which can be summarised as the requirement to establish a system of safeguards to prevent abuse in relation to measures that may be taken in the framework of this support<sup>27</sup>.

This is vitally important in the lives of women with disabilities, who are more likely to fall victim to abuse and violence than men, in many cases perpetrated by those who are supposedly providing support.

Paragraph 4 states that:

*“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*

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<sup>26</sup> Observation of the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities, OAS/ Ser.L/XXIV.3.1 CEDDIS/doc.12 (I-E/11).

<sup>27</sup> *“Where necessary, States Parties have to take appropriate measures to provide access to support for persons with disabilities so that they are able to take decisions on their own behalf.”* Report of the High Commissioner for Human Rights on progress in the implementation of the recommendations contained in the study on human rights and disability, A/HRC/4/75, paragraph 34.

*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."*

In previous writings I have noted that the text above was drafted without considering two points which had been raised by non-governmental organisations through the *International Disability Caucus* during the CRPD drafting stage<sup>28</sup>.

The first is related to the need for safeguards to be adopted in line with international human rights law, when at the time of adopting the Convention international law was not based on the supported decision making model but rather on substituted decision making.

Secondly, there is inconsistency in the same paragraph as it sets out the need for support measures to safeguard the exercise of legal capacity to be adopted "*for the shortest time possible*". Placing time restrictions would be appropriate for substituted decision making because if people's rights are being restricted or removed, it is logical to expect these restrictions to last for as short a time as possible. However, if we are talking about measures within a supported decision making system, these measures must be expected to last as long as other support measures last: that is to say, as long as they are needed<sup>29</sup>.

Having said this, the precise nature of the CRPD with respect to certain features that must be present and safeguarded when support measures are adopted is important: women with disabilities' rights, will and preferences must be respected (considering and respecting the fact that they are moral beings), there must be no conflict of interests or undue influence (this is to cover cases in which support consists of involvement by third parties), measures are to be appropriate and tailored to the needs of the woman with disabilities (it is vital to bear in mind that support will always be 'tailor made' and based on the specific needs of the individual), they should be applied for the shortest possible period of time (as mentioned above, I do not feel this is necessary if the purpose of support is to facilitate autonomy), and subject to regular review by a competent, independent and unbiased authority or judicial body. This last safeguard seeks to ensure a competent, independent and impartial authority or judicial body intervenes periodically to check to see 'if the tailor made solution needed still fits', or if some part of the support needs to be modified.

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<sup>28</sup> PALACIOS, A., *The social model of disability - origins, description and expression in the International Convention on the Rights of Persons with Disabilities*, Madrid, Cinca, 2008.

<sup>29</sup> See comments, proposals and amendments submitted electronically (seventh session) by the International Disability Caucus.

## **Safeguards for specific measures in relation to property and assets**

Finally, the Convention explicitly guarantees that states shall take steps to ensure access by all persons with disabilities to certain areas regarding property and assets; experience has shown that their right to equal opportunities in this respect is regularly violated.

*“5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.”*

In this respect, the CRPD has followed the method employed in the Convention on the Elimination of all Forms of Discrimination against Women, which contains a similar reference in article 15.2 regarding the legal capacity of women in civil matters, and more specifically regarding concluding contracts and administering property<sup>30</sup>.

This has important implications insofar as legal capacity to administer assets is absolutely essential for any person, and particularly for women’s independence. The safeguard in this provision places an obligation on states to ensure the support needed to achieve this goal is delivered, as well as to guarantee non-discrimination on the grounds of disability in access to bank loans, mortgages and all other types of financial credit.

### **1.2. The main obstacles to exercising legal capacity**

There can be no doubt in legal terms (at least in the international human rights framework): women with disabilities have legal capacity; women with disabilities are rights holders; women with disabilities are entitled to exercise these rights; and women with disabilities have the right to support, if it is required, to exercise all their rights.

Nevertheless and despite such legal clarity, sociologically women with disabilities face various barriers that lead to violations in the exercise of legal capacity.

There are several ways to classify barriers<sup>31</sup>. In this chapter I will distinguish between architectural barriers, communication barriers and attitudinal barriers, bearing in mind,

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<sup>30</sup> Article 15.2, Convention on the Elimination of all Forms of Discrimination against Women.

<sup>31</sup> The concept and classification of barriers is addressed in DE ASIS ROIG, R., et al., *Universal accessibility in Law*, op. cit.

however, that all these barriers are normally present and that they interact. To give just one example, let us consider transport: barriers include physical aspects but go further and are akin to different links in a long chain. Eliminating barriers would involve ensuring accessibility in the specific means of transport (bus, train, aeroplane, boat, and so on), but also in the communication and information processes (the communication methods of the transport system in question must be accessible, for example available in braille or easy-to-read format, or through sign language, etc.) and, furthermore, customer care services must also be free of attitudinal barriers (that is to say the people delivering these services must be sensitive to the needs and rights of persons with disabilities and trained in dealing with diversity in terms of people and circumstances).

The same occurs in legal capacity: the pathway is a chain made up of links. However, the main barriers women with disabilities must face in exercising their legal capacity are communication barriers (lack of accessibility in communication processes when the individual wishes to communicate and express wishes, needs and preferences) and, above all, attitudinal barriers, which include in some cases legal barriers arising as a result of prejudices and pre-conceived images of women with disabilities, legal rulings which are a consequence of legal interpretations based on these prejudices and stereotypes, a lack of trained staff, lack of support and no consideration of the gender perspective for exercising legal capacity, among many others.

Although women with disabilities must confront this type of barriers in order to exercise their right to legal capacity and enjoy all their rights, international law has focused on two areas. The first is related to personal rights and here the gender perspective plays a key role. The second is related to the right to property and assets, and already decades ago CEDAW underlined the need for protective measures to combat discrimination as a result of the rights violations to which women were being subjected in this area.

As has been pointed out, the Convention on the Elimination of all Forms of Discrimination against Women placed particular emphasis on protecting women's right to exercise legal capacity in the area of property. CEDAW acknowledges that in civil matters, women have an identical legal capacity to that of men and the same entitlement to exercise this capacity. In particular, states are obliged to recognise equal rights for women in entering into contracts and administering goods, and they are obliged to treat them equally in all stages of procedures in courts and tribunals<sup>32</sup>.

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<sup>32</sup> Article 15, Convention on the Elimination of all Forms of Discrimination against Women.

This provision makes sense in the historic context in which it was adopted, when women's ability to exercise rights related to legal affairs was limited and they did not enjoy access to their assets, and in some cases could not administer them. Similarly, the CRPD introduces an obligation to take all appropriate and effective steps to guarantee the rights of people with disabilities, on an equal footing with others, to own and inherit property, retain control over their own economic affairs, and have access on an equal basis with others to bank loans, mortgages and other forms of financial credit, as well as ensuring that persons with disabilities are not arbitrarily deprived of their property.

However, such injustices are aggravated in the case of women with disabilities by violations of their right to legal capacity in relation to personal rights, that is to say those rights concerning personhood which are so intimately linked to the individual, which are born when she is and cannot be separated from her throughout her existence as it would result in loss or denigration of her personhood. They include, among others, the right to life, to identity, to integrity, to privacy, to honour, to one's name, one's own image, marital status and the right to dignity itself<sup>33</sup>.

For women, having a disability is often viewed negatively in order to make it impossible for them to enjoy these rights. Women with disabilities are discriminated against currently 'on the basis of disability' when they exercise their right to motherhood, in decisions related to reproduction, in exercising their sexuality, in shaping their identity, in the right to privacy and in many others.

In consideration of the discriminatory situations described above, the International Convention on the Rights of Persons with Disabilities stresses the need to guarantee certain personal rights, including the right to dignity, the right to keep one's identity (article 3)<sup>34</sup>, the right to one's image (article 8)<sup>35</sup>, the right to liberty, including the right

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<sup>33</sup> BIDART CAMPOS, G.J., *General theory of human rights*, Mexico, UNAM, Instituto de Investigaciones Jurídicas, 1993, page 79.

<sup>34</sup> "The principles of the present Convention shall be:

(a) *Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;*

(b) *Non-discrimination;*

(c) *Full and effective participation and inclusion in society;*

(d) *Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;*

(e) *Equality of opportunity;*

(f) *Accessibility;*

(g) *Equality between men and women;*

(h) *Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.*", CRPD, article 3.

<sup>35</sup> "Awareness-raising.

1. *States Parties undertake to adopt immediate, effective and appropriate measures:*

to freedom from exploitation, violence and abuse (article 16)<sup>36</sup>, the right to physical and mental integrity (article 17)<sup>37</sup>, the right to identity (article 18)<sup>38</sup>, the right to privacy

(a) *To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;*

(b) *To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;*

(c) *To promote awareness of the capabilities and contributions of persons with disabilities.*

2. *Measures to this end include:*

(a) *Initiating and maintaining effective public awareness campaigns designed:*

(i) *To nurture receptiveness to the rights of persons with disabilities;*

(ii) *To promote positive perceptions and greater social awareness towards persons with disabilities;*

(iii) *To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;*

(b) *Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;*

(c) *Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention; (d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.”, CRPD, article 8.*

<sup>36</sup> *“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.*

3. *In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.*

4. *States Parties shall take all 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 reintegration 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.*

5. *States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.”, CRPD, article 16.*

<sup>37</sup> *“Protecting the integrity of the person.*

*Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.”, CRPD, article 17.*

<sup>38</sup> *“...2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.”, CRPD, article 18.*

(article 22)<sup>39</sup>, the right to form a family, be a mother and retain one's fertility (article 23)<sup>40</sup>, and the right to sexual and reproductive health (article 25).

However, these rights will remain a utopian pipedream if gender is not mainstreamed and if one is unable to exercise one's legal capacity and enjoy the support measures one needs.

There is a common strand in violations of these rights in the case of women with disabilities: they are viewed as weak, asexual, child-like women - subjects/objects of

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<sup>39</sup> "1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.", CRPD, article 22.

<sup>40</sup> "Respect for home and the family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.", CRPD, article 23.

protection - arising from their will being replaced, or even in prior measures, and preventing women with disabilities from discovering their own will (because exercising freedom is a learning process which many women with disabilities are not given the chance to enjoy).

Women with disabilities face legal barriers in those countries where the law itself allows them to be substituted in decisions involving their right to form a family. Laws also permit them to be deprived of their liberty without their free and informed consent (that of their representative is enough), or subjected to medical treatment without their informed consent (again, their representative's consent suffices). Or laws may allow women with disabilities to be subjected to forced sterilisation (that is to say, without having given their free and informed consent). On this last issue, the Committee on the Rights of Persons with Disabilities expressed its opinion recently when, in September 2011, it urged Spain to abolish this practise as it is a violation of the CRPD<sup>41</sup>.

These legal barriers are discriminatory and violations of human rights and, with the Convention now in force, contrary to article 12. This is why legislation is needed to eliminate them; in the meantime, they should be declared inapplicable by the judiciary. In addition to the legal barriers mentioned above, women with disabilities face attitudinal barriers when verdicts and rulings fail to take the points raised above into account: when they do not have the support they need to empower themselves and understand and exercise their right to decision making; when there are no guaranteed support measures in place to prevent situations of exploitation, violence and/or abuse, or when women are not offered tailored support to address such situations; or when available mechanisms and services do not consider their needs or the fact that in many cases the exploitation, violence and/or abuse is perpetrated by the person caring for that woman.

This does not just happen in the family; the responsibility extends to practitioners from the health sector, legal systems and education, who, through dogmatic discourse and from positions of power, continue to subrogate the will of women with disabilities.

### **1.3. Accessibility, reasonable accommodations and support for decision-making**

The obstacles faced by women with disabilities when they wish to exercise their rights are the result of society being designed to suit the needs of the standard person

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<sup>41</sup> Committee on the Rights of Persons with Disabilities, Sixth session, 19-23 September 2011, Consideration of reports submitted by States parties under article 35 of the Convention, Concluding observations of the Committee on the Rights of Persons with Disabilities, 2011CRPD/C/ESP/CO/1, paragraphs 37 and 38.

(the model is generally, among other things, masculine and without disability). We do have some strategies involving a broad and inclusive vision of human diversity to overcome these barriers.

The main strategy at our disposal is universal accessibility, which ensures everyone is engaged, enjoys access and participates. It is implicit in the exercise of rights and part of the substance of each right.

There are two complementary strategies to achieve universal accessibility: universal design (for all, both men and women) and reasonable accommodation.

Universal design consists of conceiving or designing, from the very outset, environments, processes, goods, services, objects, instruments, devices and tools so that they can be used by everyone. Through universal design we aspire to universal accessibility: it is a means or an instrument to reach that goal<sup>42</sup>.

Reasonable accommodations are those measures whose purpose is to adapt the environment to the specific needs of certain people who, for different reasons, find themselves in particular circumstances. They are measures that cannot be anticipated in the universal design process. In the same way as with accessibility, the concept of reasonable accommodation should not be limited just to gender and disability as any individual can be (and is) subject to reasonable accommodation<sup>43</sup>.

Bearing the above in mind, we could say that universal accessibility is the goal we aspire to, universal design is a general and prior strategy to achieve it, and reasonable accommodations are an individualised strategy which come into play when universal design does not secure accessibility<sup>44</sup>.

These concepts are sufficiently developed in architectural and communication accessibility, but less so in attitudinal accessibility. In the matter at hand here, legal capacity and women with disabilities, there is another strategy we can use as we seek to achieve universal accessibility: support systems.

What, then, are these systems? The support model set out in the CRPD starts with the premise that the individual does not need protection measures that deprive him or her of the exercise of legal capacity; protection measures aim rather to deliver the support needed to make that individual with disabilities equal to others. It involves creating or adapting tools to guarantee universal accessibility for people with

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<sup>42</sup> DE ASIS ROIG, R. and PALACIOS, A., *Human rights and dependence*, Madrid, Dykinson, 2007, page 63.

<sup>43</sup> *Ibid.*

<sup>44</sup> *Ibid.*

intellectual or psychosocial disabilities in exercising their legal capacity; in other words taking decision by themselves with the support each person needs. From this point of view, it is easy to see how these measures, extremely varied in nature, need not necessarily be provided for in legislation; they can perhaps also be delivered through social service provisions<sup>45</sup>.

Having said this, we must be conscious of the fact that the support measures the CRPD forecasts are complex and will require not just legal reform but also, and especially, political action on the part of states to deliver, among other things, the training and financial resources required. In addition, for support measures to be successful and effective they must be adaptable to the particular personal and social circumstances of each woman with disabilities - and for this to happen we must distinguish between different types of 'support'.

This differentiation must, first of all, be based upon the type of act and, secondly, on the most suitable type of support person. In relation to the former, it is important to differentiate between major events in the life cycle (marriage, motherhood, medical operations, buying or selling a house, donations, etc.) and everyday events (daily shopping, travelling, joining a sports club, etc.). As regards the latter, women with disabilities need to be offered different types of support people who can adapt to their particular circumstances, for instance a personal assistant, assistance from a relative, a trusted friend or a group of friends, an association or an ombudsperson...these are just some of the many options.

It should be made clear that accessibility, universal design and support systems are far from ideal for women with disabilities. One clear example of this is personal assistance. Even in countries where this right is guaranteed by law, regulation takes disability into account but does not consider the gender perspective. Spain is a good example: when legal provision was made for personal assistance the lack of gender perspective was noticeable - the specific needs of women with disabilities were absent throughout, including the exercise of the right to motherhood (no small issue)<sup>46</sup>.

The law focuses on a type of personal assistance to facilitate paid work and other activities that take place outside the home. However, we cannot forget that for people with disabilities - both men and women - independent living means both the opportunity to keep up one's private relationships as well as take part in the public

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<sup>45</sup> See BARRIFFI, F., *Legal capacity and disability: seen through comparative law*, in *Legal capacity, disability and human rights: a reappraisal in light of the International Convention on the Rights of Persons with Disabilities*, BARRIFFI, F. y PALACIOS, A., editors., page 317 on.

<sup>46</sup> Articles 2 and 19 in Act 39/2006, dated December 14th, to promote personal autonomy and care for persons in situations of dependence.

world of work<sup>47</sup>. That is why it is vital to mainstream the gender perspective as we see support systems being developed currently in different states through legislation, pilot schemes, jurisprudence, etc.

#### **1.4. Protection to exercise legal capacity in the face of violence and abuse**

Women with disabilities are normally subjected to a double form of disability based on gender and disability both in the public and private spheres. Rules, practises, programmes and policies rarely consider this double-edged discrimination. There is still a lack of awareness regarding multiple forms of discrimination, which tend to be addressed separately and not viewed as a whole in all their complexity<sup>48</sup>. Furthermore, it is worth recalling that violence and traditional practises against women may cause disability, while violence against a woman with disabilities may aggravate the disability<sup>49</sup>.

Women with disabilities are more likely to be victims of gender-based violence and abuse and face greater difficulties in accessing information and reporting these situations<sup>50</sup>. These difficulties, when indeed it is not impossible, are not due only to architectural and/or communication barriers, but also the result of psychological factors as in many cases the abuser is the carer and/or personal assistant.

Reviriego Picón and Fernández point out how women with disabilities have to overcome serious hurdles to report abuse because of communication difficulties and face barriers to accessing information and guidance; they have lower self-esteem and are looked down upon as women; there is conflict between the traditional roles assigned to women and a denial of these roles in the case of women with disabilities; they depend to a greater extent on assistance and care from others; they are afraid to report abuse as they fear breaking links and losing assistance; their reports are given less credence in some circles; and they often live in environments where violence is able to flourish: dysfunctional families; institutions; residences; and hospitals<sup>51</sup>.

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<sup>47</sup> MORRIS, J. (ed.), *Encounters with strangers: feminism and disability*.

<sup>48</sup> RANGUITA DE SILVA DE ALWIS, *Disability Rights, Gender, and Development: a Resource Tool for Action*, UN CRPD/DESA, UNFPA, Wellesley Centers for Women, 2008, page 71.

<sup>49</sup> *Ibid.*

<sup>50</sup> REVIRIEGO PICON F. and FERNANDEZ, S. P., *Gender-based violence and disability*. Available at: <http://www.articulo12.org.ar/documentos/trabajos/comision%20IV/4-reviriego.pdf> (January 2012).

<sup>51</sup> *Ibid.*

Now, do laws, public policies and programmes acknowledge this reality? The answer is that almost always they do not. These and other questions should be considered when formulating a comprehensive approach that truly responds to the needs of women with disabilities.

The CRPD takes this problem on board and obliges States Parties to adopt the legislative, administrative, social, educational and other steps needed to tackle the problem. It also imposes an obligation to introduce 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 are to ensure protection services are age-, gender- and disability-sensitive<sup>52</sup>.

As a remedial measure, the CRPD compels states to take all appropriate steps 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 reintegration 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. Finally, the Convention requires effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted<sup>53</sup>.

However, when formulating these measures to prevent and tackle violence and abuse on women with disabilities, both the gender and the disability perspectives must be properly mainstreamed. To achieve this we must first of all remember that persons with disabilities form a heterogeneous group. This is a complex question which is normally simplified by *invisibilising* certain disabilities (especially intellectual and psychosocial disabilities). Secondly, the gender perspective poses a real challenge because the gender concept was developed (and is applied even today) without taking into consideration people with disabilities.

Consequently, if we wish to protect and safeguard women with disabilities' right to exercise legal capacity, it is not enough to combine existing tools to eliminate both causes of discrimination; the pathway is far more complex and women with disabilities must also be part of the journey.

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<sup>52</sup> Article 16, CRPD.

<sup>53</sup> Ibid.

As the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union says, to achieve this aim we must train male and female practitioners and professionals working in protection services to combat violence and sexual abuse on the specificities and concrete needs of women and girls with disabilities, with a specific focus on their diversity and heterogeneity. This training should also be made available to all professionals working directly with women and girls with disabilities (in their organisations, care centres, residences, homes for older people and schools, among others).<sup>54</sup>

At the same time, training is also needed for practitioners and other staff involved in the subsequent process, both when the case is reported and during the police and legal proceedings which are initiated by reporting the case. This is related to a broad concept of access to justice which will be addressed in the next section, but it is important here to underline the need for the woman, throughout the process, to enjoy full access, reasonable accommodations and, above all, to have backing and personalised support for decision making.

Among the varied types of support, informal networks play a valuable role. We are all part of a wide range of social networks, many involving affective support. From birth and during our entire lives we move from network to network - it is a vital part of our development as individuals. Many of these networks run in parallel to the institutions governing our society, and while networks cannot be considered more important than family, the truth is that both individuals and families are linked to multiple social networks individually or collectively<sup>55</sup>.

There is a body of empirical evidence highlighting how important support networks are in terms of quality of life for people in situations of vulnerability. Networks not only improve objective conditions by providing material and instrumental support; they also have a significant emotional impact. As regards this latter point, for instance, the perceptions older people who form part of social networks develop with respect to key social roles is considered a key factor in their quality of life<sup>56</sup>.

As the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union points out, the creation and development of local, national, European

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<sup>54</sup> Chapter 6, paragraph 6.5, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers.

<sup>55</sup> GUZMAN, J.M., HUENCHUAN, S., *Social support networks for older people: a conceptual framework*, CELADE-División de Población de la CEPAL, presentation, *Old Men and Women: participation, citizenship and social inclusion* symposium at the 51st International Congress for experts on America, Mexico, Universidad Nacional Autónoma de México. Available at: [http://www.cepal.org/celade/noticias/paginas/9/12939/EPS9\\_JMGSHNVMO.pdf](http://www.cepal.org/celade/noticias/paginas/9/12939/EPS9_JMGSHNVMO.pdf) (20/02/2012).

<sup>56</sup> Ibid.

and international networks of women with disabilities would be an important step forward in information sharing and dissemination, raising awareness and motivation and fostering empowerment for women with disabilities to become actively involved in movements forming part of organised civil society (awareness raising, the media and social image)<sup>57</sup>.

## 2. EFFECTIVE ACCESS TO JUSTICE

How can women be fair and generous when they are slaves to injustice?

**MARY WOLLSTONECRAFT**

### 2.1. The main obstacles to accessing justice

The right to justice is, in addition to an autonomous right, instrumental in realising other rights such as civil, political, economic, social and cultural rights. As Ana Lawson says, when the right to justice is denied, the outcome is the ‘civil death’ of the individual<sup>58</sup>.

The right to justice (both the autonomous and the instrumental dimensions) is a fundamental human right which essentially covers effective access by individuals to “systems, procedures, information and places used to administer justice”<sup>59</sup>.

Effective access does not only refer to the individual as an administered person, but also to the individual as a part of the administration. Historically, persons with disabilities, and especially women with disabilities, have been denied access to justice and equal treatment by courts, tribunals, legal practitioners, prison systems and others involved in administering justice, not only when attempting to access justice to seek reparation, but also when aspiring to become judges or to take on other positions in the field of legal administration. As such, various barriers restrict the opportunities people with disabilities have to make use of the justice system and also limit and/or impede them from contributing to the administration of justice, society and the community<sup>60</sup>.

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<sup>57</sup> Chapter 2, paragraph 2.3, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers.

<sup>58</sup> Lawson, A. “*The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn*”, 34 Syracuse J. Intl. L. & Com. 563, 573, 2007.

<sup>59</sup> ORTOLEVA, S., “*Inaccessible justice: Human Rights, Persons with disabilities and the legal system*”, ILSA Journal of International & Comparative Law, Vol. 17:2.

<sup>60</sup> Ibid.

The right to access to justice is present intrinsically in all human rights treaties<sup>61</sup>. Articles in these treaties and their interpretation by the relevant committees formed the underlying basis for CRPD article 13, which seeks to address the historic exclusion of persons with disabilities from justice by proposing the following:

**“Article 13 - Access to justice**

*1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.*

*2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.”<sup>62</sup>*

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<sup>61</sup> The Declaration of Human Rights includes the right to access to justice in several articles, although it is not explicitly referenced. Article 7 on equality before the law, article 8 on the right to an effective remedy, article 10, which guarantees the right to a fair trial in both criminal and civil proceedings; the International Covenant on Civil and Political Rights establishes this right in article 14 (all persons shall be equal before courts and tribunals). Article 14.2, f sets out, in relation to court proceedings, the right to have the free assistance of an interpreter if the individual cannot understand or speak the language used in court. Article 16 holds that everyone shall have the right to recognition everywhere as a person before the law; In general comment number 13, the Human Rights Committee acknowledges the importance of communication in the judicial process when a person cannot understand a language; although the International Covenant on Economic, Social and Cultural Rights does not have a specific article on access to justice, in its general comment number 9 it recognised the importance of judicial or administrative remedies; the Convention on the Elimination of all Forms of Discrimination against Women also recognises (article 15) the right to equality between men and women under the law and in courts of law. In its general comment 21, the CEDAW Committee sets out the fundamental importance of the rights of women in justice systems. For instance, it recognises that without effective access to justice, there is no way of taking steps to counteract and/or remedy gender-based violence; the Committee on the Elimination of Racial Discrimination addressed the right to equal treatment in tribunals, enshrined in article 5 of the Convention, in its general comment number 20. Furthermore, in general comment number 25 it pointed out the significant role played by multiple discrimination on the basis of race and other factors. It also affirmed that racial discrimination does not affect men and women in the same way; the Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities addresses eliminating discrimination in exercising the right to and the administration of justice in article III; the European Convention for the Protection of Human Rights and Fundamental Freedoms protects the right of all persons to effective recourse.

<sup>62</sup> Article 13, CRPD.

The CRPD also lists a number of obligations for States Parties and introduces a series of inter-related rights regarding equality, such as the importance of overcoming stereotypes, ensuring accessibility, and equal recognition as a person before the law.

If we follow the classification system we used when we looked at legal capacity, we can say that women with disabilities are faced with a series of barriers which result in their right to access justice being violated: architectural barriers, communication barriers and attitudinal barriers. In line with Ortoleva, we can see that the main obstacles are:<sup>63</sup>

– When women with disability look for information or want to learn how the legal system works: information on human rights, the legal system, and the way in which one can claim one's rights, are rarely designed with the gender perspective in mind, nor are they available in accessible formats for women with disabilities (architectural, communication and attitudinal barriers);

– When organisations of persons with disabilities advocate for disability rights: the slogan 'nothing about us without us', which is explicitly reflected in the CRPD, is not a reality in procedures, laws and policies regarding access to justice and women with disabilities. This is the result of a lack of measures to ensure persons with disabilities can participate in these processes, as well as the lack of a gender approach in the few cases when organisations actually do engage in the process;

– When they are awaiting trial: availability, affordability and adaptability are the three main challenges people in situations of vulnerability face in obtaining legal assistance. A fourth obstacle in this case is ignorance on the part of legal practitioners of how to deal with clients with disabilities and lack of knowledge on legal questions regarding women with disabilities (in law faculties gender is not generally mainstreamed, nor are students taught about respect for disability rights or how to work with clients with disabilities). In addition, many women with disabilities live in poverty, and this prevents access to justice as they cannot afford to pay legal fees. Consequently, access to justice vanishes if there is no access to free legal counsel, and this is a far more serious situation for women with disabilities due to their ignorance of the legal system and the extreme poverty in which many live;

– When they act as lawyers: although it is true to say there are few women lawyers with disabilities due to the fact that this group has historically been excluded from further education (lack of accessibility and reasonable accommodations due to

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<sup>63</sup> ORTOLEVA, S., *Inaccessible justice: Human Rights, Persons with disabilities and the legal system...*, op.cit. Although the author enumerates these barriers for people with disabilities in general, many of them are noticeably aggravated when disability and gender (woman) interact.

disability and gender, among other reasons), discrimination and exclusion continue to be commonplace when they do work as lawyers;

– When they are denied the opportunity to be jurors: the responsibility of being a juror is a fundamental right in most countries. When a person with disabilities is denied that right he or she is being denied the chance to serve the community. All types of barriers are present in this respect - architectural, communication and attitudinal barriers;

– When they are unable to enter buildings where justice is administered: the lack of physical accessibility to courtrooms and other premises related to the legal system is a major problem which is symbolic of a serious issue;

– When they are accused and/or in custody: the difficulties women with disabilities face in society are aggravated noticeably when they are deprived of their freedom. In the same way as others in society, women with disabilities also confront the legal system as the accused or when in custody. However, prisons and other premises in the prison system are inaccessible and the reasonable accommodations needed to take into account gender and disability and ensure women with disabilities are not discriminated against in the prison system are not adopted<sup>64</sup>;

– When they are victims of crime: unfortunately we have no up-to-date international data in this field, but the information we do have leaves no room for doubt: women with disabilities are more exposed to crime than others<sup>65</sup> and, once a crime has been committed, police and judicial systems are far from ideal in resolving the situation. Inaccessibility, lack of disability-awareness training to deal with women victims with disabilities, no gender perspective, no sign language interpretation available or alternative means of communication, among many others, demonstrate clearly the discrimination and double victimisation women with disabilities face.

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<sup>64</sup> Ortoleva highlights two key United Nations documents dealing with the need to understand that there are people who are deprived of freedom and who need measures and steps to be taken to ensure their freedom is removed in conditions of dignity, without discrimination and with respect for diversity and identity. To achieve this, and among other measures, accessibility needs to be guaranteed and reasonable accommodation secured. See *Handbook for prison managers and policymakers on women and imprisonment* (2008) and *Handbook on Prisoners with Special Needs* (2009), Criminal Justice Handbook Series, UN. Available at [http://www.unodc.org/pdf/criminal\\_justice/](http://www.unodc.org/pdf/criminal_justice/). Despite the name of the handbook, it is reported that prisoners with special needs are in fact the vast majority. It is highlighted that in several countries, between 50% and 80% of all prisoners have a mental disability.

<sup>65</sup> Harrell, E. and Rand, M.R., *Crime against people with disabilities*, (U.S. Department of Justice, Bureau of Justice, Stat., 2007). Available at: <http://bjs.ojp.usdoj.gov/content/pub/pdf/capd07.pdf> (last visited Feb. 27, 2011).

It is also worth stressing that court judgements that fail to consider the gender perspective or the social model of disability and ignore the rights laid out in the CRPD and CEDAW constitute serious attitudinal obstacles which seriously undermine commitments by other governmental departments and agencies to adhere to international human rights law. The obligations states acquire through international human rights treaties are to be met, and if they cannot be met immediately states must take legal or other steps, including court rulings, to make these commitments a reality<sup>66</sup>.

## **2.2. Accessibility, reasonable accommodations and support to ensure access to justice**

As we explained above, the essence of the right to access to justice is broader than accessibility, reasonable accommodations and support measures, although these are all part of it.

Accessibility in all its aspects, however, is a prerequisite for access to justice. Ortoleva approaches law from two perspectives: as a form of oppression and as a form of liberation. This is the case for women with disabilities (more so even than for women without disabilities and men with disabilities). In some cases, the law acts as a remedy against injustice and discrimination (liberation), while in others it prolongs injustices (oppression). For instance, a woman with disabilities who feels she has been discriminated against in her right to work can turn to the law to seek a remedy. However, if the system fails by not adopting reasonable accommodations or due to any other type of discrimination, denial of access to the legal system also involves a refusal to offer her protection for her right to employment. This reflects the fact that the right to access to justice, just like the right to have her legal capacity recognised and, in short, in the same way as the rest of her human rights, are indivisible, interdependent and interrelated<sup>67</sup>.

Conversely, restrictions to other rights will have an impact on the right to access justice. So, if a woman has no accessible means of transport it will be very difficult for her to reach the place where justice is administered. If a woman does not have her right to legal capacity recognised and does not enjoy appropriate support and reasonable accommodations, she will not be able to file complaints or act to defend

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<sup>66</sup> CEA EGAÑA, J., *Human rights treaties and the political constitution of the Republic*, *Ius et Praxis*, Talca, Universidad de Talca, Facultad de Ciencias Jurídicas y Sociales, 1997, pages 81-92.

<sup>67</sup> ORTOLEVA, op. cit.

her right to justice. Consequently, a correct interpretation of the right to access to justice means establishing a direct link with article 12 of the CRPD as due process must, by its very nature, consider the legal capacity of women and men with disabilities as they manifest their will in courts of law and other parts of the legal system, including the respective support systems.

Given that many women with disabilities find themselves dependent on the person who is providing assistance, who is also the person responsible for the assaults and abuse, there is a need to ensure independent communication to enable the woman to report such situations and guarantee immediate temporary referral to comprehensive care centres until the case has been resolved. To achieve this, it is first necessary to ensure the basic tenets of accessibility are in place for women with disabilities, and they must also be granted access at all stages of the process to support systems and technologies for the method of oral communication they choose, including sign language interpreters and guide-interpreters for people who are deafblind, in order to ensure proper communication with police and justice personnel<sup>68</sup>.

Services, including services for violence against women and childcare services, must be provided in all languages, forms and formats possible and must be easily-accessible and safe. If such services are provided by means of a telephone hotline or tele-assistance, they should also be accessible for deaf and deafblind women<sup>69</sup>.

Documents related to women and girls with disabilities and their rights must be understandable and available in local languages, sign language, braille, augmentative and alternative formats of communication, and all other accessible modes, means and formats of communication, including electronic ones<sup>70</sup>. Equally, all targeted services and material aimed at women with disabilities must also be accessible to women and girls with intellectual disabilities. Easy-to-read formats, pictograms or having a support person to assist with communication, when necessary, are resources which should be considered to address this matter properly<sup>71</sup>.

This is why accessibility safeguards form part of the right to justice, and it is the same with reasonable accommodations. While amending legislation in accordance with the existing procedures in each national legal system is the duty of legislators, the judiciary will be responsible for implementing accommodations in procedures set out in law.

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<sup>68</sup> Chapter 5, paragraph 5.6, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers.

<sup>69</sup> *Ibid.*, Chapter 3, paragraph 3.10.

<sup>70</sup> *Ibid.*, Chapter 3, paragraph 3.13.

<sup>71</sup> *Ibid.*, Chapter 3, paragraph 3.12.

Nevertheless, as Soledad Cisternas has underlined, the jurisdictional pyramid shall directly prevail in the implementation of article 13 in two other ways. The first is related to regulations: by virtue of the disciplinary and financial powers the judiciary has been granted, it is entitled to set its own internal rules to regulate how courts of law operate. In this respect, the judiciary may self-regulate to complement the provisions of the law and in accordance with standard practise in their respective areas of competence. Secondly, the judge should apply his or her common sense and order accommodations in each case he or she is responsible for, even though there may be no provision in law or in the judiciary's own internal rules. Cases normally vary greatly and some adaptations may not be fully regulated before occurring, so the role of the judge in each individual case is decisive in such circumstances<sup>72</sup>.

As Ganzenmüller points out, the need for real reform in judicial systems to ensure people with disabilities are fully protected requires a new methodology whereby 'new spaces' are created to ensure justice is truly accessible. This ranges from suitable means of transport allowing citizens to travel to legal premises to physical accessibility of the building, waiting areas, removal of steps, platforms and benches in areas where practitioners perform their duties, in comfortable and accessible areas<sup>73</sup>.

At all stages of the process, access to support systems for decision making shall undoubtedly determine if the woman dares to enter the dreaded unknown which is ever present, even when considering the possibility of turning to legal systems which appear to treat her vital needs with disdain.

### 2.3. Training programmes

To ensure women with disabilities are able to exercise their rights and are not subjected to discrimination as a result of their gender or disability, all agents involved either directly or indirectly in legal systems must be sensitive, trained and sufficiently qualified. The CRPD, conscious of shortcomings in this respect, includes concrete provisions in this area under the heading 'awareness raising'. Article 8 of the CRPD therefore states that:

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<sup>72</sup> CISTERNAS REYES, S., *International obligations on States Parties by virtue of article 12 of the CRPD, linked with article 13, and their impact on national law*, in *Legal capacity, disability and human rights*, op. cit., pages 237 and following pages.

<sup>73</sup> GANZENMÜLLER ROIG, C., *Capacity on trial and the Public Prosecutors Office as defender of people with disabilities in protecting and guaranteeing fundamental rights*, in *Legal capacity, disability and human rights*, op. cit., pages 477 and following pages.

## **“Article 8 - Awareness-raising**

1. *States Parties undertake to adopt immediate, effective and appropriate measures:*

(a) *To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;*

(b) *To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;*

(c) *To promote awareness of the capabilities and contributions of persons with disabilities.*

2. *Measures to this end include:*

(a) *Initiating and maintaining effective public awareness campaigns designed:*

(i) *To nurture receptiveness to the rights of persons with disabilities;*

(ii) *To promote positive perceptions and greater social awareness towards persons with disabilities;*

(iii) *To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;*

(b) *Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;*

(c) *Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;*

(d) *Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.”*<sup>74</sup>

Awareness raising and training in this area are the first steps towards breaking down attitudinal barriers. In the case of administration of justice, all practitioners in the legal field must receive training in gender, disability and human rights.

First of all, thorough institutional reform is needed and legal research and analysis must include the gender and disability perspectives in line with the standards of international human rights law (and especially the CRPD and CEDAW). Legislation must be reviewed from this perspective and with the engagement of women with

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<sup>74</sup> Article 8, CRPD.

disabilities. All discriminatory practises, policies, regulations and legislation which either directly or indirectly, deliberately or accidentally, restrict or prevent women with disabilities from acting as witnesses, jurors, lawyers or judges must be amended<sup>75</sup>.

Male and female judges, lawyers and other legal practitioners should receive training: in addition to specific training on gender and disability, this requires disability rights and the gender perspective to be mainstreamed in training, education and career development programmes for all professionals in the justice system, the police and the prison system.

Women with disabilities should be given more opportunities to study law and other course leading to professions and positions in the administration of justice. Reasonable accommodations and other anti-discrimination measures must be in place to facilitate this.

Women with disabilities themselves should be involved and sufficiently self-represented in all awareness raising, education and training programmes.

### 3. RECOMMENDATIONS FOR POLICY MAKERS

In the first place, public policy formulation and implementation must undergo a paradigm shift in how they are approached and the gender and disability perspectives must be mainstreamed. To achieve this, it is vital that women with disabilities are involved both in the formulation phase and the subsequent implementation stage.

The paradigm shift involves not just implementing legislative reform, but making sure the core elements of the reform are sufficiently known and understood by those whose task it is to implement the reforms; to this end, one of the first public policies needed is a training policy.

The principle of mainstreaming must be adopted in this field; this means that both perspectives must be included in all areas, not just those normally identified as specific ones in terms of gender and disability.

### 4. RECOMMENDATIONS FOR LEGAL PRACTITIONERS

Male and female practitioners in the legal field must receive training in gender and disability from a human-rights based approach. It is therefore vital to reach a deeper

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<sup>75</sup> ORTOLEVA, op. cit.

understanding of international human rights treaties, including legal-philosophical training on the implications of the paradigm shift.

Disability rights and the gender perspective must also be mainstreamed in all training, education and career development programmes for professionals in the justice system, the police and the prison system.

Women with disabilities must be involved and self-represented in all these processes, so accessibility must be ensured, reasonable accommodations made and support systems put in place, where necessary, to enable them to exercise their right to legal capacity.

## 5. RECOMMENDATIONS FOR THIRD-SECTOR ACTIVISTS

The disability movement must check to ensure the gender perspective is appropriately mainstreamed within the movement itself, in its demands and decision-making processes. Women with disabilities must play a leading role in this process.

It is essential the movement offers support and training to women with disabilities on their rights and stands side by side with them in their struggle to realise these rights.

To ensure public powers become aware of these issues, women with disabilities must occupy more position of power within the disability movement.



# Chapter V

## VIOLENCE AGAINST WOMEN

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## Chapter V

### VIOLENCE AGAINST WOMEN

#### 1. CURRENT STATE OF PLAY

##### 1.1. The concept of violence against women

*Violence against women is a form of discrimination and a violation of their human rights. The term violence against women shall be taken to mean all acts of gender-based violence that result in, or are likely to result in, physical, sexual, psychological, or economic harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life<sup>1</sup>.*

Gender-based violence is the ultimate expression of inequality between men and women. It has a strong ideological basis and is structural in nature. The social construct of masculinity and femininity is based on gender, that is to say assigning different roles to different sexes. This construction defines, constitutes and promotes a number of thoughts, beliefs and behaviours around the feminine and the masculine and imposes a dichotomic division on the identity of subjects, who behave, think and act in line with the group to which they belong. The construct legitimises behaviours and sets patterns for relationships. It is ingrained in patriarchal societies where specific types of behaviour are acquired and reproduced on the basis of the woman-man dichotomy. It promotes a hierarchical structure in which the masculine sex is more important and has greater social prestige than the female sex.

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<sup>1</sup> Declaration on the Elimination of Violence against Women, Resolution number 48/104 adopted by the United Nations General Assembly (on the basis of the report submitted by the Third Committee - A/48/629). This definition is included in section 6.1 of the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union, 2011.

This ideology characterises masculinity as brave, wise, intelligent, strong, autonomous and independent, while femininity is defined by such things as caring, parenting, dependence and weakness. On the basis of these considerations, the masculine corresponds to the most highly-rated values and is associated with public spaces, dominance, power and control, while the feminine is linked to private spaces, is consigned to the background and is less visible, receives less protection and enjoys less influence. The feminine is undervalued. Dividing spaces in this way means men constitute the dominant group while women form the dominated group and are subjugated to the former.

Gender-based violence is a consequence of patriarchal systems in which an asymmetrical division of power enables, tolerates and justifies certain behaviour that helps shape the foundations for the hierarchical relationship between men and women. Gender-based violence is one of the worst blights on our society, not just because thousands of women are killed at the hands of their partners, but because there are many cases of women who are dead in life, women and their daughters and sons who suffer this violence daily.

Gender-based violence is not composed of isolated acts; it is part of a strategy whose ultimate aim is control and subjugation of women. It takes several shapes: it can be physical, psychological, sexual, economic, social...all leave their mark, although the mark is not always visible.

Gender-based violence occurs in a variety of contexts. The following, *inter alia*, are manifestations of this type of violence: violence on a woman perpetrated by her partner; sexual abuse of girls and boys (the former are more likely to be victims than their male siblings); sexual attacks; sexual harassment in the workplace; trafficking in women and involuntary prostitution; violence in situations of armed conflict; genital mutilation; forced marriages; virginity tests; dowry-related violence; and forced sterilisation.

Violence targeting women in general often goes unnoticed because it is performed subtly and is part of the normal social framework. Structural violence also exists, and the following are some examples of this sort of violence: use of sexist non-inclusive language overlooking women; obstacles which in practical terms prevent access to positions of responsibility; lower salaries than men for the same job; and reducing women to a mere body in advertising (objectification)<sup>2</sup>. These types of violence are commonly used on all women and go unnoticed by most people as certain behaviour

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<sup>2</sup> Objectification: a process consisting in turning the female body into an object or thing, thus dehumanising the person and removing all those qualities which allow us to be persons.

has been assimilated and has become the norm, thus making them very difficult to detect (microsexism).

Women are not the only people to suffer from gender-based violence. Men who do not conform to the dominating profile are also victims, as are the daughters and sons of women who are victims. If there are children in a situation involving gender-based violence, they are direct victims of the violence, either because they suffer attacks explicitly or due to exposure to violence. Children fall victim both to violence targeting them and violence against their mother, and this violence is highly likely to have a serious effect on them.

## 1.2. Violence against women with disabilities

As women, not all of us are exposed to violence in the same way; there are differences in each case which cause some women to be more vulnerable than others to certain types of attacks. Vulnerability to violence involves differences in the likelihood of suffering violence and the manner in which it is suffered, and causes situations of heightened defencelessness combined with greater risks.

The gender variable<sup>3</sup> is a determining factor in falling victim to sexist violence. If this variable combines and relates to disability the result is a group of women which is far more exposed to violence. The violence suffered by women with disabilities is invisibilised even in measures combating gender-based violence. A woman with disabilities suffers multiple discrimination: as a woman and as a woman with disabilities. This fact means that often a woman with disabilities enjoys no privacy, has her rights violated regularly and systematically, is isolated, is denied normalised access to culture and shared leisure activities, and is discriminated against when attempting to access the labour market.

When disability is discussed one single image is put forward. This constitutes labelling to classify, set aside and *distinguish* persons with disabilities from the rest of society. The term 'disability' is used to refer to any type of pathology which results in one or more disabilities, whether they be physical, intellectual or sensory. 'Disability' offers an overarching vision which fails to dig down to the particular and differentiate between disabilities included in 'disability': it is a viewpoint lacking insightfulness and unwilling to see.

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<sup>3</sup> Gender is understood to be the cultural construct of masculine and feminine characteristics that is to say the features a particular society attributes to and instils in men and women.

Women who have a disability do not constitute a homogeneous group. There is wide diversity within the group. That is why it is necessary to look at different realities and offer different types of support based on the particular characteristics of each individual. If we do not take different types of disability into account we could contribute to making discrimination worse. The violence marker depends on the degree of dependence.

Women with disabilities are, first and foremost, women who, in addition, have one or more disabilities. Consequently, they are affected in the same way as other women and, furthermore, due to their disability.

Disability may be present prior to the gender-based violence or it may be acquired after or due to the violence, in other words a disability caused by the abuse to which the woman is subjected. It could be a physical disability —deafness, for instance, is often caused by blows to the ears— or intellectual. Disability can also be a consequence of abuse suffered by the mother of the individual during pregnancy. When the disability is present prior to abuse, abusers often take advantage of the factors associated with the disability to carry the abuse out with greater impunity.

Many women feel their lives have been irrevocably affected by gender-based violence. They often suffer the effects for long periods. Some of the consequences are: a feeling that their quality of life has been noticeably restricted; negative self-assessment; affective, cognitive and behavioural dysfunction; career breakdown; deterioration in intimate relationships; altered states of beliefs and emotions about the world; and reduced engagement in pleasurable activities. In the case of women with disabilities, escaping from abusive situations is more difficult.

### *1.2.1. Characteristics*

Violence against women and girls with disabilities has the following characteristics:

- Women and girls with disabilities find it more difficult to gain awareness that they are victims of abuse and express this fact: this is due to the existence of different communication methods and barriers. They find it more difficult to reach places where information and guidance are available because of all types of physical, architectural, communication and mental barriers;
- There is a conflict between the roles assigned to the woman and a refusal to acknowledge these roles due to disability: physical appearance, the hallmark of our society, imposes strict norms and patterns which cause a wide range of

pathologies in women who do not conform to the rules it sets: anorexia, bulimia, rejection of one's body. In an attempt to remedy the situation and conform to the standards imposed, women and girls resort to violent extremes such as plastic surgery for aesthetic purposes. Many women with disabilities conform to a lesser degree with the artificial standards of beauty and this has a devastating impact on their self-esteem, leading them to reject their own bodies. Motherhood is expected of women, but is often denied to women with disabilities;

- Greater dependence on assistance and care: assistance and care provided by others and, in particular, the abuser. Emotional dependence forms part of abusive relationships, and notably so where women with disabilities are concerned. If we add emotional dependence to the dependence on care women with disabilities require, we can see an extremely high level of dependence;
- Fear of being abandoned and uncared for: if abuse is reported. This fear is combined with the feeling of gratitude the woman with disabilities is supposed to show for receiving assistance and, on the other hand, a desire not to rock the boat and cause problems to those closest to them if the 'carer' leaves. This means that the family often prefers the 'see no evil' maxim when it comes to abuse, because they would have to provide support and perhaps care for the person;
- Greater difficulties in defending themselves from the abuser: both physically and psychologically. Physically because their disability may prevent them from taking evasive action when faced with violence; for instance, a woman with a hearing impairment may receive no warning and be unable to react because she does not realise the abuser is approaching, and a woman with a visual impairment may not locate or see an abuser's gestures and may not be able to act accordingly to defend herself;
- Heightened isolation: at home or in institutions;
- Reduced opportunity to communicate and access information and new technologies: women with disabilities are more limited in this respect and have less chance of receiving personal and employment-related training;
- Lower rate of engagement in employment: thus creating greater economic dependence;
- Heightened economic violence: as they are refused access to their savings and allowances, others administer these funds for them;
- Greater risk of sexual exploitation;

- Less credence granted when reporting abuse: in addition to the lack of credence, it is an extremely difficult situation for professional personnel when faced with these cases. When abuse is reported, professionals prefer to believe that nobody would dare abuse a woman in such circumstances;
- Isolation increases the risk of violence: both in the family setting and in residences and institutions. Violence perpetrated by fellow residents, carers and others is commonplace in such centres;
- Gender denial: this constitutes one of the most severe acts of violence suffered by women with disabilities. The fact that they are thought to be *asexed* means they do not receive sex education and frequently share spaces which should be private with males.

There are a number of myths<sup>4</sup> in our culture which humiliate and destroy the identity of women who have some type of disability:

- Dehumanisation: they are treated as members of an inferior category, as if they were incapable of feelings, and as beings in a vegetative state;
- Damaged goods: women with disabilities are portrayed as damaged merchandise and, therefore, less worthy;
- Feeling no pain;
- Disability as a threat: they are seen as dangerous and a menace to society (in particular those with a psychosocial disability);
- Helplessness: image of a weak being, thus weak being, thus creating the circumstances for that person to become a victim.

The perception of women with disabilities as *imperfect, dependent and weak beings*<sup>5</sup> leads the perpetrator to believe that abusing a woman with disabilities is less important and less serious and that there is greater impunity. This, in turn, paves the way for women with disabilities to suffer even greater violence.

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<sup>4</sup> Violence and disabled women, report by Iglesias, M., Gil, G., Joneken, A., Mickler, B. and Knudsen, J.S., METIS Project, European Union DAPHNE initiative, 1988. Available at: [http://www.independentliving.org/docs1/iglesiasetal1998sp.html#\\_Toc446678988](http://www.independentliving.org/docs1/iglesiasetal1998sp.html#_Toc446678988) (consulted on 22-01-12).

<sup>5</sup> Ibid.

## 2. LEGAL FRAMEWORK

### 2.1. The 2006 United Nations Convention on the Rights of Persons with Disabilities

Paragraph q of the preamble to the United Nations Convention on the Rights of Persons with Disabilities recognises 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*' and that they suffer different types of discrimination. The Convention also acknowledges the need to include the gender perspective in all efforts towards promoting the full enjoyment of rights and liberties (preamble, paragraph s).

The Convention urges States Parties to take measures to promote women (article 6) and to take into account the interests of children (article 7) as women and girls with disabilities are subject to multiple forms of discrimination.

### 2.2. 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union, 2011

The manifesto addresses violence against women both in the home and beyond, by members of the family, by those responsible for their care and by strangers (article 6.2). It holds that all types of exploitation, violence and abuse constitute violence against women. It also explicitly includes forced sterilisation and coerced abortion as types of violence. The manifesto affirms the need to take into consideration diversity among women with disabilities with regard to their sexual orientation and identity (heterosexuals, lesbians, bisexuals and transsexuals) (article 6.4).

### 2.3. Spanish Organic Law on comprehensive protection measures against gender-based violence, 2004

In Spain the Organic Law on comprehensive protection measures against gender-based violence was a significant step forward in the fight against this evil. Among its guiding principles are measures targeting women with disabilities (article 2.k) to provide them with information in accessible and comprehensible formats. The economic rights recognised by the law include increased financial assistance for victims who are legally *handicapped*<sup>6</sup>.

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<sup>6</sup> This is the term used in article 27 of the law. We do not consider this term appropriate as it is demeaning and undermines the dignity of those to whom it is applied.

The law also makes reference to the need to incorporate the disability perspective in training courses for practitioners (article 47).

This legal recognition is the first step, but it is crucial to make further progress by promoting targeted measures for victims with disabilities and delivering effective and efficient support based on their needs. The last few years have seen great progress in the fight against gender-based violence by those involved in the political, legal and social spheres through the development of policies and measures to prevent and eliminate it. Nevertheless, it must be said that disability has not been included in these measures.

## **2.4. Differences in the concept of violence against women**

The concept of gender-based violence in the organic law is far more restrictive than the one in the manifesto, which offers wider and more effective protection to women with disabilities. The organic law contemplates only violence perpetrated by the partner or former partner (spouse or person connected by an affective relationship, even though they do not live together) (article 1), while among acts of violence against women with disabilities the 2<sup>nd</sup> manifesto includes those perpetrated by relatives, carers and strangers in the home and in institutions, thus taking into consideration that women and girls with disabilities may fall victim to particular forms of violence (article 6.2).

## **3. PREVENTING VIOLENCE AGAINST WOMEN WITH DISABILITIES**

Initiatives to prevent violence must include those measures necessary to combat violence as a whole and specific measures targeting women with disabilities, who are currently largely ignored. We set out below measures to prevent violence against women with disabilities:

### **3.1. Teach equality**

Education in equality forms the basis on which to combat and eliminate violence against women effectively: questioning and rejecting gender roles through proposals that take into account differences between individuals. Human rights should be the foundations on which society is built, and educating with the same standards is essential if we are to overcome inequality. It is the first step towards combating gender-based violence in order subsequently to call for the right to equality in all participatory social spheres.

### 3.2. Integrate diversity

Disability has traditionally been viewed through the lens of the medical model which conceived it as a *deviation* from the health standard. This model must be cast aside.

### 3.3. Shift the concept of disability to the environment

The concept of disability must be transferred to the environment instead of being considered a feature of the individual. The environment must integrate everyone and avoid discrimination by making space for diversity. In our societies disability is still seen as a characteristic of the individual, a 'defect' which defines the person with a disability (referred to as 'handicapped' or 'disabled') and condemns that person to a life on the edge of society, rather than viewed as an inability on the part of the environment to integrate all people in society.

Placing disability in the sphere of the environment implies forsaking the medical model as a means of explaining disability, a model which holds that women with disabilities are considered weak and are, therefore, unable to play an active role in society and ignored socially, thus perpetuating relationships based on dependence. We must seek to get rid of an ideology that intensifies the situation of defencelessness and discrimination faced by women with disabilities, and attempt to rethink all our actions and act constructively to resolve the serious problems we encounter by placing disability in the context of an environment that fails to adapt to people.

### 3.4. Gender roles

Make gender roles visible, overcome developmental differences based on the man-woman dichotomy (different skills and abilities based on occupying spaces), deobjectify women in the mass media and advertising...we must expose microsexism in our everyday lives and question it.

The frustration women with disabilities experience becomes greater when they are rejected socially and removed from the group of 'women', as it is constructed by patriarchy.

Exclusion from public spaces is further intensified when their role in private spaces is construed to be a passive one. This means that women with disabilities are also not 'socially suitable' for the role set aside and imposed upon women. They cannot be carers and must be 'cared'. Under the same parameters women with disabilities are considered 'unsuitable' to form a family, first of all because they are held to be

‘undesirable’, ‘unhealthy’ and do not conform to socially-imposed standards of beauty, and also because they are not considered ‘capable’ of taking on responsibility for caring and, therefore, motherhood, a right they are deprived of regularly due to their disability. Women with disabilities do not have the power to choose over their own lives and are subjected to forced sterilisation.

In addition, the power social images hold over women (beauty) places them once again in a disadvantageous position; the frustration felt by a women with disabilities who has also interiorised her gender role, due to the fact that beauty is synonymous with universal success leads to her constructing a self-concept and, as a result, to her suffering low self-esteem.

### **3.5. Independence, leadership and empowerment**

Education is the cornerstone of development to enhance independence and further empowerment for all women.

Exclusion from public spaces and resources exacerbates situations of poverty and vulnerability and perpetuates dependence. So, being sidelined from ‘productive’ employment in capitalist societies removes the opportunity to acquire and administer one’s own goods, while at the same time harming and jeopardising health in the widest sense of the word and women with disabilities’ wellbeing.

They are left aside and excluded from socio-political engagement because they are women (public space is reserved for men according to traditional social and cultural values) and for having a disability (persons with disabilities are thought of as ‘incapable’). This double barrier prevents the empowerment of women with disabilities, violates their rights and automatically excludes them from the system.

As a result of these considerations, it is necessary to equip women with disabilities with tools which allow them to take control over their bodies and lives. Strengthening leadership through training, education, specific positive action measures enabling them to take up positions of power, decision-making and responsibility...all are vital in order to boost and develop independence.

### **3.6. Sex education**

Denying sexuality is directly linked to violence. Human development cannot be conceived without sexuality and denying sexuality, an aberration which is widespread and tolerated by the system, constitutes one of the most invisible and harmful forms

of all the types of violence women with disabilities suffer. We should point out that in the account we have given so far there is a link between all forms of discrimination against women with disabilities and gender-based violence as they are practises which violate women's rights, damage their identity building, exclude them from the system and place them in vulnerable situations. Because of these practises women with disabilities remain invisible.

Women with disabilities are often considered to be asexual and neutral beings, and this does not happen in the case of men. Women with disabilities are thought to have no sexual desires and, at the same time, held to be unattractive as they do not conform to modern strict standards of beauty. They are not seen as desirable. They are denied the right to a private life. This abominable and harmful process of depersonalisation —which goes on quietly and in an underhand fashion under the socially-accepted pretext of protecting the woman— must be wholeheartedly condemned.

The perception that women with disabilities are asexual beings is a curious one as, at the same time, a very high percentage of women with disabilities are victims of sexual abuse and rape perpetrated by those close to them in their family and social environments. They are particularly vulnerable and subject to social invisibilisation, exclusion, dependence and isolation, circumstances which contribute to their being more likely to suffer abuse. Of all women with disabilities, women with intellectual disabilities suffer most. Women with disabilities cannot perform the role that, as women, they are supposed to but, nevertheless, they are victims of abuse and exploitation.

### **3.7. Isolation and invisibilisation**

Women with disabilities are put through a horrific process of isolation and confinement. This process is justified socially using arguments about protecting them.

In many places, and above all in rural areas and more isolated towns and villages, families decide to hide people with disabilities away in their homes so that they make the least possible contact with society. This situation is worse for women with disabilities as it creates a heightened sense of vulnerability and makes intervening extremely difficult. We do not have statistics on this issue as they rarely appear in public life.

### **3.8. Accessibility**

Women with disabilities are confronted by barriers which are not only physical. In this respect it is incumbent upon us to discuss accessibility in the widest sense of

the term, ranging from architectural barriers to accommodations in the media. Architectural (physical) barriers are also an undeniable social reality caused by how disability is viewed by society. Abandonment and neglect in urban areas must be reproached in the same way as overprotection, and independence must be fostered.

### **3.9. Romantic love**

The concept of romantic love we hold in our societies is highly destructive. It focuses on the idea of pain, suffering and hurt and helps to perpetuate very harmful relationships involving dependence. There is a loss of identity favouring the other party and love is portrayed as synonymous with giving oneself over completely to another person, thus destroying and ignoring one's social networks and giving priority to one's partner above everything else. It helps to give strength to destructive relationships, invisibilising and allowing violence to occur as part of the relationship. Jealousy and control over women (who are in turn programmed to make do with a role involving sacrifice and submission), combined with the isolation to which women are subjected, brings about relationships of dependence which have a far greater impact on women with disabilities due to the vulnerable situation in which they find themselves.

Love should be positive and constructive, not invasive. Relationships based on equality and founded on respect, in which each person has his or her own spaces, should be encouraged.

Questioning and revisiting gender roles (in workshops, by mainstreaming the gender perspective in all levels of teaching and education, along with an inclusive concept of disability), exercising one's autonomy and independence to gain back control over one's own body, and taking one's own decisions are fundamental and necessary tools in the fight against gender-based violence.

### **3.10. Furthering personal autonomy and independence**

Women with disabilities must be encouraged to become more autonomous and independent. We must leave behind social prejudices that affect women in general but have a greater impact on women with disabilities, leading them to play a passive role.

The system must move on from welfare-based models and promote autonomy, above all in the case of women, generally in a disadvantageous position, and with

respect to men with disabilities in particular. Empowerment is a key tool in promoting autonomy and independence.

Access to employment is linked to the right to independence, and every effort must be made to achieve and enhance access to work.

Women who receive allowances must administer them; others should not be allowed to perform this task and have access to their savings or allowance. Hidden economic violence is widespread in allowance administration.

### **3.11. Mainstreaming the gender perspective**

Mainstreaming gender in all areas is also essential in the fight against gender-based violence. The gender perspective must be included in all fields in order to visibilise the specific situation faced by women and overcome prejudices and discrimination.

### **3.12. Schools for mothers, fathers and carers**

Specific guidelines for action help to resolve highly complex situations successfully and are necessary to prevent situations of gender-based violence and discrimination. Due to existing widespread ignorance regarding both gender and disability, and the consequences of this ignorance, mothers, fathers and carers need specific skills in order to meet the needs of their daughters and sons. They should be given tools to help promote autonomy, independence, sexual development and sex education, equality and many more things. Educating parents is one of the cornerstones for the development of individuals.

## **4. CARE AND RECOVERY OF THE VICTIM**

### **4.1. Including women with disabilities in the care and recovery of victims**

Women with disabilities must be included in the care and recovery of victims, and they must have access to the resources assigned to combating gender-based violence.

Positive action measures ensuring women with disabilities are represented are required, not only to make them more visible but also to bring a new approach to centres - an approach from within.

## 4.2. Accessibility

Infrastructures ensuring resources are accessible must be provided. Universal accessibility to all services and provisions must be guaranteed.

The first step that needs to be taken in the area of care and recovery of women who are or have been victims of gender-based violence is to reach out to them. In order to do this the particular circumstances surrounding women with disabilities need to be considered.

Women with disabilities must be included in all gender-based violence programmes and protocols. They need to be informed, advised and supported to make them aware of what gender-based violence is so that they can identify it and learn about their rights. It is vital to get across to them the message about what gender-based violence is and how to escape from it, and equally necessary to check that the message has really reached them.

Information must be offered in comprehensible, varied and clear terms and adapted to accommodate the existing multiple forms and degrees of disability. The information must reach women who are deaf, blind, have an intellectual disability...in short, all women with disabilities.

However, it is not enough just to provide accessible information; it is also vital to make active efforts to inform, to reach out to these women and children who are victims of gender-based violence, in places like schools, social services, leisure time facilities and health care facilities. It is also not enough to offer support in these areas; it is also vital to promote positive action measures that take into account the specificity of gender-based violence against women and girls with disabilities. Staff must be trained in disability and gender and guarantee access to resources, and practitioners should make efforts to reach out to women with disabilities. We cannot wait for them to turn to social services; social services must establish contact with the women, interview them and monitor the situation. For instance, social workers should be sent to their homes to interview them alone.

The personal assistant is a key figure for those who need support to perform basic daily duties such as personal hygiene, cooking, etc., and special care must be taken when choosing the assistant. Not having a personal space for oneself is very tough, and a lot of violence is perpetrated completely unnoticed in the context of this *support*. If the carer is a man intimate personal hygiene becomes an issue of violence, or the woman with disabilities asking him to put make up on her...there are other more visible types of violence that can be detected using **pointers** that appear in different areas: food, medicine (both a lack of medicine and too many sedatives, hygiene, clothing

(suitable for the woman's age, personal conditions and the prevailing weather), and restricted mobility.

### **4.3. Targeted information and training**

Practitioners working in the fields of gender-based violence and disability must be aware of and consider the peculiar circumstances involving the intersection of these two variables, which very often feed off each other. There is a widespread ignorance surrounding disability and gender-based violence. No work is being done in the area.

Practitioners should know that:

- Many acts of violence perpetrated by abusers on women with disabilities are not noticeable in the same way as in the case of women without disabilities. It is necessary to get to know the peculiarities involved in the ways violence is exercised by the perpetrator;
- The image a woman with disabilities has of herself and the image society has of her have a powerful bearing on the existence or not of gender-based violence;
- Due to their disability, there are barriers to information enabling women with disabilities to understand and explain what is happening to them, escape from the situation, become more autonomous and gain a healthy self-esteem.

### **4.4. Comprehensive care**

One of the key aspects in preventing and eliminating gender-based violence is to gain a deep understanding of the context in which it occurs. Gender-based violence is not an isolated act that happens to women at random. In fact it conforms to a behavioural pattern whose purpose is to gain control over the woman and submit her and in which the aggressor takes advantage of all circumstances leading to her isolation and weakness. In the case of women and girls with disabilities, the particular characteristics surrounding these cases of gender-based violence make them completely invisible in society. Training in this field is needed to be able to deal with them.

The goal of comprehensive care for women and girls who suffer or have suffered gender-based violence is to enable victims to recover and re-establish control over their own lives, their autonomy, self-esteem and empowerment. In the case of women and girls with disabilities these questions must be addressed while taking into

consideration the particular circumstances surrounding the (real or imagined) perception of dependence on others. To do this, one needs to work in parallel on those aspects related to the disability itself, whether it was present prior to violence, was acquired after it occurred or was a result of the violence.

During the initial stages, when the woman has just reached the support networks for victims of gender-based violence, it is very important for her to be aware of the following:

- The process involved in gender-based violence;
- The myths surrounding gender-based violence and disability;
- Her rights and the comprehensive social care she can ask to be given;
- Safety protocols specifically in place for these cases.

Above all the main aim is to provide care to the victim and, subsequently, achieve complete recovery. The resources she needs to escape from violence and to help her to overcome the consequences must be provided; she cannot remain a victim —she must become a survivor.

#### **4.5. Protective measures**

The government must adopt targeted measures to ensure women with disabilities are safe. These measures must take into account that they are particularly vulnerable and must combat the lack of protection and defencelessness they face.

### **5. ACCESS TO JUSTICE**

Chapter 5 of the 2nd Manifesto on the Rights of Women and Girls with Disabilities addresses equal recognition before the law and effective access to justice. It seems incredible that a self-evident and recognised fundamental right needs to be explicitly addressed but, as paragraph 5.1 of the 2nd manifesto points out, reality shows that inequality and discrimination continue to prevail as a consequence of invisibility, misconceptions and a lack of acknowledgement of the human rights and fundamental freedoms women and girls with disabilities have. Women with disabilities barely conceive of themselves as rights-holders and are widely ignored when they attempt to report violations.

The Spanish constitution and other legal instruments recognise that all citizens hold equal rights, and these rights must be effectively upheld in practice. Inequality and lack of access to the same rights as other citizens constitute social violence. What purpose does it serve for women with disabilities to have legislation on gender-based violence if the situation and special circumstances users may have are not considered in each and every resource made available?

In order to safeguard effective access to justice for women with disabilities, systems and interpreters ensuring they are able to communicate correctly with police and legal personnel must be available at all stages of the process (2nd manifesto, paragraph 5.6).

Interpreters, whether they are sign-language interpreters or interpreters for other languages, have a key role to play; they interpret the message in the first place and pass it on. The plausibility of the women with disabilities relies on the person transmitting the message, and the plausibility granted to the interpreter is crucial in the different stages the woman goes through: social services, psychological assessment and treatment, police stations, courts, etc. To a large extent believability is in the hands of the interpreter who is expressing herself, although the content of the message may originate elsewhere.

It is vital to have interpreters who are aware of the gender perspective; if they are not, shades of meaning are lost.

As violence against women is often perpetrated by the person in charge of caring for them, measures are required to enable them to communicate the violence they are suffering, report it and receive care in a centre. All information and training programmes targeting women and girls with disabilities should also be made available to mothers of boys and girls with disabilities and their carers.

For access to justice to be effective and for each person to be given equal treatment, gender- and disability-awareness training must be provided to personnel in the legal system in order to reinforce the fact that disability is a circumstance of the individual which has no bearing on the fact that the individual is a rights-holder nor affects his or her legal capacity either in the personal sphere or in terms of family or patrimony. This positive image, highlighting that the individual is in fact a woman, is vital, above all in divorce and separation proceedings and especially if a ruling is to be given on guardianship and custody of children (2nd manifesto, paragraph 5.9).

Paragraph 5.11 of the 2nd manifesto states that, "Disability should never be used as a justification for separating boys or girls from their mothers with disabilities or boys or girls with disabilities from their mothers in legal proceedings. Any support

required by mothers with disabilities to perform their role as mothers should be provided in accordance with their individual and personal needs and the best interests of the boy or girl.”

Cases involving exploitation, violence or abuse of minors or boys and girls with disabilities must be identified, investigated and, if appropriate, prosecuted (2nd manifesto, paragraph 6.19). To achieve this, the measures needed to ensure these cases reach the light of day and do not remain unpunished because the victims are more vulnerable must be put in place.

## 6. STUDIES AND RESEARCH

No major research studies focusing specifically on violence and disability have been carried out. There have been some studies on violence and disabilities, but these are partial and cannot be extrapolated to the entire population of women with disabilities.

A wide-ranging and detailed study looking at the reality of violence suffered by women with disabilities is needed. Personal and social aspects, potential defence mechanisms, who are the perpetrators, what types of violence can be identified, what violent acts are not considered as such, etc., are all areas for study.

Any study or report on gender-based violence must take disability into account and include disability-related indicators. The lack of studies in the field highlights the invisibility surrounding women with disabilities.

Based on the ideas set out in this chapter - women with disabilities are victims of gender-based violence, they suffer multiple discrimination, they are invisible to society, due to their disability in many cases their potential and capacities are undervalued, at times they are part of overprotecting family structures and of a society which, at the best of times, treats them with the typical indulgence found in those unaware of the reality of their situation - and in order to remedy the situation it is necessary to make women with disabilities visible, empower them and give them the floor. One way to achieve this is by gaining an understanding of the reality they face through studies and research highlighting and analysing the physical, psychological and social violence they suffer.

We suggest research is conducted, and in order to do this data must be gathered from official and reliable sources to determine how prevalent gender-based violence is among women with disabilities and what disabilities are caused by violence against women with disabilities.

Data and literature gathering must take diversity in disabilities into account and consider different environments such as rural and urban settings. Special attention

should be given to the number of inhabitants in each place. Information and data should come from:

- National, regional and local law enforcement agencies;
- Legal systems;
- Social care providers in the field of disability (residential centres, day-care centres and any other similar services);
- Representative organisations of persons with disabilities and their families.

Whatever methodology is used in research to gain an understanding of the reality faced by women with disabilities, it must always consider not only the particularities regarding the type of disability, but also the socio-affective environment and the woman's degree of dependence on others.

A lack of contact with women's organisations active in the field of gender-based violence means that women with disabilities are rarely referenced in the reports they publish. Women with disabilities have yet to find their position in women's associations because the associations do not take on board the peculiarities affecting them; nor have they been accommodated for in disability organisations, which are generally governed by men and have, to date, only addressed issues related to disability. We are, however, making progress in this area and women are represented more and more in disability organisations.

The invisibility faced by women with disabilities is clearly illustrated if we consider those women who have been fighting for years for the rights of persons with disabilities in general, and more particularly women with disabilities. The lack of recognition they face is just one more sign of the invisibility to which women with disabilities are subjected, a situation which, in short, is one of invisible women within the usual invisibility to which women are subjected... one more example of the social violence they suffer.

As Ana Peláez Narváez has stated clearly and forcefully, "Mutual oblivion between the gender and disability perspectives in policy and legislative initiatives... means the needs of women with disabilities remain invisible and women with disabilities themselves remain victims of a persisting structural inequality. Empowering women with disabilities is, therefore, an urgent necessity at the present time as neither society nor public authorities nor women's movements nor disability movements have truly acknowledged their needs and interests."<sup>7</sup>

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<sup>7</sup> Chair of the European Disability Forum's Women's Committee. Quote from the introduction to the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union.

Within civil society women with disabilities are currently making progress in implementing the principle of gender mainstreaming. One of the fruits of these efforts is this book published by CERMI, which will undoubtedly be a spearhead for subsequent studies in the field.

## 7. RECOMMENDATIONS FOR POLICYMAKERS

- Redefine and extend the legal concept<sup>8</sup> of gender-based violence to include the disability perspective<sup>9</sup>. Violence perpetrated by people who have no legal relationship with the victim must be added, and recognition should be given to all types of violence suffered by women with disabilities, including institutional violence, coerced abortion, forced sterilisation and failure to act or provide due care;
- Extend legal protection to include the mothers of victims with disabilities;
- Carry out awareness-raising campaigns involving all stakeholders on violence suffered by minors of both sexes and gender-based violence;
- Organise informative campaigns among the at-risk population. The first step towards improvement is acknowledging the situation;
- Disseminate information. Rights cannot be effective or exercised if rights-holders are unaware of their existence or how to exercise them. Women with disabilities who are victims of gender-based violence must be aware of the steps they can take to safeguard their protection and safety, the rights and support they are granted by law, and the resources in terms of care, emergency services, support and recovery they can access;
- Campaigns and information must be in accessible formats and use comprehensible language. This includes the use of means and modes of communication to ensure it reaches all women with disabilities;
- Gather data in registry offices. Data must be gathered in such a way that it can be disaggregated by sex and type of disability and can be cross-referenced. Data should also take into account environment (rural or urban) and focus particularly on the number of inhabitants;

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<sup>8</sup> Spanish Organic Law 1/2004, dated December 28th, on comprehensive protection measures against gender-based violence.

<sup>9</sup> Proposal from Fekoor, the organisation of persons with physical and/or organic disabilities in Vizcaya. Women's Equality Commission for a Basque gender-based violence law. 9.11.2011. Cermi Galicia has put forward a similar proposal.

- Include gender- and disability-sensitive indicators in mainstream programmes to enable performance analysis and to uncover the causes of any imbalances and the mechanisms on which they are based, in order to introduce improvements;
- Introduce protocols for detection, assessment and specialised intervention for situations of gender-based violence against women with disabilities. Protocols for detection must consider settings which are particularly propitious to violence and abuse. Areas for action include:
  - Health: primary health care, specialist health care, hospitals and other health facilities;
  - Law enforcement agencies;
  - Actors in the legal system;
  - Social services;
- Study why some women do not report violence and abuse, withdraw charges or do not proceed with criminal actions;
- Provide specialised training in gender-based violence and disability to practitioners in all areas;
- Provide specialised interpreters with an awareness of the gender perspective for sign language interpretation and other languages;
- Accompany and assess. The role of a person who accompanies and assesses women with disabilities who are victims of gender-based violence should be recognised;
- Make accommodations in public resources. In addition to removing architectural barriers, resources must be adapted to suit blind people, deafblind people and those with a hearing impairment;
- Provide adapted care services for women;
- Institutions should not encourage women to demonstrate forgiveness and show 'understanding' for offenders;
- Women who suffer abuse but as yet are not considering the possibility of reporting the crime should be supported and have confidence instilled in them as a step towards protecting them;
- Listen to the voices and opinions of women with disabilities who are victims of gender-based violence in order to address their reality, often an unknown for

practitioners. They should be given the opportunity to play a prominent role and should not have their fate settled for them;

- Fully support new technologies. New technologies are still not accessible for the majority of women. They should be delivered to women with disabilities as they have a huge potential; deaf women, for instance, can use video conference technologies. Training courses for women with disabilities should be promoted and computers provided;
- Ensure emergency services are accessible. *REACH 112* European project. It is vital to keep working on designing and implementing a fully-accessible emergency service. The goal of the *REACH 112* project is to allow everyone, regardless of disability, age or the use of unconventional technologies for web access, to surf the pages on this web site with no access issues, in accordance with the Web Content Accessibility Guidelines version 1.0 set out by the World Wide Web Consortium (W3C). This will benefit everyone as the user will be able to adapt the visual features of the portal (font, font colour, font size, background, etc.)<sup>10</sup> and, through the Total Conversation concept, is given communication tools to be able to find a means for communication in each situation, such as holding a conversation through real-time texting, sign language, lip reading, voice or any simultaneous combination of these methods;
- Ensure telephone-based assistance technologies are accessible for deaf women. Encourage projects such as TELPES (telephone-based assistance solutions for deaf people), currently being developed by the CNSE (National Confederation of Deaf People) in partnership with the CNSE Foundation, Red Cross Spain and the Vodafone Foundation Spain;
- Ensure accessible telephony. Talking on the telephone is currently not an option for many people with a hearing impairment or a speaking disorder; as a result, text telephony should be encouraged as a means to overcome a communication barrier. Depending on the type of device, the connection to the telephone network is established by a lead or an acoustic coupler placed on the earpiece of a standard telephone. Current difficulties are caused by the variety of systems available and incompatibility problems. Systems should be unified internationally as soon as possible;
- Eliminate barriers to accessibility in communications. The 016 number is not accessible for women with hearing disabilities or speech disorders, nor is the number 900 116 016, which is also difficult to remember;

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<sup>10</sup> These are set through style sheets enabling the user to adjust text to suit his or her preferences.

- Women with disabilities should be engaged in institutions. It is absolutely necessary to count on their experience and capabilities.

## 8. RECOMMENDATIONS FOR THIRD-SECTOR ACTIVISTS

- Expand information- and data-gathering efforts in the field of violence against women and girls with disabilities;
- Promote research and studies on gender-based violence in the disability field;
- Civil society must contribute to visibilising gender-based violence against women with disabilities;
- Set up self-help groups and women's networks;
- Draw up a directory containing contacts by region so that women with disabilities know who they can turn to if they suffer abuse;
- Set up web sites with all the information women who are abused need (resources, legal advice, procedures, etc.);
- Hold targeted workshops to disseminate specific information in accessible formats depending on the type of disability;
- Organise informative workshops on self-esteem, self-defence and rights;
- Encourage the use of new technologies. Women should be encouraged to use computers and should be provided with one. Extend the process of adapting technologies;
- Engage with the media and participate in all programmes and sections, not just those related to disability;
- Leadership by women within civil society is a key motivator towards empowering other women with disabilities and women in general. These leaders are key references for society and leadership of this type must be fostered as it contributes to portraying women as capable, strong, brave and educated. We must continue along the pathway these leaders have initiated.

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## Chapter VI

### COMMUNITY LIVING

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1. COMMUNITY LIVING
2. HABILITATION, REHABILITATION AND ASSISTIVE TECHNOLOGIES
3. ADEQUATE STANDARD OF LIVING AND SOCIAL PROTECTION
4. LEISURE TIME, CULTURE AND SPORT
5. RECOMMENDATIONS FOR THE FUTURE
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6. BIBLIOGRAPHY

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## Chapter VI

### COMMUNITY LIVING

#### 1. COMMUNITY LIVING

The *World Report on Disability* states that in 2010 between 15.6% and 19.4% of all people over fifteen years old had a disability - between 785 and 975 million people. The calculation is based on the total estimated population and disability prevalence rates (also estimated) from the 2004 *World Health Survey* and *Global Burden of Disease*. Of all people with disabilities, between 110 million (2.2%) and 190 (3.8%) million face major difficulties in everyday life.

To complete the figures we need to add children and young people and, as a result, we reach the figure of approximately one billion people with disabilities worldwide (or around 15% of the total world population). We should point out, however, that there are greater difficulties involved in studying the reality and calculating the figures for boys and girls with disabilities.

In 2004 the *Global Burden of Disease* estimated that there were 106 million boys and girls with disabilities under the age of 14, and the following year the *United Nations Children's Fund (UNICEF)* estimated a figure of 150 million under the age of 18. Several more recent studies have put the figure for boys and girls in low- and medium-income countries at between 0.4% and 12.7%. This means that boys and girls with disabilities are not identified and not properly addressed. In addition, we know that in many so-called developing countries boys and girls are exposed to multiple risks, including poverty, malnutrition, health problems and life in homes with no incentive whatsoever, which may cause delays in cognitive, motor and socio-emotional development.

Furthermore, according to UNICEF research boys and girls who are at risk of disability are more likely to come from poor families and suffer discrimination, they are less likely to make use of social services, including primary education, they have

greater health problems, starting with low weight and growth problems, and they are more likely to receive corporal punishment from their parents.

The *World Report on Disability* makes it evident that experiences in disability are myriad if we consider health conditions and personal and environmental factors; there is, therefore, great variation between countries, and even within each country depending on the type of disability, age, sex, level of education, income, environmental risks, resources, and so on. At the same time, the report confirms the difficulties in comparing information and data from censuses and research in different countries.

With these difficulties in mind, and in a similar vein to the introduction to the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union: a toolkit for activists and policymakers*, we recommend registers and indicators are put in place to be able to understand the situation faced by girls and women with disabilities and act accordingly in order to remove the causes of the specific types of discrimination they suffer.

### **1.1. Where and how do women and girls with disabilities live?**

Attempts have been made to find data offering information on the main subject of his chapter: where and how do women with disabilities live, focusing particularly on those in institutions as they are particularly defenceless.

The outcomes of a research project carried out in 2003 and published in the report *Included in Society. Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People* - a project involving 2 500 institutions in 25 European countries and detailing conditions and community-based services in four countries (France, Hungary, Poland and Romania) - highlighted the difficulties faced in gathering and comparing data and, more specifically, the problems caused by considering people with disabilities as a homogeneous group and failing to distinguish between different disabilities. It should also be noted that, at least in the report mentioned above, there is no reference to the fact that it is important to consider another variable when researching the situation: sex.

In 2007 the European project *Deinstitutionalisation and community living - outcomes and costs*, the purpose of which was to “provide scientific evidence to inform and stimulate the development of financial resource redistribution policies to better meet the needs of persons with disabilities by moving from large institutions to a system of community-based services and independent living”, looked at gathering

data on persons with disabilities in 28 countries (including Turkey) and studied economic, financial and organisational resources for optimal deinstitutionalisation in three countries: England, Germany and Spain.

The first common conclusion reached is that it is extremely difficult to find data and, above all, comparable data (type of institution, age and type of disability of the residents, type of service provision, features of the services provided, etc.). Despite this, the figure given was almost one million two hundred thousand people with disabilities in institutions. Of those whose age is known, more than one hundred and eighty thousand seven hundred were boys and girls, and more than seven hundred and sixty-six thousand were adults. In terms of sex, a variable included in this study, the lack of data was considerably higher and it could only be determined that more than two hundred and thirty-two thousand were boys and men, while around two hundred and twenty-five thousand were girls and women.

The results of the *Survey on Disabilities, Personal Autonomy and Dependence 2008* (EDAD-08) were published in Spain in 2008. A later study - *Dependence and family: a socio-economic perspective* - points out that the innovative feature of this macro survey was that it included data on people living in institutions and centres.

According to EDAD-08, in Spain there are more than four million people with disabilities<sup>1</sup> or limitations<sup>2</sup>, and the majority - 93.5% or 3.8 million people - live at home.

The number of people with disabilities rises with age, and those over the age of 65 constitute almost 58% of all people with disabilities living at home and 82.5% of those in institutions.

A breakdown by sex shows that there are more women than men both living at home and in institutions, although a deeper study of the data indicates that 94.29% of all men with disabilities live at home, in comparison with 92.90% of women. There are also more

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<sup>1</sup> Disability (six years or over). For the purposes of the survey, disability is understood to be any type of significant limitation in performing daily living activities which has been present, or is foreseen to be present, for more than one year and is caused by an impairment. A person is considered to have a disability even though it is overcome through the use of external technical aids or with the help and supervision of another person (except in the case of glasses and contact lenses). Forty-four types of disability were included in the survey, classified in eight groups: visual; hearing; communication; learning, applying knowledge and performing tasks; mobility; self-help; domestic life; and personal interactions and relationships.

<sup>2</sup> Limitations (under six years old). In boys and girls from 0 to 5 years old, a detailed study of disabilities was not carried out due to the difficulties involved in detection. Potential limitations which may have been detected in children in this age group were researched.

women living in centres than men, although while the number of women over 65 represents 71% of those living in centres in that age group, between the ages of 6 and 64 there are fewer women than men residing in centres - around 38% of the total for that age group.

To gain a deeper understanding of the situation - above all regarding young Spaniards with disabilities - and with respect to this and the other topics addressed below, a detailed study by age groups of the data the survey provides is needed.

## 1.2. Living in centres

In respect of **distribution by type of centre**, *Dependence and family: a socio-economic perspective* highlights the prevalence of centres for older people, where 80.3% of all people with disabilities aged 6 or over live, and where 72.7% are eighty years old or over. 13.3% of all persons with disabilities, mostly over the age of 6, live in centres specially designed for them, and the remaining 6.4% are in psychiatric or geriatric hospitals.

Regarding other issues which may be of interest, such as a disaggregated analysis of the relationship between type and size of centre and age and sex of residents, this data is not given in the tables on the INE (National Institute for Statistics) web site, although the vast majority live in centres for more than 20 people.

A key factor in determining if there is any gender difference between women and men is the data on **participation in decision-making**. According to EDAD-08 data, only 52.33% of those living in centres responded to these questions, and this fell to 33.12% for those living in psychiatric or geriatric hospitals and 36.76% in other centres for persons with disabilities. In addition to showing once again how difficult it is to gather data, the figures seem to indicate where there are greater difficulties and where lower participation (greater discrimination) can be expected.

Responses show how people who live in centres have reduced decision-making capacity; in addition, they demonstrate how gender shapes decision-making capacity. In general, women take part in decision-making less than men and, when this is not the case, it is normally on questions about activities which are traditionally considered 'women's issues' - what clothes to wear, how to decorate one's room with one's own things - or issues which they are thought to care less about than men, for instance who to share a room with.

If we carry out the same analysis on participation in decision-making by type of centre and sex to check for statistically-significant differences, we can see that it is in hospitals - psychiatric or geriatric - where residents have the lowest participation

rate. This was expected given the lack of data, as pointed out above, and because in these places the notion of 'patient' - an inactive subject - is more deeply rooted. On the other hand, in centres for persons with disabilities there is generally less decision-making capacity, and women face greater discrimination; it is the only case where women's capacity to take decisions is always lower than men's. This may mean that it is in centres specifically designed for people with disabilities where the social significance of impairment is strongest as people whose disability is clearly not age-related are looked after by staff who are trained and specialised in caring for them.

While on this subject, we can return to the European studies mentioned above, which measure the social consequences of institutionalisation: loss of or reduced contact with family and friends; inflexible daily routines and daily activities; depersonalisation; the individual is treated as part of a group...en bloc according to certain characteristics - environmental shortcomings (buildings, toilets, bedrooms), shortage of staff, poorly-trained staff...

This all indicates that shaking off institutional thinking is difficult, and this is backed up by opinions such as the following regarding life in a sanatorium in Spain which was closed down at the end of the 70's:

*"In general the residents didn't go anywhere. They stayed for hours on end in the huge terrace they had to sit in the sun when the weather was good. They spent the rest of the time inside in enormous rooms and bedrooms where they lived their lives...they slept there, ate, studied, attended the compulsory mass once a week, and watched television.*

*Most residents stayed there for years, and they have mixed feelings about those years: they spent their childhood, adolescence and a good part of their adult life in the sanatorium."*<sup>3</sup>

Or this testimony from 2004:

*"I'm a woman and I have a severe physical disability...caused by cerebral palsy. I can't perform daily activities, so I need someone to see to me.*

*For some years now I've been concerned by the idea that some day in the not too distant future I'll have to go to a large, depressing institution where there's no privacy and you have to go along with strict timetables, like in a hospital. I'm sure my self-esteem is going to go way down - staff wear white uniforms like health care staff, and to top it all they're called 'carers'" (MGI)<sup>4</sup>.*

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<sup>3</sup> 'Memoires of disability in Spain', ACCESIBLE, issue 25.

<sup>4</sup> Letter published in the magazine ACCESIBLE, issue 25.

Or this more up-to-date testimony from January 2012, given to us by Nuria Villa<sup>5</sup>:

*"I'm a 37 year-old woman with 78% physical and intellectual disabilities. I've been living in different centres for people with disabilities for more than 15 years, and for more than 12 years I've been asking IVIMA<sup>6</sup> for a house so that I can live like a normal person and lead a normal life. I'm fed up and tired - a lot of the time I feel like a 'prisoner' in these centres. I can't ask my male and female friends over, or my partner, as I could if I had my own home, I can't eat what I want, I can't choose what time I want to get up at the weekend...I have no privacy - if I go to the toilet the carers can open the door whenever they want to get something. I work in a special employment unit, and although I don't earn a lot of money I have some savings, but I don't have the option of living an independent life" (AVM).*

It is striking that practitioners are clearly aware of the effects of institutionalisation, as we can see from the study *Institutionalisation and dependence*<sup>7</sup>, which publishes observations from the multidisciplinary team from the CAMF<sup>8</sup> in Guadalajara on the effects of an institution on residents.

They cite the following as negative consequences for residents: no contact with reality; lack of responsibilities and control over daily life; egocentricity; the emergence of social classes according to the needs of the individual and level of independence; emotional outbursts towards practitioners or more dependent residents, etc., due to the fact that they are considered sick or subject to professional guidelines, at times arbitrary to facilitate working arrangements and at times mistaken as they treat everyone as part of a group instead of individuals, denying residents their sexuality and preventing them from expressing their emotions.

The expectations of the individual vary greatly according to the length of time the person is due to be in the institution, or the time he or she has already spent there. The perception they have of their stay ranges from terrible, awful, acceptable, and even sometimes enjoyable, although in all cases they are deprived of contact with reality.

The same study lists a number of positive effects regarding institutions: it appears to be an optimal use of financial resources (although the study suggests this is an area

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<sup>5</sup> One of the members of the expert group for this chapter.

<sup>6</sup> Madrid Housing Authority.

<sup>7</sup> *Institutionalisation and dependence*, IMSERSO, 2006, from the collection *Estudios - Serie Dependencia*.

<sup>8</sup> Assistance Centre for Persons with Severe Physical Disabilities.

for further research); it brings respite and replacement for residents' relatives, who in many cases ask for the person to be admitted; and it delivers an efficient response to the individual's basic needs, medical requirements and needs in terms of rehabilitation as staff are highly specialised and centres are accessible. Surprisingly, the study concludes that the environment is not considered propitious as it *"further contributes to the idea of a ghetto; measures to eliminate architectural barriers in society, as laid down in legislation on non-discrimination and equal opportunities, are therefore overlooked."* It also points out that psychological and cognitive stimulation therapies are interesting and positive aspects, as are sports activities, access to new technologies and occupational workshops, the only place where the individual can choose what to do.

Of all the aspects which are considered to be positive, practitioners themselves really only evaluate those concerning their own activities as professionals, at times even to criticise, as they are fully aware that residents want to be independent; however, as they have no other option, *"they can only put their names on the waiting list to get a place at an institution."*

Doubts surrounding the lower cost of institutionalisation when compared to the community-based services called for by the independent living movement are confirmed; there is no evidence that this is true, as the European study cited above highlights. It would be advisable to carry out studies, or disseminate the outcomes of studies already conducted, covering smaller areas in order to avoid the problems associated with macro studies and channel efforts in the right direction.

The claim that an institution is beneficial because it serves as a 'replacement for the family' is negated by a subsequent explanation when outlining the difficulties those caring for persons with disabilities have, and especially women with disabilities, when they argue that they should become employees with rights to weekly rest periods, holidays, income, social security and so on.

As regards the accessibility of centres, in addition to the statements by practitioners being extremely paradoxical, they contradict the reality borne out by data from EDAD-08 on **difficulties in functioning in centres and in other settings**.

More than 67% of all people in centres state they have difficulties functioning inside and outside centres. The main problems they face in centres - and this refers to all centres and to both women and men - are related to gaining access and departing from the centre and the toileting facilities. In global terms 55.47% and 44.11% respectively of all residents in centres mention these difficulties.

The fact that women in all types of centres point to difficulties in all areas is striking. While a detailed study has yet to be carried out, this may be due to a number of reasons:

when women are admitted to centres they may have a more severe disability than when men are admitted; staff may dedicate less time and effort to women than to men; and they may want to retain their independence more (or habits as they may have been 'trained' to look after themselves) in performing daily living activities, and this may make them more sensitive than men to existing difficulties.

EDAD-08 also offers us data on **perceived discrimination**: 94% of all respondents in centres - 54.65% of men and 53.27% of women - say they have never felt discriminated, while 5.1%, 0.65% and 0.25% say they have felt discriminated against at some point, on many occasions or constantly. In absolute terms this means that over 8 500 people with disabilities who responded have felt discriminated at some time. A detailed study of responses by age indicates that the number of people who feel they have suffered discrimination is higher between the ages of 6 and 64 years old and the perception of discrimination is higher in relative terms among men than women, although in absolute terms more women feel discriminated against than men.

In respect of the situations in which residents in centres have felt discriminated against, women mentioned greater discrimination than men only in the fields of health, relationships and social participation.

The data on perceived discrimination contrast sharply with previous data: women with disabilities who are resident in centres recognise that they participate less in decision-making and say they have greater difficulties than men in terms of personal development, but at the same time the proportion of women claiming to have felt discriminated against is lower than in the case of men. Perhaps the key here is that women with disabilities, who sadly are culturally and socially 'used' to suffering discriminated, end up not recognising discrimination when it happens to them.

### *Living at home*

If we turn to the **situation faced by women with disabilities living at home** - the majority of women - EDAD-08 offers us the following summarised data on types of homes:

- 19.65% of all women with disabilities live alone, compared with 10.59% of all men with disabilities;
- 32.76% of all women with disabilities live with their partners or with their partners and children, compared to 62.77% of all men with disabilities;
- 25.96% of all women with disabilities live in 'another type of home', compared to 18.9% of all men.

Part of the explanation for some of these figures may lie in the greater longevity of women as many older women live alone or may have been forced to move to homes other than their own, but there are also other causes, especially for the fact that there are far fewer women living with their partners than men with disabilities. These are related to social concepts about the role of women and the belief that it is impossible for women to perform this role if they have a disability. This has been demonstrated on numerous occasions in national and international studies, research and conferences.

To cite some examples, we can quote Carme Riu, editor of *Social Exclusion Indicators for Women and Disability*:

“In many parts of the world the physical image of a woman determines her value and, ultimately, her chance of getting married. The ability to care for children and be a capable parent determines her skills as a woman. We don’t meet those requirements in some cases as our sexuality is judged by society through our physical appearance. Consequently, society undermines our femininity and motherhood.”

“In domestic life this hidden and forgotten differentiation leads to rejection due to the social construct surrounding women with disabilities, so ‘disabled’ women, in inverted commas, are isolated and held prisoners in their own homes, untrained, exploited by having to perform routine tasks, unpaid slaves, responsible for all the family ills and taking care of all older people in the family until they die, with no economic or social resources, no maternal reproduction...but sustaining the family; we would say they are burdened with the most negative aspects of reproducing the same every day - what is needed for the subsistence of women and men that their limited relations allow.”

Or as Marita Iglesias has stated in several articles:

“As someone with a disability, one is expected to be submissive, dependent and genderless, but when I *am* given a gender I’m given the negative parts: dependence, weakness, submission...not the positive aspects: singularity, motherhood, femininity, sensuality, sensitivity, and so on...we, women, are caught between two cultural roles which condemn us to confusion and a feeling that we don’t belong anywhere, a lack of identity or, at the very least, a confused identity, if that can happen without being contradictory.”<sup>9</sup>

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<sup>9</sup> *Women and independent living*, MINUSVAL, issue 146.

“Here too (marriage and family) a woman with disabilities generally suffers discrimination as women are judged, first and foremost, by their physical appearance and not for their qualities as people.

Women with disabilities do not meet standard patterns and their sexuality remains unacknowledged. The more visible the disability is, the more likely they are to be thought of as asexual beings and deprived of their right to establish a family, have children, adopt children and run a home. Society permanently questions the role they expect a woman to perform and the role assigned to her as a person with a disability.

As a result and based on the perception of disability held by others, women with disabilities are denied the roles generally given to women or granted a limited role. Not fitting in with the standard view of beauty or ‘good looking’ diminishes our likelihood of having intimate relationships, heightens physical differences and destroys the self-perception we have of our bodies. Consequently, a woman with disabilities ends up perceiving her disability as something negative, among other reasons because it removes any chance of having relationships or being valued socially as she is unable to live up to assigned standards and roles. Her invisibility increases as she is unable to perform or fit in to these traditional moulds (she fails to take part in activities appropriate for her age and sex, she is not thought of as a potential girlfriend, mother or wife, she is denied access to jobs where ‘being on show’ or image is considered important, etc.); however, parts of her life which in people without disabilities would be viewed as normal are highlighted (studies, cooking, personal hygiene, etc.) or their existence is distorted to create portrayals of extraordinary life and tales of ‘overcoming personal circumstances’, heroism and romanticism...”<sup>10</sup>

Although there are cultural and ethnic differences between countries, it is well known that for women health problems leading to impairments have the same impact, socially speaking, in modifying roles. As the Mexican writer Susana Sandra Oliver rightly says in *Those completely unknown women*:

“Being a woman necessarily leads to talking about the female body not just as a biological and natural reality, but also as a socio-cultural reality. Even though the female body and sexuality have been important subjects for

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<sup>10</sup> *Violence and women with disabilities, women and disability: an outstanding subject for analysis.*

reflection and discussion among feminists, the pressure women with disabilities face because they 'don't have a perfect body or conform to social norms of femininity' have been ignored..."

"...So the patriarchal ideology moulds both the bodies society desires and the bodies it fights against tooth and nail: ugly and 'abnormal' bodies. The fact that eugenic practises exist in some countries to prevent people with disabilities from being born is no accident. This is why a gender-based approach is needed to dismantle power and shed light on the mechanisms used for oppression by questioning the imposition of standards related to beauty and perfect bodies as the only way to live. Stone (1995) stresses that society must find a way to acknowledge in disability a means to honour humanity."

The *Study on the situation of women with disabilities in light of the UN Convention on the Rights of People with Disabilities*<sup>11</sup> points out that:

*"Intersectionality is particularly strong in the area of respect for home and the family; there is a body of research demonstrating that women with disabilities, in particular, do not yet fully enjoy the right to marry and form a family, decide freely on the number and spacing of their children, have access to family planning information and retain their fertility on an equal basis with others."*

In the words of one Indian woman with disabilities<sup>12</sup>:

*"The problems faced by women with disabilities are the same, albeit more complex, than those faced by other women in India as we don't enjoy access to education. This leads to all the problems associated with illiteracy such as poverty, lack of empowerment to take decisions and a lack of options open to us. Due to our disability we aren't viewed as women who are capable of performing the traditional roles given to women in India. Worse than that, I have seen that most women with disabilities who are leaders really believe this. So the most pressing issue to be addressed is the failure to recognise our rights. The idea that a woman has rights is widespread here in India, but the idea that a woman with disabilities has rights is not."*

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<sup>11</sup> Study on the situation of women with disabilities in light of the UN Convention on the Rights of People with Disabilities (VC/2007/317), Final Report for the DG Employment, Social Affairs and Equal Opportunities, European Commission.

<sup>12</sup> What is exemplary about women?:

<http://www.minusval2000.com/literatura/articulos/mujeresConDiscapacidad.html#india>

Chavia Ali, Chairwoman of the Cultural Association for People with Special Needs in Syria, claims that:

*“Being a woman in the Middle East is not easy. We are subjugated by family traditions that enslave us and keep us in the shadows. We live to serve men, to give birth and bring up our children - this is our purpose in life.*

*...a woman with disabilities is normally overprotected by her mother to the point where her personality is wiped out. At the same time, her father, brothers and others simply repeat the mantra that “she shouldn’t go out in case something happens to her”. It’s not surprising then that in the end a woman with disabilities doesn’t dare go to school and that, among other things, she doesn’t even learn to read. Her family can’t even conceive of the idea that she could work in the future. We are talking about a person who is absolutely useless.*

*...for instance, women with disabilities in the Middle East don’t have the right to get married, so any sexual relationship by a woman with disabilities, consensual or not, is punishable by the death penalty. Evidently, blind women or women in a wheelchair are even easier prey for rapists. It is normally the woman’s own relatives that take it upon themselves to kill their own daughter with disabilities if she has had sexual relations outside marriage, while the rapists and murderers are generally found not guilty.”*

As regards **where boys and girls with some type of limitation live**, EDAD-08 estimates that 81.6% of boys and 75.4% of girls live in homes made up of a couple with their children, while 6.9% of all boys and 4.6% of all girls live in homes with a single parent and children. Surprisingly, a considerably higher percentage of girls (20%) with some type of limitation live in a different type of home in comparison with boys (11.5%), although to reach a conclusion it is necessary to study the reasons why by either using the micro data given in response the macro survey or carrying out additional research.

As in the previous section, EDAD-08 provides data on cases where people with disabilities have some type of **difficulty in functioning in the home**. Difficulties mainly occur on stairs and in bathrooms.

Women with disabilities say they have more problems than men in all places and age groups. As in the previous section when we looked at people in institutions, in the absence of detailed research, this may be due to a number of reasons: many more women with disabilities than men with disabilities live alone; women with

disabilities may receive less family support than men (socially, women in general, and women with disabilities in particular, are thought to take care of themselves better than men in general and, above all, a lot better than men with disabilities); a wish to remain independent (or the habit coming from being 'trained' to take care of themselves) in terms of performing everyday activities, leading them to perceive more sharply than men any difficulties present, and so on.

Women with disabilities encounter similar difficulties in **functioning outdoors**. These increase with age and, in practically all cases, are perceived to a greater extent by women than by men. Paradoxically, however, there is no difference in how difficulties are perceived according to type of disability, and this leads us to believe inaccessibility involves multiple factors which affect different types of disability.

Moving on to **perceived difficulties when using transport**, it is useful to know beforehand if women and men use different modes of transport. The difference in use turns out to be minimal, although greater in the 6-64 age range, in which fewer women than men use their own vehicle, use private unadapted vehicles more and, above all, make greater use of public transport. In older age groups women use public transport less than men. Evidence suggests men and women do use transport in different ways, and this is a subject for more in-depth research. It would also be interesting to have detailed data by type of disability and age group, because if we look at the responses overall the greater prevalence of disability among older people skews the results.

In private transport use, we can see how in all situations of disability women have greater problems than men in reaching and accessing transport and, in public transport, the outcomes are the same for all actions studied, except some where the situation is inverted in some cases in mobility, self-care and domestic tasks.

Women's lives in cities differ from men's and they use facilities differently. In addition, the city can generate disability<sup>13</sup>, especially for those at greater risk. It is women who experience that, "*life in the city gets tougher and tougher, less and less safe, less accessible and more and more denying of independence*" because they relate to it, experience it and use it far more intensely than men while, at the same time, participating far less in how it is arranged and in its processes. The lower the participation the greater the invisibility and difficulties, especially for those who have reduced mobility. In the end invisibility causes 'economic and social poverty discrimination'.

In terms of the **possibilities of maintaining social relations**, the data shows that more women than men with disabilities have problems with relations in all

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<sup>13</sup> *Cities as generators of disability, women and disability: an outstanding subject for analysis.*

circumstances covered in the survey - addressing strangers, relationships with friends and those closest to the person, making new friends. This is the case for all types of disabilities.

As regards frequency of visits to or by family and friends, women are visited less frequently than men by most relatives, except when those relatives are their own descendents - sons, daughters, grandsons and granddaughters. This is true for all age groups and types of disability. Women with disabilities also do not report having friends in a higher proportion than men, although in this case the figures are reversed for the 6 to 64 year old age group. Again, it would be helpful to study the real situation in shorter age groups and also relate it to the time when health deteriorates as a result of impairment in order to understand better the effect it has on such an important issue as the possibility and reality of social relations.

To conclude this section we shall look at the **perception of discrimination on the grounds of disability**. The figure is slightly lower for women than it is for men, except when the type of home is with the partner only and for those aged 80 and above.

As regards the frequency of the perception that one is being discriminated against due to disability, when this is cross-checked with activity, we see that women who are active - those in employment - perceive such discrimination in a significantly higher proportion than those who are inactive or unemployed and, in this case, also more than men in the same position. This is surely a clear sign that objective situations involving discrimination occur in the workplace, although, possibly and considering there are no in-depth studies on the subject, it may be the case that discrimination exists in general but is picked up on when the woman has better training and can escape from the habitual marginalising environment.

More of the low number of reported cases of discrimination are reported by women in all age groups and with all types of disability, except those with a disability affecting home life.

## 2. HABILITACION, REHABILITACION AND ASSISTIVE TECHNOLOGIES

The *World Report on Disability* includes estimated figures for needs and unmet needs for rehabilitation. It defines rehabilitation as “*a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments*”; that is to say not merely as therapy or functional rehabilitation from the medical point of view or even when an impairment is acquired, but with the concept of prevention included.

The reality, as demonstrated, is very different. For example in 2005 the *International Society for Prosthetics and Orthotics* and the *World Health Organisation* estimated that 180 000 rehabilitation professionals were needed in Africa, Asia and Latin America, while only 400 such specialists graduated each year. In terms of access to assistive technologies, gender inequalities were evident in “*Malawi (25.3% men and 14.1% women) and Zambia (15.7% men and 11.9% women)*”. A study of rehabilitation service needs in three districts in Peking reports that while 75% of the people interviewed required services, only 27% had received them. In Ontario, Canada, a study of people with arthritis and rehabilitation service delivery by regions concluded that there were gaps in provision and discovered a lack of services in certain areas.

The executive summary of the world report concludes that, “*Unmet needs for rehabilitation services (including assistive devices) can result in poor outcomes for people with disabilities including deterioration in general health status, activity limitations, participation restrictions and reduced quality of life.*”

Comments related to the additional difficulties faced by women with disabilities include some pointing out the lack of women practitioners in rehabilitation and cultural attitudes towards gender which affected rehabilitation services. For instance In India the low number of women prosthetics and orthotics professionals partly explains why women with disabilities are less likely to be given assistive devices; in Afghanistan access to treatment is restricted as women can only be seen by women therapists and men by male therapists. In addition, in all countries where women suffer travel restrictions or cannot move freely rehabilitation practitioners find it difficult or impossible to attend training and professional courses, and their ability to carry out home visits is limited.

Data for Spain regarding **health or social services provision** for persons with disabilities indicate that the percentage of women who report they have had need of some type of service is higher than men (65% compared with 60.2%). The figure is also higher for those who needed some type of service but did not receive it (7.12% compared to 5.54%), while the percentage for those who have had no need is lower (33.2% compared to 38.2%).

The differences between the types of service delivered do not appear significant, although it would be helpful to perform a detailed and disaggregated study using shorter age groups to verify if these differences amount to differentiated treatment due to gender. For instance it would be necessary to find out why, in the 6 to 64 age group, women are given more medical-related services - medical care, nursing care, medical-functional rehabilitation - and fewer social services such as occupational centres, occupational therapy, accessible transport and employment counselling,

given that women enjoy fewer opportunities to access education and employment and it is precisely in that age group where these social services could facilitate access to a job.

Data on the method of payment for health or social services show that women receive a lower percentage of free services than men in general, with some variations according to age. This fact is also noteworthy given that women generally have lower incomes.

More women than men with disabilities have needed some type of service but not been provided with it - 6.62% compared to 5.04% for men. The biggest difference is among those between the ages of 6 and 64 - 7.46% compared to 5.49%.

A review of this information in conjunction with data given elsewhere in this guide, and especially in the chapter on health, could lead one to conclude that women, when they are considered or consider themselves to have a disability, reach **higher levels of severity in associated impairments** than men. This assertion is supported by figures for the total number of women and men with disabilities according to type of disability and degree of severity, although there are significant differences among the age groups and this is closely linked to greater longevity among women. If the 6 to 64 age group is considered, the degree of severity is reversed in most cases of disability and is higher for men than for women. Paradoxically it is also in this age group where women have higher rates of moderate and severe severity than men and a lower overall rate of severity for activities such as cooking, dressing oneself, getting undressed, washing oneself, body care and several activities related to travelling, which suggests an association with stereotypes and taking on social roles. The far higher rates among women in comparison to men, and especially in the overall severity rate, for disability related to access to goods and services is also striking.

Only 29.22% of women, compared to 43.78% of men, have their disability acknowledged, and these figures may help us to interpret some of the data on the services they have received.

When data are broken down by age, as we recommended previously, we receive more information that enables us to postulate as to what is happening, although there is still a lack of more in-depth research and analysis. If the **satisfaction level for assistive devices - technical aids** - is studied we can see that although the overall percentages indicate that women with disabilities are happy with the devices they are given, they are only content in the 80 or over age group. The figures must be further disaggregated to discover that they are also satisfied in the 6 to 44 years old age group.

The proportion of people with disabilities who do not use assistive technologies, although they need them, and who are unsatisfied is very high - 29.11% among men and 33.52% among women.

There are small differences between men and women who use braille and sign language, and these are greater between the ages of 6 and 64. Considered the traditional systems for access to information and communication by the blind and deaf, the statistics seem to show that women have more difficulties in accessing them than men.

On the same subject and regarding **boys and girls with some type of limitation**, although they may have been taken into account in other questions, it would be an interesting exercise to determine if the lower proportion of limitations in girls is actually because they are affected less by the causes of impairment, or if their symptoms receive less treatment, are not recognised to the same extent or are treated as less important. At the same time, in-depth research is needed to find out why there are such significant differences between boys and girls in the rates for certain types of limitations: those related to physical and sensory capacities are recognised in a higher proportion in girls, while those related to cognitive capacities are recognised to a much lower degree in girls. Equally, an explanation is needed as to why participation rates in early intervention programmes for girls are almost eleven percentage points lower than for boys. According to EDAD-08 data, the percentage of boys who receive some type of early intervention is 60.99%, while for girls the figure is 50%.

As for girls who require treatment (whether it is given or not), the gap is confirmed: 75.55% of boys, compared to 64.17% of girls, need some type of treatment. In addition, the percentage of girls who need it is higher.

As regards assistive technologies, the percentage of girls who have some type of assistive device is higher than for boys. No assistive technologies, assistance or personal support is given to 29.58% of girls and 34.93% of boys.

It is worth pointing out that the degree of severity of the limitation in the case of girls who receive assistance, when considered in relation to the total number of girls with limitations (not the total who receive assistance) is higher in percentage terms than in the case of boys (considered in the same way).

Girls with some type of limitation are more unsatisfied with the personal help placed at their disposal than boys, although the opposite is the case for technical assistance.

To conclude, the section on **care** is worth commenting on. Care should always be considered from the point of view of the person with disabilities, the so-called 'cared

for', and not from the viewpoint of 'carers', a sector which, as is well known, is traditionally female and suffers discriminated.

EDAD-08 data indicate that a higher percentage of women receive care than men with disabilities - 60.52% of all women and 47.02% of men - although the difference varies with age and is lower in the 6 to 64 years old bracket. These figures lead us once again to the conclusion that women have more severe disabilities in general.

In terms of the relationship between the carer (man or woman) and the person with disabilities, the results are as expected: the percentage of people with disabilities who receive direct care from professional practitioners or through social services (personal assistance or other types of care) is negligible: 4.2% and 0.75% respectively for men who receive personal care, and 7.5% and 2.4% for women). This is a key finding as it demonstrates the lack of freedom people with disabilities have in general when choosing by themselves who they want to live with.

If we look at the most important figures for care by type of disability and sex, there are significant differences in the proportions of women and men in terms of receiving care or not. The proportion of men who receive assistance to manage things, administer their money, use the telephone, cook, eat, etc., is considerably higher, while the proportion is higher for women who are assisted to move around their homes, climb stairs, go shopping and perform other housework. This shows behaviour associated with the social roles assigned to men and women.

In reference to care, in *Care and its perversities: the violence culture* it is stated that "*the solution feminists find to the 'care conflict' is EFFECTIVE EQUALITY between women and men...Nevertheless, this liberation does not reach the 'cared for' person, who therefore believes that this care system is not valid to allow them to experience full citizenship in their own lives and realities.*" Consequently, the independent living philosophy "*looks to transform the care conflict creatively and, to do this, that is to say for both parties (the carer and the person who is cared) to find a balance, it holds that the best way is through creating and developing a new role named 'Personal Assistance'*".

A personal assistant offers freedom of choice and the chance to develop as a person with the same rights and duties as others, and is the means by which one can consider life projects with whoever one wants and control services to act freely.

The Forum for Independent Living points out that *Law 39/2006, dated 14th December, to promote personal autonomy and care for dependent persons*, by establishing an allowance for personal assistance, enables this role to be developed in Spain. If properly administered, personal assistance can also be an option for boys

and girls with disabilities who are students, bearing in mind only their income<sup>14</sup>. As it turns out, it appears only one child is receiving assistance in Spain, through the *Independent Living Office* in the Madrid region.

To quote an example, according to a report by the Madrid *Independent Living Office*, in 2010 59 people received assistance from 114 personal assistants, of whom 75 were women and 39 men, 57% were Spanish, 35% from Latin America, 7% from the rest of Europe and 1% from Africa, confirming comments made previously.

Other independent living programmes are in place thanks to funding from Barcelona City Council, the Catalanian Regional Government, the Andalusia Regional Government and the Galician Regional Government. Other experiences in independent living include those by people with intellectual disabilities, managed or with support from different organisations, although there is no information available on cost or, with regard to the subject matter of this guide, if there are any significant gender differences in terms of participation.

Personal assistance has also been put forward as an efficient economic model. An article under the headline *Personal assistance: an investment in rights and an effective investment in employment* sets out how assigning public resources to hire personal assistants is an efficient investment as it creates jobs with very low indirect management costs and enables people with disabilities and the relatives who care for them (normally women who are replaced) to regain their freedom<sup>15</sup>. The article points out (as others have also done) another advantage of providing personal assistance, which is its flexibility; needs can be met more quickly than through other types of services, for example in rural areas. This is something to be borne in mind considering the problems that exist in rural areas in all countries, including the richest ones.

### 3. ADEQUATE STANDARD OF LIVING AND SOCIAL PROTECTION

*“The confluence of factors such as a lack of competitive vocational training, digital illiteracy, high labour inactivity rates, lack of access to the labour market, performance of non-market activities, existing gaps in salaries between men and women, obstacles caused by the absence of conciliation between family and professional life, longer female life expectancy and, in*

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<sup>14</sup> *Personal assistance for children in the Law promoting personal autonomy and care for dependent persons.*

<sup>15</sup> *Personal assistance: an investment in rights and an effective investment in employment.*

*general, the different forms of gender- and disability-based discrimination, mean that women with disabilities form one of the poorest social groups.”<sup>16</sup>*

It is estimated that most women and girls with disabilities in the world live in rural areas in poor countries or low economic development countries. Although progress has been made in including women in rural areas in human rights treaties, United Nations has recognised that greater focus should be placed on the situation faced by specific groups of rural women such as women with disabilities.

Research on women with disabilities in rural areas in many Asian and Pacific countries has shown that 80% of all women with disabilities do not have access to an independent means to live and are completely dependent on others for survival. Women with disabilities encounter a higher number of obstacles in rural areas due to inaccessibility of environments and lack of resources, information, awareness, education, income and networks. This leads to extreme isolation and invisibility. This brief summary of the situation in which women live says it all but, to complete the picture, we may quote from the Summary of the World Report on Disability on poverty rates:

*“People with disabilities thus experience higher rates of poverty than non-disabled people. On average, persons with disabilities and households with a disabled member experience higher rates of deprivations - including food insecurity, poor housing, lack of access to safe water and sanitation, and inadequate access to health care - and fewer assets than persons and households without a disability.*

*People with disabilities may have extra costs for personal support or for medical care or assistive devices. Because of these higher costs, people with disabilities and their households are likely to be poorer than non-disabled people with similar income. Disabled people in low-income countries are 50% more likely to experience catastrophic health expenditure than non-disabled people.”*

The 2011 World Report on Disability reported the following regarding pay and vulnerable groups:

*“If people with disabilities are employed, they commonly earn less than their counterparts without disabilities; women with disabilities commonly earn less*

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<sup>16</sup> Men and women with disabilities in Europe: statistical analysis of the ad hoc module on disability in the European Labour Force Survey and the European Statistics on Income and Living Conditions (EU-SILC), Final Report, European Commission, DG Employment, Social Affairs and Equal Opportunities (2007).

*than men with disabilities. The wage gaps between men and women with and without disabilities are thus as important as the difference in employment rates. In the United Kingdom of Great Britain and Northern Ireland only half of the substantial difference in wages and participation rates between disabled and non-disabled male workers was attributable to differences in productivity. Empirical research in the United States found that discrimination reduced wages and opportunities for employment.”*

*“Disability disproportionately affects vulnerable populations. There is a higher disability prevalence in lower-income countries than in higher-income countries. People from the poorest wealth quintile, women, and older people have a higher prevalence of disability. People who have a low income, are out of work, or have low educational qualifications are at an increased risk of disability.”*

As was mentioned previously, world poverty has a woman’s face and many studies have addressed the feminisation of poverty. On the subject of women with disabilities and poverty, we can quote once again Susana S. Oliver<sup>17</sup>:

*“Poverty itself is a cause and consequence of disability. People with disabilities are the poorest people in each community, but among them women with disabilities are the poorest of the poor. The barriers and prejudices against women with disabilities mean girls and women with disabilities are viewed as sick, having medical problems that need to be ‘cured’, defective and flawed; they are seen as patients with a clinical background and not human beings with a biography, forever children who need to be protected ‘for their own good’ and incapable of taking decision, so experts and relatives are authorised to take charge of them, thus preventing them from the dignity of risk.*

*This means that poor families with daughters with disabilities face a combination of prejudices and scant resources to feed them, for schooling and for medical care and rehabilitation, so girls with disabilities are left in the background. They will probably not be sent to school, they won’t be fed because resources are scarce and they won’t be given rehabilitation...”*

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<sup>17</sup> *Those completely unknown women.*

In Canada, the eighth country in the world according to the 2010 Human Development Index (in 2009 it was fourth), the 2008 guide *Breaking the links between poverty and violence against women* stated that,

*“...poverty is a reality for a large number of Canadian women. Despite improvements in women’s earnings and incomes relative to men’s, women form the majority of the poor in Canada.*

*Poverty rates for women and men have dropped somewhat since the recession times of the early 1990’s... Nevertheless, in 2004, 2.4 million (one in seven) Canadian women were living in poverty compared to 1.9 million men. And as governments across Canada cut funding to social services and other programs, we are seeing the depth of this poverty worsening.*

*Of all Canadian women who live in poverty today, female lone-parent families are especially vulnerable: 51.6% of lone parent families headed by women are poor. There is also an over-representation of women who are seniors, women with disabilities, Aboriginal women, and immigrant women and visible minority women. These women also face additional barriers - they are often subject to gender discrimination and racism, and in the case of women with disabilities, to a lack of respect and understanding of their physical and mental abilities.*

*Poverty is recognized in Canada as a key factor in determining physical and mental health. People with lower incomes tend to have shorter lives and more health problems. Living in poverty presents women with multiple challenges. These challenges include navigating the welfare system, finding and keeping a job, finding adequate housing and childcare, and dealing with the stigmas and stares associated with being poor. Many are caught in a seemingly hopeless cycle in which the physical and emotional costs of poverty make it difficult to meet existing challenges and make changes in their lives.”*

Moving on to Spain, we have data from the ‘*Study on the economic inequality of people with disabilities in the city of Barcelona*’ carried out in 2006. The study suggests that the illiteracy rate among women with disabilities is higher than the average for persons with disabilities and, furthermore, three times the rate for the population without disabilities; the unemployment rate among women with disabilities is 30%, while for men with disabilities it is 21.15% and for people without disabilities 6.62% (the rate for women in general is 8.34%); the average annual gross salary for women with disabilities is 15 134.40 Euros while for men it is 23 266.30 Euros, amounting

to an 'economic inequality' with respect to the population without disabilities of 8 556.56 Euros per annum for women and 3 443.39 Euros for men; the average non-contributory pension was 5 000 Euros less annually in comparison with the average pension in Catalonia.

*"People on low income were four times more likely to have a disability than those whose financial situation was more comfortable..."*

*"...the disability rate in Spanish households with income under 1 000 Euros per month is 8.4% - almost four times the rate in families earning over 2 500 Euros per month, which is 2.4%."*

The quotes above were taken from the presentation of '*Disabilities and social inclusion*'<sup>18</sup>, a study based on data from EDAD-08. This study, along with other chapters in this book on the situation faced by women with disabilities in education, activity rates and employment, and, among others, '*Employment for people with disabilities*', a study by the National Institute for Statistics in collaboration with IMSERSO, the Spanish Committee for Persons with Disabilities (CERMI) and the ONCE Foundation in 2010, will undoubtedly confirm that women with disabilities are in a worse position in terms of finances and resources than men with disabilities, and in a considerably worse situation if we compare them to people without disabilities. It is also necessary to consider the pensions, often non-contributory, on which older women in general and older women with disabilities are expected to live.

#### 4. LEISURE TIME, CULTURE AND SPORT

*"Femininity has been re-conceptualised to include traditionally male skills. Limits between the masculine and the feminine remain but they are ever hazier, although we are still different."*

*These are the opening ideas in the conclusions to the qualitative report carried out by the market research company QUID, based on several sociological and ethnographic studies and taking a multidimensional approach to women's leisure time.*

*According to the report, from 'superwoman', a multi-faceted and multi-tasking women whose life goal was to be on top of all these tasks and find a space*

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<sup>18</sup> Study by Colectivo loé (an independent social studies team), published by Obra Social "La Caixa" - <http://www.solidaridaddigital.com/SolidaridadDigital/Noticias/Nacional/DetalleNoticia.aspx?id=12271>.

*and identity in the world, we have evolved to 'smart woman', who is also multi-function but chooses to prioritise some areas to be able to enjoy them fully. The model has shifted, therefore, from one where the more tasks the better to one where the woman seeks happiness and quality in moments. The shift comes about because the previous model, far from producing happiness, generated stress, superficiality and a loss of oneself; as a result 'smart woman' decides to prioritise tasks, consciously giving up those that do not satisfy her and are a chore for her, while giving herself over 100 per cent to the tasks she selects, according to QUID experts. This is the key to communication with women consumers, and the approach to women needs to be altered.*

*The studies were carried out in groups involving women between the ages of 18 and 45, looking at different topics and focusing on leisure time. What emerges is a woman who questions traditional roles, demands change, respects herself and her real needs more, lets herself make mistakes and seeks to conquer. This profile is the key to realising that up to now businesses in the leisure sector, and above all in new types of digital leisure, have failed to take into account this shift which has come about in half the population. While for men leisure is a right and an end in itself (the warrior at rest), for a woman it is a means to express herself, to socialise, disconnect and learn; a conscious experience involving a myriad of aspects.*

*As far as the use and meaning of technologies is concerned (personal computers, mobile telephones, MP3 players and video consoles), they are tools to do what one traditionally used to do in a more modern way, with no new habits involved (unlike in the case of men). Our 'smartwoman' demands gadgets and digital leisure devices that respond to her interests, aspirations and needs. According to the study, in her leisure activities 'smart woman' is looking for integrated and satisfactory experiences including learning, enjoyment and socialisation. This poses a challenge to businesses, but also provides an opportunity to conquer a new group: today's women, 'smart woman'."*

This article from March 2010 - *From superwoman to smart woman: women and present-day leisure* - is closely linked to a subject studied and highlighted in research projects in previous years: the huge difference between how men and women use leisure and rest time and the activities they perform. Men have more total leisure and rest time both on working days and on Saturdays and Sundays. Women tend not to break off activities to have a nap, watch less television and participate less in physical

activities (sports) than men, above all if they are mothers and they have young children. The average time a woman spends on active leisure is half the time men spend.

These differences are more pronounced in rural areas, where there are fundamental cultural differences in women's and men's leisure time behaviour - handicrafts as a form of leisure is one example and the very differing uses of technologies (computers, mobile phones, television, etc.) is another<sup>19</sup>.

The EDAD survey provides data that confirms the same behavioural trends in the use of leisure time by women with disabilities and the difficulties associated with disability.

The activities women with disabilities perform in their leisure time differ from those of men and vary according to age, confirming the difficulties related to disability. Women between the ages of 6 and 64 watch television and DVDs less and read or visit relatives much more frequently than men, while the differences become less pronounced and the trends are reversed in some cases in the 65 to 79 years old age group and in others in the over 80 age group.

Women perform other activities such as chatting on the phone with relatives and friends, attending classes and hobbies, craftwork and handicrafts more than men in all age groups, and carry out other activities such as physical exercise, surfing internet, chatting on-line and sending emails, going to sports and cultural events, travelling and going to the library and museums less than men, again in all age groups.

While women with disabilities clearly find themselves in a disadvantageous position compared to men in terms of active leisure time, the available data do not permit us to find out if they are also at a disadvantage in relation to women without disabilities. It would be necessary to compare activity rates among women with disabilities with those of the population in general and women without disabilities. We know difficulties arising from gender-based stereotypes continue to exist, and difficulties related to situations involving disabilities are myriad.

We can cite as an example the documentary *The spiralism theory*, produced by the Spanish Paralympic Committee and sponsored by the Banesto Cultural Foundation. The film documents the lives of female Paralympians Teresa Perales, Eva Ngui, Raquel Acinas, Sara Carracelas and Cristina Campos and highlights the problems they face in their daily lives. It is known that there are fewer women athletes in Paralympic events than in the equivalent men's events, and it is thought that women

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<sup>19</sup> *Women and leisure time: New networks in space and time.*

athletes with disabilities are subject to greater discrimination than women athletes without disabilities<sup>20</sup>.

Taking into account the importance of considering people with disabilities in all types of activities, the *Communication accessibility guide for tourist accommodation*, published by the Andalusia Foundation for Accessibility and Deaf People, stresses how important social tourism is in Spain, an ideal destination for older people who frequently have a disability. The guide points out what needs to be done to offer accessible infrastructures and activities and meet demand.

A recently-published book, *Tourism and gender*, addresses the need to have gender-based data and concludes, among other things, that despite the numerous consultations held every year in Spain, the ‘strategic objective of adapting statistics to include the gender perspective set out in the National Statistics Plan’ has still not been met, although it is hoped that by 2012 this will be resolved. This information is considered to be very helpful by marketing and product design experts in the tourism industry, as well as important if we are to put in place measures to prevent sex tourism, as incorporating the gender perspective “has brought to light the negative impact causes by the behaviour of the tourism consumer who places women and men in unequal positions according to the context; those who are worst affected are girls, boys, adolescents and women in a market where human exploitation proliferates”<sup>21</sup>. Unfortunately this book, written for students, does not address the reality faced by girls and women with disabilities in relation to tourism.

Data is gradually becoming available thanks to programmes by organisations such as PREDIF, which in its annual report has the following to say about the Tourism and Spas Programme it runs in partnership with IMSERSO:

*“Of all beneficiaries, 53.10% are men while 46.89% are women, which represents practically an equitable gender participation. The difference can be encountered if we consider the sex of accompanying persons, where we can see women are over-represented: 68.40% are women compared to 31.60% who are men.”*

## 5. RECOMMENDATIONS FOR THE FUTURE

In order to suggest recommendations for the future, first of all it is a worthwhile exercise to start with some comments from the *2nd Manifesto on the Rights of Women*

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<sup>20</sup> Solidaridad digital - 18/2/2009.

<sup>21</sup> This book looks in detail at three types of behaviour by tourists; two have a positive impact and the third has negative repercussions.

*and Girls with Disabilities in the European Union: a toolkit for activists and policymakers.*

So, **to ensure the right of women and girls with disabilities to live in society** and enjoy equality in terms of their inclusion and participation, place of residence, where and with whom they wish to live, it is vital to:

- Give them the opportunity to live outwith segregated settings, promoting access, on an equal basis with others, to in-home community support services, including in shared housing, social housing and small-scale community-based residences, assistance in the home, and so on;
- Ensure these community-based support services are suitable, affordable, accessible and acceptable;
- Enable them to have the choice of single-sex or mixed-sex accommodation, select the staff and their personal assistants;
- Speed up the deinstitutionalization process from segregated institutions (such as sanatoriums, psychiatric hospitals, reformatories, homes for older people, orphanages and children's homes, among others), and provide support for them to develop their personal independence;
- Promote information campaigns aimed at families and providing information on community resources which are available for the future care and development of girls and women with disabilities;
- Promote efforts to break down sexist and discriminatory stereotypes;
- Facilitate alternative care arrangements within the extended family and, if this is not feasible, within the community in a family setting, if the immediate family is unable to care for a boy or girl with disabilities;
- Encourage fostering and adoption for boys and girls with disabilities, including simplified bureaucratic processes and offering suitable information to foster and adopting families regarding human rights and fundamental freedoms;
- Guarantee access to social housing programmes, whether to live alone or in shared accommodation, and offer financial support to eliminate barriers in the home, including in rented accommodation;
- Ensure all services and programmes designed to assist people with disabilities are monitored by independent watchdogs in order to prevent violations of their human rights and fundamental freedoms, as set out in the Convention on the Rights of Persons with Disabilities;

- Ensure women and girls with disabilities participate in schemes providing advice to service providers, through their representative organisations, carrying out quality control and ensuring services are appropriate to meet the specific needs of women and girls with disabilities;
- Make residential services in the community accessible for women with disabilities and include the gender perspective in the location, the built environment and services and fittings design;
- Provide suitable training in the particular circumstances of women with disabilities to staff in community-based residential services and put in place protocols to prevent gender-based violence;
- Facilitate access to community residences for mothers with disabilities and their sons and daughters should they require it, and provide the necessary resources for them to perform their roles as mothers.

At the same time, to **ensure women and girls with disabilities secure and maintain the maximum possible independence, physical, mental, social and vocational capacity, and full inclusion and participation**, it is necessary to:

- Develop specific habilitation/rehabilitation programmes for women and girls with disabilities in close co-operation with their representative organisations;
- Provide comprehensive habilitation and rehabilitation services and programmes, in particular in the areas of health, employment, education and social services, without discrimination on the grounds of sex or other intersectional factors, with access open to everyone, free of charge and without age limits;
- Train women and girls with disabilities to make them more self-confident;
- Train practitioners in the field of habilitation/rehabilitation to enable them to respond to the specific needs of girls and women with disabilities;
- Offer women and girls with disabilities the opportunity to choose the person - man or women - who is to provide care;
- Provide information on assistive devices and support products in accessible forms and in different formats;
- Ensure the provision of affordable devices and support products which are suitably designed for them and meet their functional, quality and aesthetic requirements. If necessary, introduce regional and national programmes to boost production and importation;

- Consider cultural and religious traditions when providing habilitation/rehabilitation services to ensure they are successful;
- Facilitate access to guidance services given by other women with disabilities and with similar experiences;
- Make sure they are afforded suitable representation in women's organisations and organisations of persons with disabilities;
- Support social volunteering programmes supporting them and, in particular, their participation as volunteers by promoting peer learning, exchanges and best practises at local, regional, national, European and international level through networks of women with disabilities.

**To guarantee women and girls with disabilities enjoy their right to an adequate standard of living and effective social protection:**

- Msainstream the gender and disability dimensions in all policy measures taken to combat poverty;
- Ensure women with disabilities are included and retained in the workforce, above all when economic and financial crises strike, and promote employment in strategic growth sectors; Introduce targeted measures for their initial and ongoing training; make working hours more flexible; enhance effective equal salaries, provide tax benefits and introduce steps to enable them to exercise their rights during pregnancy, motherhood and while breastfeeding; ensure they are part of the social security system and have pension rights;
- Deliver social protection - allowances, social security - to make sure they enjoy an adequate standard of living (food, clothing, housing, disability-related costs, personal assistance for them and, where necessary, for their children) regardless of their marital status or age and independently of their income and social security payments;
- Ensure the built environment and community-based services are accessible to them and boost legal measures and economic support to remove barriers in the home, whether it be their own home or a rented property;
- Give women with disabilities who have no income, are victims of violence or at risk of being abandoned priority when granting access to housing;
- Recognise the informal economy and quantify the value of the 'life economy' through a specific gender focus;

- Deliver appropriate social benefits to women, including women with disabilities, who care for relatives with disabilities, mothers with disabilities and older women;
- Provide them with credit services such as family loans, bank loans, mortgages and other services, on an equal basis with others; encourage savings plans, soft credit and programmes offering financial advice and training, in addition to other measures related to economic affairs to help women with disabilities improve their position;
- Amend consumer legislation to ensure access to information on goods and services on an equal basis with others;
- Initiate a structured social dialogue between networks of women with disabilities and organisations working in the field of poverty reduction;
- Make sure states systematically gather and provide disaggregated data and information by gender and disability in annual reports and, in the case of Europe, in the *joint annual report on social protection and social inclusion*.

Furthermore, to **ensure women and girls with disabilities enjoy all aspects of culture, sport and leisure activities independently and engage fully** in these areas;

- Ensure women and girls with disabilities and the organisations that represent them participate in the relevant authorities as consultants, advisors or experts to make sure cultural and leisure time environments, goods and services are designed in such a way that their specific needs and demands are considered;
- Take cultural, sports and recreational activities to their homes, including centres and residential institutions, and to spaces and centres where community-based social services are delivered such as day centres and occupational centres;
- Ensure they have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society;
- Encourage well-balanced artistic development by supporting artistic output and supporting them, if they so wish, to become professional artists in various professions within the arts field;
- Make cultural activities accessible, including those aimed at children, and introduce activities which also fulfil the interests of girls and women with disabilities;

- Promote cultural projects in which they can develop their creativity;
- Ensure they take up, continue to practice and are encouraged to engage in school and grassroots sport and in both individual and team sports and strengthen elite sport, including Paralympic sport;
- Make sports facilities and sports, recreational and leisure time activities accessible, including those designed for children.

To achieve these recommendations and strategic action areas, future policymakers and third-sector activists need more specific recommendations for action.

### 5.1. Recommendations for policymakers

It is worth reminding policymakers that no action aimed at ensuring the rights of girls and women with disabilities can achieve satisfactory results if it is not linked to radical policies (in the literal sense of the word radical) to advocate to promote the rights of women and the rights of people with disabilities in general in order to **eliminate the root causes of the terrible discrimination they face every day.**

- Develop suitable legislative support:
  - Ratify the Convention on the Elimination of all Forms of Discrimination against Women and the Convention on the Rights of Persons with Disabilities (article 19);
  - Implement the Convention on the Elimination of all Forms of Discrimination against Women and the Convention on the Rights of Persons with Disabilities (and especially article 19) jointly;
  - Adopt suitable legislative steps to facilitate independent living and social inclusion for girls and women with disabilities;
  - Introduce suitable legislative measures to prevent, outlaw and punish violations on the part of third parties of the provisions of both conventions in the fields of independent living and social inclusion, including those committed in private homes and the community;
  - Ensure victims are suitably compensated:
    - Evaluate the damage caused by not implementing these conventions and violations in any action by any public authority or persons representing them (politicians or civil servants), or by any company or company representative;

- Put in place a system to deliver services or compensation for the damage caused, when it can be compensated for in this way, and a system of penalties which is commensurate with the damage caused;
- Establish closer relations with people with disabilities, including girls and women with disabilities and either directly or through their representative organisations:
  - Set up participatory bodies at all levels and especially at local level, where proposal can be tabled, consultations carried out, and policies and actions planned with the aim of equipping the community with the services needed to ensure all persons with disabilities are able to live independently;
  - Set up and maintain reporting mechanisms in case of complaints and systems to resolve complaints;
  - Establish monitoring and assessment processes and mechanisms to make sure actions undertaken are completed;
- Introduce policies favouring inclusion and participation in society:
  - Carry out research to find out the real situation girls and women with disabilities face (early detection and intervention to prevent impairments; preventing all types of risk situations; efforts in the fields of health, education and the family; respect independence when delivering services, including in institutions);
  - Carry out in-depth studies from the gender perspective on the many research projects already conducted and statistics gathered in each country in order to extract more and better information on the reality faced by girls and women with disabilities, differentiating by age between adolescents and young people, in those countries where similar studies on the rest of the population are performed;
  - Compare the quality of life people with and without disabilities enjoy and the life quality of those who live in institutions and those who receive community-based services;
  - Carry out early impairment detection campaigns aimed especially at girls, programmes to prevent illnesses and injuries (these differ in each country and region according to available data on the cause of disability) leading to impairments and campaigns to reduce risks in the home;
  - Put in place universal ongoing preventive rehabilitation programmes for those with chronic illnesses;

- Include girls and women with disabilities in rehabilitation programmes (as defined by the World Health Organisation) which are suitable to their needs in terms of independence;
- Set up support services for independent living, for functioning in the home and everyday life, studying, working, leisure time activities, relationships, etc., beginning by offering personal assistance, including to children, to ensure boys and girls develop normally and to provide support to mothers and fathers, covering all their needs - accessible transport, support products (technical aids) for all situations and activities, home help, paying particular attention to rural areas;
- Promote Independent Living Offices (ILO) which are managed by people who have personal assistance, and bear in mind gender equality at all times;
- Provide and maintain allowances to cover basic needs and compensate for the cost of targeted services if they are not provided free of charge, and check closely to ensure the woman with disabilities receives and controls such allowances or, should she be unable to, that her guardian is making proper use of them and attempting to maximise her empowerment, as one mechanism to prevent poverty;
- Facilitate the right to free choice by the woman in selecting who should provide personal assistance services and ensure direct payment;
- Offer women with disabilities different options in types of residence so that they may choose their own lifestyle - living alone, with a partner, in shared flats, small residences, etc. These alternatives must also cover the need for temporary stays;
- Agree a timetable for transition from institutions to other residential services with organisations representing people with disabilities and, above all, with organisations representing girls and women with disabilities;
- Provide accessible spaces for persons with disabilities in rural areas so that they can take part independently, fully and safely in social life in the same way as others;
- Provide accessible and affordable public transport in rural areas to enable people with reduced mobility to take part independently and fully in family and community life;
- Assess the accessibility level of built environments and the services delivered therein (both environments designed for use by the general public and those

- specifically for people with disabilities), to ensure they are accessible; include accessibility management in quality control systems in all services;
  - Provide women with economic support to make their homes accessible, including rented accommodation;
  - Refrain from building inaccessible environments and creating inaccessible services (this includes equipment therein, with the classic example being gynaecology clinics);
  - In all organised leisure and free time activities, include whatever measures are required to ensure the gender perspective is mainstreamed and the principles of universal accessibility and design for all are respected;
  - Promote cultural and leisure activities that take into account the interests of women and encourage women with disabilities to engage in them.
- Enhance the capacity for action of persons with disabilities and the organisations representing them:
    - Provide therapeutic support services (psychological treatment, escorting services, body language, relaxation, stress and emotional relief) from the moment a disability is detected, both to the person involved and to his or her relatives and friends;
    - Educate girls with disabilities in the meaning and reality of gender differences;
    - Set up self-help networks and groups for people with disabilities to enable them to exchange practical resources and mutual emotional support, thus promoting personal autonomy in everyday life. These should be open also to people with a newly-acquired disability and their family and friends;
    - Promote training for personal autonomy to empower girls and women with disabilities;
    - Support the establishment of organisations of women with disabilities;
    - Fund programmes to exchange experiences among girls and women from different countries.
  - Support current and future practitioners to allow them to apply mainstreaming policies suitably and provide support for them:

- Include respect for the rights of women and girls with disabilities at all levels of education, within the framework of the rights of women, the rights of persons with disabilities and respect for human diversity;
  - Carry out information campaigns to demonstrate the importance of respectful professional practises in the case of girls and women, and especially in the case of girls and women with disabilities;
  - Train practitioners in all areas - education, medicine, general health, psychology, therapy, law, legal, police, journalists, rehabilitation, management, etc - in human diversity as a means of preventing discriminatory behaviour. Priority should be given to training those already working with people with disabilities and supporting them in order to shed acquired prejudices;
  - Special focus should be given to educating policymakers in diversity, equality, the independent living philosophy and human rights;
  - Protocols for ethical intervention should be established for practitioners, focusing on protecting girls and women with disabilities;
  - Women practitioners with disabilities should be promoted to act as role models in respecting and developing human rights in their work.
- Media interest in mainstreaming measures should be encouraged to support them:
    - News about positive experiences - good practises - in independent living by women and girls with disabilities should be disseminated;
    - Girls and women with disabilities should be included as presenters, actresses, participants or in the audience in TV and radio programmes and in the cinema;
    - Cases where women and people with disabilities, and in particular girls and women with disabilities, are ridiculed, mistreated or their image is used unsuitably should be penalised.
  - Systems should be put in place to protect and promote the rights of persons with disabilities in institutions and services and cases of guardianship and wardship (both personal and institutional):
    - Set up teams of inspectors to protect and promote individual rights;
    - Carry out independent audits;

- Establish reporting systems to denounce infractions and cases of discrimination and allow women and girls with disabilities themselves to express their needs and level of satisfaction with measures and services targeting them;
- Innovate in delivering activities and in service provision:
  - Design services in such a way that independent living for girls and women with disabilities is facilitated to promote human diversity, that is to say any situation involving needs and all types of impairment - cognitive, physical or neurological, hearing, visual, mental illness, etc. - in order to respond quickly and efficiently to all needs;
  - Keeping institutions such as residences and geriatric homes open to the community, such as for example through outreach activities involving all local residents, will prevent isolation among residents, make it easier for an exchange of information about potential violations of residents' rights, and contribute to empowering residents;
  - Take advantage of existing social infrastructures and resources of whatever type in order to meet the needs of girls and women with disabilities, in particular in rural areas where populations are lower and there are generally few resources;
  - Establish communication channels to allow the general public to become aware of the situation and needs of girls and women with disabilities and put forward suggestions and proposals;
  - Strengthen social networks as powerful tools for communication and exchange of experiences, and organise information and practical workshops in the field of ICTs;
  - Promote relations and knowledge of different groups of people through all types of activities and mixing different activities; girls and older women with disabilities could engage in storytelling, women with and without disabilities discuss marriage, etc.;
  - Take advantage of existing social infrastructures and resources - social services, cultural and educational services - in each town or neighbourhood to make contact through awareness-raising programmes with girls and women with disabilities who are victims of discrimination.

## 5.2. Recommendations for third-sector activists

It is also worth reminding activists in third-sector organisations that no action aimed at ensuring the rights of girls and women with disabilities can achieve satisfactory results if it is not linked to radical policies to advocate to promote the rights of women and the rights of people with disabilities in general in order to **eliminate the root causes of the terrible discrimination they face every day**.

- Advocate for the rights of girls and women with disabilities in the framework of the rights of women and the rights of persons with disabilities;
- Work to promote a culture of peace, inclusion and emancipation and encourage full participation in socio-political issues, education and economic and cultural affairs by women and men with disabilities in an environment of respect for the principles of equal opportunities and non-discrimination, human rights, gender equality and the world philosophy of independent living, both in peaceful areas and post-conflict situations<sup>22</sup>;
- Encourage the use of ethical action protocols in civic organisations and social movements;
- Engage with civic organisations and social movements, in particular at local level in neighbourhoods or towns, to make them aware of gender and disability issues;
- Carry out joint activities with civic organisations and social movements. These activities should take into account all diversity factors - age, functionality, gender, etc.;
- Raise awareness of the need for spaces, activities and services organised or delivered by civic organisations and social movements to be accessible;
- Set up fora for participation within organisations of persons with disabilities to discuss the situation faced by women and with the aim of putting forward policies and activities to improve that situation, including training programmes and with proper assessment and monitoring mechanisms;
- Put in place mechanisms to ensure equal representation by men and women in all representative and management positions within organisations of persons with disabilities;
- Set up and maintain internal complaint management and resolution systems within organisations;

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<sup>22</sup> Constitution of the Institute for Peace, Human Rights and Independent Living (IPADEVI).

- Within civic organisations and social movements - whether they are of persons with disabilities or not - set up and maintain mechanisms which are open to society so that any person may report cases of discrimination affecting their members or others, and co-operate with the person reporting the case in order to resolve it;
- Link up support networks for women with disabilities and those in civic organisations and social movements, and in particular in the feminist movement;
- Seek support from civic organisations and social movements, and especially from those working in women's rights, to exchange experiences with women and girls with disabilities in different countries;
- Promote women with disabilities as leaders in mainstream civic organisations and social movements, and in particular in the feminist movement;
- Share positive experiences and good practises in independent living by women and girls with disabilities with civic organisations and social movements;
- Mobilise civic organisations and social movements to promote services for girls and women with disabilities and encourage them to take part in independent auditing;
- Raise awareness among civic organisations and social movements of the need to use available facilities in institutions such as residences and geriatric homes for activities open to everyone in the neighbourhood or town, thus preventing or reducing isolation among residents, facilitating exchanges of information in the face of potential abuses of their rights and contributing to their empowerment;
- Take advantage of existing social infrastructures and resources - social services, cultural and educational services - in each town or neighbourhood to make contact through awareness-raising programmes with girls and women with disabilities who are victims of discrimination;
- Establish co-operative systems for service provision - volunteering, time banking, exchange schemes, etc. - with civic organisations and social movements.

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## Chapter VII

# SEXUAL AND REPRODUCTIVE RIGHTS

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## Chapter VII

# SEXUAL AND REPRODUCTIVE RIGHTS

### 1. INTRODUCTION

In this chapter it is our intention to offer an overview of the sexual and reproductive rights of women and girls with disabilities, using an approach based on the conceptualisation of these rights in international United Nations treaties. To do so, we shall begin by giving an overview of how the conceptual framework for these rights has been shaped by different UN instruments from a broad and ever-developing perspective.

Once we have studied in some detail the genesis of the inclusion of sexual and reproductive rights for persons with disabilities in the specific treaty addressing them and during the negotiation process leading up to the final text (thanks to insight provided in an invaluable report by Sigrid Arnade and Sabine Haefner, two important human rights activists, which was published recently in Germany), in the third section we shall move on to reflect in some detail on the obstacles which make it difficult or impossible for women and girls with disabilities to enjoy these rights. This analysis will be based on the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers*, adopted by the European Disability Forum at its general assembly in 2011.

The following two sections shall specifically address the right to motherhood and forced sterilisation and coerced abortion, in the latter case making use of the European Disability Forum's contribution in 2010 to the general discussion on the right to sexual and reproductive health held by the United Nations Committee on Economic, Social and Cultural Rights. With minor modifications, the same document was submitted one year later - in July 2011 - in response to a call for papers from the United Nations Commission on the Status of Women.

The final section sets forth recommendations as practical guidance which, we believe, can help to show the way in advocating for the rights and fundamental

freedoms of women with disabilities in relation to their sexual and reproductive rights, and coherent arguments in favour of their being mainstreamed in public policies on the matter.

To complement this chapter, sexual and reproductive health and sexual abuse have been addressed in this guide in the chapters on health and violence respectively.

## 2. CONCEPTUALISATION OF SEXUAL AND REPRODUCTIVE RIGHTS

Sexual and reproductive rights are those rights safeguarding free choice on how one experiences one's own body in the areas of sex and reproduction. This involves the right of all individuals to decide when, how and with whom one wishes to have sexual relations and descendents.

As agreed at the 4th World Conference on Women, sexual rights<sup>1</sup> include women's human right to have control over their sexuality, including sexual and reproductive health, and to decide freely and responsibly, free of coercion, discrimination and violence. These rights assume equal relationships between women and men in matters of sexual relations, including full respect for the integrity of the person, and require mutual respect, consent and shared responsibility for sexual behaviour and its consequences.

Reproductive rights include the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information, education and means to do so, and the right to attain the highest standard of sexual and reproductive health. They also include the right of all to make decisions concerning reproduction free of discrimination, coercion and violence.<sup>2</sup>

All these rights, both sexual and reproductive, presuppose other basic rights such as the right to sexual health and reproductive health<sup>3</sup>. The conceptual framework for sexual health involves enhancement of life and personal relations, so sexual health services should not focus merely on counselling and care related to reproduction and sexually-transmitted diseases. Reproductive health should be understood to be a state of complete physical, mental and social well-being, which implies that people

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<sup>1</sup> *Platform for Action*, paragraph 96, 4th World Conference on Women, Beijing, China, September 1995.

<sup>2</sup> As we shall see below, reproductive rights are recognised in various human rights treaties and other United Nations supporting documents.

<sup>3</sup> *Platform for Action*, paragraph 94, 4th World Conference on Women, Beijing, China, September 1995.

are able to have a satisfying and risk-free sex life, have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the rights of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which do not contravene the law. Furthermore, reproductive health means the right to appropriate health-care services enabling women to go safely through pregnancy and childbirth and providing couples with the best chance of having girls and boys.

Although these sexual and reproductive rights are not explicitly set out as such in any international human rights instrument, many of them can be found in some way in all of them, so it is possible to assert that most reproductive rights are acknowledged internationally and are legally binding.

We can state then that women's sexual and reproductive rights in international human rights law are the sum of a range of civil, political, social, cultural and economic rights; the right to health; to sexual and reproductive health; to family planning; the right to decide how many children one wishes to have and the spacing between them; the right to marry and form a family; the rights to life, liberty, integrity and safety; the right to freedom from discrimination on the basis of gender; the right to freedom from sexual attacks and exploitation; the right to freedom from torture and other cruel, inhuman or degrading treatment or punishment; the right to modify customs which discriminate against women; the right to privacy; the right to intimacy; the right to benefit from scientific progress; and the right to give consent to be the subject of experiments.

What then is the basis for recognising and protecting these rights? The Universal Declaration of Human Rights; the International Covenant on Civil and Political Rights; the International Covenant on Economic, Social and Cultural Rights; the Convention on the Rights of the Child; the Convention on the Elimination of All Forms of Discrimination against Women; and, more recently, the Convention on the Rights of Persons with Disabilities, include explicit references to sexual and reproductive rights, so they form an integral part of the legal systems in those countries which have ratified them.

While it would be an interesting exercise to look specifically at how these rights are addressed and complement each other in these international treaties, due to lack of space and time we shall study only the Convention on the Elimination of All Forms of Discrimination against Women and other documents on the matter agreed at United Nations level, then go on to look at the Convention on the Rights of Persons with Disabilities in a later section.

The Convention on the Elimination of All Forms of Discrimination against Women<sup>4</sup> focuses on three aspects concerning the status of women. On the one hand it deals with women's civil rights and legal and social status, which are addressed in detail. In addition, however, and unlike in other human rights treaties, it also includes human reproduction and the consequences of cultural factors in relations between the sexes.

As well as civil rights, the convention focuses closely on the right to procreation, a matter of some concern for women. The preamble sets the tone by stating that, "*the role of women in procreation should not be a basis for discrimination*". In fact, the link between discrimination and the procreating role played by women is a constant in the convention. Article 5, for example, calls for "*a proper understanding of maternity as a social function*", which requires both sexes to share responsibility for bringing up their children fully. Consequently, the provisions on protection for maternity and childcare are enshrined as essential rights and are to be included in all areas covered by the convention, whether dealing with employment, family rights, health or education.

The obligations placed on society extend to providing social services, and particularly childcare, to allow parents to combine family responsibilities with work and participation in public life. Moreover, special measures for maternity protection are recommended and "*shall not be considered discriminatory*"<sup>5</sup>.

One noteworthy fact is that the convention, which also establishes the right to reproductive choice, is the only human rights treaty to mention family planning. In this respect, States Parties are obliged to include advice on family planning in the education process<sup>6</sup> and to develop family codes that guarantee women's rights "*to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights*"<sup>7</sup>.

Consequently, those states that have ratified the convention are also obliged to "*prevent discrimination against women on the grounds of marriage or maternity and to ensure their effective right to work*"<sup>8</sup>. They must prohibit dismissal on the grounds of pregnancy or maternity leave, introduce paid maternity leave and encourage the provision of social services to offer support in these areas to enable fathers and

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<sup>4</sup> *Convention on the Elimination of All Forms of Discrimination against Women*: <http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm>.

<sup>5</sup> Article 4, *Convention on the Elimination of All Forms of Discrimination against Women*.

<sup>6</sup> Article 10 h, *Convention on the Elimination of All Forms of Discrimination against Women*.

<sup>7</sup> Article 16e, *Convention on the Elimination of All Forms of Discrimination against Women*.

<sup>8</sup> Article 11.2, *Convention on the Elimination of All Forms of Discrimination against Women*.

mothers to combine family obligations with work responsibilities and participation in public life.

Evidently the adoption of the convention and its entry into force were landmarks for women, who were also instrumental in ensuring the approval of the convention's optional protocol, an instrument which adds power and effectiveness to the treaty by putting in place mechanisms to submit complaints regarding violations by states and investigate them.

As we said above, there are, however, other international documents which have been agreed within the United Nations system and refer to these rights. This is the case, for instance, of the World Conference on Human Rights, held in Vienna in 1993, where women's sexual rights were recognised as human rights for the first time.

Just one year later, the World Conference on Population and Development (Cairo, 1994) was the first international conference to define the term 'reproductive rights', in addition to defining 'reproductive health', and lay down the basis for these rights: *"...to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, without suffering discrimination, coercion or violence."*<sup>9</sup>

In the Platform for Action adopted at the 4th World Conference on Women (Beijing, 1995) the concept of 'reproductive health'<sup>10</sup> was included in the same way as it had been expressed the year before in the Cairo Programme of Action, going one step further by defining sexual rights as they were set out at the beginning of this chapter. Furthermore, there is explicit reference to unwanted pregnancy and a recommendation to deliver social services in those cases where it is permitted: *"Women who have unwanted pregnancies should have ready access to reliable information and compassionate counselling. In circumstances where abortion is not against the law, such abortion should be safe."*<sup>11</sup> The platform also refers to unwanted pregnancies as a consequence of sexual and sexist violence, thus reaffirming the Vienna text, and declares forced pregnancy to be a violation of fundamental human rights and international humanitarian law<sup>12</sup>.

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<sup>9</sup> Paragraph 7.3, *Cairo Programme of Action* (1994).

<sup>10</sup> *Platform for Action*, paragraph 94, 4th World Conference on Women, Beijing, China, September 1995.

<sup>11</sup> *Platform for Action*, paragraph 106 k, 4th World Conference on Women, Beijing, China, September 1995.

<sup>12</sup> *Platform for Action*, paragraphs 132, 135, 145 c, 145 e and 114, 4th World Conference on Women, Beijing, China, September 1995.

Finally, another key instrument worth mentioning is the Statute of the International Criminal Court (Rome, 1998) which, for the first time in international criminal law, defines and codifies rape, sexual slavery, forced prostitution, forced pregnancy, forced sterilisation and other forms of sexual violence as crimes against humanity and war crimes. The Rome Statute places rape and other sexual and reproductive crimes on a par with the most atrocious international crimes, many of which constitute torture and genocide. Moreover, it acknowledges for the first time that violations of women's reproductive self-determination - both forced pregnancy and enforced sterilisation - are extremely serious crimes under international humanitarian law.

### 3. SEXUAL AND REPRODUCTIVE RIGHTS IN THE *CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES*

With a view to familiarising ourselves and gaining a deeper understanding of how the sexual and reproductive rights of women with disabilities are promoted, and bearing in mind the information given above, we must now turn our attention to the Convention on the Rights of Persons with Disabilities (CRPD). We shall attempt to provide some explanations to understand better what circumstances worked in favour and which hindered or prevented these rights from being included in the CRPD.

As we set out elsewhere<sup>13</sup>, by virtue of Resolution 56/168, in December 2001 the United Nations General Assembly created an Ad Hoc Committee tasked with drafting the convention. The committee met during eight periods of meetings once negotiations began in 2002, and its work concluded in August 2006. However, discussions on protecting women and girls from discrimination and, as a result, their inclusion in the convention, did not take place from the outset, and this had a direct bearing on the outcomes in terms of gender and, even more so, their sexual and reproductive rights. Neither the government delegations nor the civil society organisations involved realised the urgency of the matter - most likely due to their lack of training in gender affairs and the lack of feminists in the government and civil society deputations.

It has to be said it was sad to see women's organisations overlooking the demands of women with disabilities and not engaging in the negotiation process. At the same time, many committee members felt that women with disabilities were already covered

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<sup>13</sup> Ana Peláez Narváez, '*Non-discrimination, women and girls with disabilities and the International Convention on the Rights of Persons with Disabilities*' in '*2003-2012: 10 years of anti-discrimination legislation for people with disabilities. Studies in tribute to Miguel Ángel Cabra de Luna*', CERMI, Fundación Derecho y Discapacidad, Madrid, 2012, pages 244-271: <http://www.fderechoydiscapacidad.es/>.

in a specific treaty, so they believed it wasn't necessary to focus especially on them. They did, however, argue the need to reform the CEDAW reporting system in order to improve reporting on women and girls with disabilities.

Having overcome these hurdles and limitations, in the end a specific article addressing women with disabilities and clearly acknowledging that multiple discrimination exists was included in the convention. In addition, other explicit references to women and gender were included throughout the convention.

As regards sexual and reproductive rights, there are very limited and generic references in the treaty in the articles addressing respect for the home and family (article 23), health (article 25) and freedom from exploitation, violence and abuse (article 16).

It is important to mention that ensuring protection for the reproductive rights of women with disabilities in the convention was a key issue for women with disabilities and their representative organisations during the drafting stage. For this reason, the few organisations of women with disabilities who eventually joined the International Disability Caucus fought until the eighth and final Ad Hoc Committee meeting to ensure the reproductive rights of women with disabilities were included in CRPD article 6<sup>14</sup>. However, in the final text reproductive rights for persons with disabilities were included only in articles 23 (respect for the home and family) and 25 (health), without explicit reference to the specific needs of women with disabilities.

It is also fair to say that including references to health care in sexual and reproductive health was the subject of discussions in the committee until the very end of the drafting phase, despite the fact that the right to family planning and healthcare during pregnancy, childbirth and breastfeeding had already been confirmed in binding human rights conventions<sup>15</sup>. Those most opposed to it included some governments and some non-governmental organisations who were afraid that explicit mentions of such health services would open the door to recognising new rights, and in particular the right to abortion<sup>16</sup>. They argued that the instructions given by the Ad Hoc Committee, which had made it clear that no new rights could be created by virtue of the convention, did not rule out other potential interpretations<sup>17</sup>.

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<sup>14</sup> See, for example, the International Disability Caucus' comments on article 6 during the 8th period of sessions of the Ad Hoc Committee. Available at: [www.un.org/esa/socdev/enable/rights/ahc8contngos.htm](http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm).

<sup>15</sup> Article 12, Convention on the Elimination of All Forms of Discrimination against Women.

<sup>16</sup> See, for example, discussions during the sixth meeting of the Ad Hoc Committee, 8th August 2005: [www.un.org/esa/socdev/enable/rights/ahc6sum8aug.htm](http://www.un.org/esa/socdev/enable/rights/ahc6sum8aug.htm), and during its seventh meeting (24th and 25th January 2006): [www.un.org/esa/socdev/enable/rights/ahc7summary.htm](http://www.un.org/esa/socdev/enable/rights/ahc7summary.htm).

<sup>17</sup> See, for example, comments submitted by the Society of Catholic Social Scientists and the Pro-Life/Pro-Family Coalition for the Protection of Persons with Disabilities during the sixth Ad Hoc Committee meeting: [www.un.org/esa/socdev/enable/rights/ahc6contngos.htm](http://www.un.org/esa/socdev/enable/rights/ahc6contngos.htm).

To settle the discussion, the President was forced to clarify on several occasions that the intention was in no way to establish any new rights in the convention or influence national family or reproduction policies. During his statements he added that the convention did not impose any obligation to adopt new legislation in the field of reproductive health or in any other related area; the goal was rather to ensure that people with disabilities enjoyed the same access, without discrimination, to reproductive health services<sup>18</sup>.

Having then made it through despite all these shortcomings and differences of opinion during the negotiations, article 23 of the convention recognises the rights of persons with disabilities to marry and form a family, decide freely on the number and spacing of their children, to have access to information on family planning and to retain their fertility on an equal basis with others.

Article 25 includes a specific reference to the need to provide gender-sensitive healthcare, including sexual and reproductive health. Despite the fact that unfortunately it was not possible, as many countries and organisations wished<sup>19</sup>, to oblige States Parties to protect people with disabilities from forced sterilisation and coerced abortion, paragraph d in article 25 does also place a duty on States Parties to require health professionals to provide care to persons with disabilities only on the basis of free and informed consent.

Moving on to freedom from exploitation, violence and abuse, in general terms these issues were addressed by the Ad Hoc Committee from the outset of their deliberations. During the committee's third meeting, the European Union put forward a proposal for a recital in the convention preamble to highlight that women with disabilities are exposed to greater risk of violence and abuse. This was adopted despite opposition from some delegations to including gender references. Subsequently, in 2004, when the time came to discuss what was then article 13 on freedom from torture and other cruel, inhuman and degrading punishment, the text from the working group already included a specific paragraph on violence and abuse calling for special focus on women and children:

*3. States parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, and in particular*

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<sup>18</sup> See, for example, the report on the sixth period of sessions of the Ad Hoc Committee, A/60/266, 17th August 2005: [www.un.org/esa/socdev/enable/rights/ahc6reporte.htm](http://www.un.org/esa/socdev/enable/rights/ahc6reporte.htm).

<sup>19</sup> See, for example, discussions during the sixth meeting of the Ad Hoc Committee, 8th August 2005: [www.un.org/esa/socdev/enable/rights/ahc6sum8aug.htm](http://www.un.org/esa/socdev/enable/rights/ahc6sum8aug.htm), and the joint proposal on women and children, 28th January 2006: [www.un.org/esa/socdev/enable/rights/ahc7facilitator.htm](http://www.un.org/esa/socdev/enable/rights/ahc7facilitator.htm).

*women and children with disabilities, from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse.*

Although exploitation, violence and abuse were considered at a later date in a separate article, this paragraph would subsequently serve as the basis for the final wording of article 16, using article 19 of the Convention on the Elimination of All Forms of Discrimination against Women as a guide.

Article 16 of the Convention on the Rights of Persons with Disabilities, therefore, focuses on protection to ensure freedom from this type of treatment. The article establishes that, “*States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home...States Parties...[are obliged] to put in place all measures to provide assistance and support for persons with disabilities and their families and caregivers,...and effective legislation and policies,...to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.*” Sexual abuse, however, is not explicitly referenced.

#### 4. ENJOYMENT OF SEXUAL AND REPRODUCTIVE RIGHTS BY WOMEN WITH DISABILITIES

Without a doubt we can assert that as a result of the misconceptions society in general has surrounding women with disabilities, and the fact that they are undervalued by their own families in particular - they are viewed as asexual, unsuitable for life in a relationship or as a mother and, at the same time, their sexual needs are firmly controlled - many are still unable to enjoy their sexual and reproductive rights<sup>20</sup>.

In fact, despite the fact that women with disabilities of marrying age have the right to marry and form a family on the basis of their free and informed consent, as well as the right to be part of other types of affective relationships involving a stable partner and worthy of protection from public authorities, such as, *inter alia*, civil partnerships, many countries in the world, including in the European Union, continue to impose practises and legislation that prevent many women from enjoying their rights. In Romania, for instance, and although the right to marry and form a family is enshrined

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<sup>20</sup> *Recognising the rights of Girls and Women with Disabilities - an Added Value for Tomorrow's Society*, report from the European Conference, Madrid, CERMI-EDF (2008).

in the Civil Code, the same code bans people with intellectual disabilities and those who are not “*in full possession of their mental faculties*” from marrying and forming a family<sup>21</sup>. Other types of relationships are still very rare and tend to survive despite strong resistance from families and the community.

The situation, however, becomes much worse when we talk about the right of women with disabilities to be mothers and decide how many children they wish to have and how and when they wish to do so. Whether they enjoy this right or not is questioned openly and without reserve by society, the political class and legislators, based on eugenic arguments or on preserving the “*superior interests of the child*”<sup>22</sup>. As a result, we should not be too surprised that access to reproduction and family planning services for women with disabilities is not a particular concern in public policies and that reasons are still found to justify practises that are inconsistent with human rights, such as forced sterilisation and coerced abortion. Women and girls with disabilities have the right to retain their fertility on an equal basis with others and without exception.

Despite these flagrant human rights violations, organisations of persons with disabilities, organisations representing families and women’s organisations failed to address these issues until just a few years ago. In fact it could be argued that on occasions these issues were considered in the same way as women with disabilities have been treated by society in general, and as a result nobody has considered their sexual and reproductive rights. Thanks to the efforts of a few activists committed to defending the human rights of these people - often working individually and without support - in recent times some organisations have begun to speak up and condemn the fact that practises like forced sterilisation and coerced abortion continue to be performed on young women and women with disabilities, mostly, but not exclusively, with intellectual or psychosocial disabilities. Despite this, the question is still far from being resolved in many organisations that disagree, either openly or privately, with the universality of this right. Fear of pregnancy and its consequences (such as believing that the mother will not have the skills and/or means to raise the child, the physical repercussions for the mother, fear of passing on the disability, etc.) were for many years the greatest concern for the families of women with disabilities, a fear often shared by their health service practitioners. This concern has influenced the lives of these women with disabilities and led to them having less independence and privacy as they are unjustifiably supervised and controlled.

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<sup>21</sup> *Study on the situation of women with disabilities in light of the UN Convention for the Rights of Persons with Disabilities* (VC/2007/317), a final report for the DG Employment, Social Affairs and Equal Opportunities of the European Commission, ECOTEC, 2009.

<sup>22</sup> *Motherhood and Disability*, CERMI, 2008.

The situation, however, goes further: the sexual and reproductive rights of women and girls with disabilities cannot be safeguarded simply by eliminating such practises as these rights are seriously violated in other ways which, in the best of cases, go unnoticed.

Sexual abuses, sexual exploitation, denial of undesired sexual orientation or separating women with disabilities from their children are just some examples. This is why it is necessary for civil society to press forward in actively calling for action in other areas which are equally important for these women. Sexual rights, understood to mean liberty to decide freely and responsibly on all questions related to sexuality, implies also the right to exercise one's sexuality safely, free from discrimination, coercion and violence; the right to physical and emotional pleasure; the right to freely-chosen sexual orientation; the right to information on sexuality; and the right to access sexual health services. Reproductive rights, taken to mean the freedom and independence each individual has to decide responsibly if she or he wants to have children or not, how many, when and with whom, encompasses also the right to access information, education and the means to do so; the right to take decisions on reproduction free from discrimination, coercion and violence; the right to access quality primary healthcare, and the right to measures to protect motherhood. All these rights must be fully guaranteed for female adolescents and women with disabilities under conditions of equality, free consent and mutual respect: to date this has not been the case.

Empowering women with disabilities therefore becomes an urgent necessity as neither society nor public powers, nor women's movements, nor the disability movement has shown a real interest in furthering their needs and demands; nor have they made efforts to advocate for their rights and fundamental freedoms. That is why there is a need to support and strengthen organisations, networks and groups managed and led by women with disabilities to defend their own collective interests as they are set out by women with disabilities themselves.

Undoubtedly one of the reasons why discrimination prevents women and girls with disabilities from enjoying these rights is the lack of suitable training on the matter. This training should be delivered in accordance with their age and disability and should be extended to include families and professionals also. As has been pointed out elsewhere<sup>23</sup>, the restricted access and limited control female adolescents and women with disabilities have over their own sexuality makes them vulnerable to sexual exploitation, violence, unwanted pregnancies and sexually-transmitted diseases. Consequently, girls, female adolescents and women with disabilities must have access to affective-sexual education programmes in order to experience it healthily.

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<sup>23</sup> Paragraph 8.5, *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers*, CERMI-EDF, 2011.

They must know enough about how their bodies function (how one becomes pregnant and how to avoid it, how to make sexual relationships more communicative and pleasurable, how to say no to unwanted practises, how to avoid sexually-transmitted diseases, etc.) through programmes led by professionals who are experts in the subject matter such as local public social service educators.

As we said above, sexual exploitation, that is to say illegal activities involving one person, usually a woman or someone who is underage, being exposed to violence or intimidation to force her or him to perform sexual acts or practises against her or his will, with a third party benefitting economically, is a crime to which women and girls with disabilities are particularly exposed, yet the problem remains unaddressed, not even when women with disabilities are used to advertise content of a sexual nature. Something similar happens in the sexual abuse to which many girls and women with disabilities are exposed and which is perpetrated in many cases by their own relatives or carers - these cases are barely reported<sup>24</sup>.

Once again organisations of persons with disabilities and women's organisations must make an effort to stand up for the rights of these women and girls with disabilities, who are treated as objects and suffer physically and psychologically from this torture and inhuman and degrading treatment. They must raise awareness among the most at-risk groups regarding sexual abuse and exploitation and publicly report any cases which come to light. Public authorities must put in place safeguards and preventive measures to protect them from this kind of behaviour, particularly in closed and segregated environments.

Violations of sexual rights, however, do not end here. They extend to include other groups who, due to their being minorities, are hidden and invisible from reports and reparations for victims. We refer to the manifest discrimination faced by lesbians, bisexual and transsexual women with disabilities, who are often victims of heightened prejudices against homosexuality due to their disability. Research on the causes of discrimination on the grounds of religion or belief, age, disability or sexual orientation are of little assistance in these cases as these factors are almost never interrelated in global population reports. As the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union* points out<sup>25</sup>, they must be guaranteed freedom from discrimination in securing the financial support they need, technical aids, economic independence or an autonomous life as a lesbian, bisexual or transsexual woman, regardless of whether they are in an independent living environment or live in an institution.

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<sup>24</sup> *Report by the United Nations Special Rapporteur on Violence*, 2010.

<sup>25</sup> *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers*, CERMI-EDF, 2011.

## 5. THE RIGHT TO MOTHERHOOD

There is evidence to show that women with disabilities still do not enjoy the right to motherhood, as it is set out in article 23 of the Convention on the Rights of Persons with Disabilities. Negative and discriminatory attitudes towards those women with disabilities who wish to become mothers or already are, and existing discriminatory legislation and administrative arrangements based on these prejudices, prevent them from accessing assisted reproduction and artificial insemination programmes, adoption schemes, fostering, child custody in divorce cases and other types of social motherhood.

Worse still, they are deprived of the right to remain with their sons and daughters or are threatened with having them taken away. In fact in the few studies conducted in this field there are reports of cases where the mother's disability was considered sufficient cause to separate children from their mother<sup>26</sup>, and situations where it is thought women with disabilities should not have children precisely because of their disability, as a study carried out in the Netherlands highlighted<sup>27</sup>.

Women with disabilities should enjoy the right to raise their boys and girls in terms of guardianship, wardship, custody or adoption, or any other analogous legal status should they exist in national law. To secure this right, they must be given suitable assistance, which involves appropriate provision of support services to enable them to perform this important social responsibility.

In addition to the obstacles outlined above, ignorance, a lack of understanding of the needs women with disabilities have concerning motherhood, and inaccessible services are further barriers to enjoyment of this fundamental right. To illustrate this point, a report by the Royal College of Midwives in the United Kingdom stresses that there are, "*serious shortcomings in the assistance offered to women with disabilities when they are going to have a child and in the training they receive on childcare to look after the baby confidently and in a safe and healthy way*". The report goes on to publish research data which shows that women with disabilities, "*complain mainly about maternity services in relation to pregnancy, and especially about the lack of understanding and sensitivity regarding the nature of their disability*"<sup>28</sup>.

<sup>26</sup> *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - A toolkit for activists and policymakers*, CERMI-EDF, 2011.

<sup>27</sup> "The Netherlands - How to analyze and improve the situation of women with disabilities", in *Recognising the Rights of Girls and Women with Disabilities - An Added Value for Tomorrow's Society*, report from the European Conference, Y. Den Brok, Netherlands National Disability Council.

<sup>28</sup> Maternity Alliance, 1994.

Unfortunately the situation described above in the United Kingdom is replicated constantly in numerous testimonies by women with disabilities in many other parts of the world. As a result, suitable programmes must be drawn up with a view to ensuring women and girls with disabilities who are pregnant receive support to prepare them for motherhood and that mothers with disabilities who require childcare support have access to appropriate assistance and services.

Discrimination, however, can even occur before birth by undervaluing the life of an unborn child which is seen to have ‘malformations’. This happens in many countries with abortion legislation and is contrary to the principles and mandates of the Convention on the Rights of Persons with Disabilities, as the CRPD Committee pointed out when studying the national report from Spain recently<sup>29</sup>. Where a prenatal diagnosis indicates a potential future disability, the pregnant woman should be provided with appropriate care in terms of respect and proper treatment in order to promote equal opportunities and non-discrimination on the basis of disability.

## 6. FORCED STERILISATION AND COERCED ABORTION AS FLAGRANT HUMAN RIGHTS VIOLATIONS

There is clear evidence to suggest that forced sterilisation continues to be carried out on many persons with disabilities, above all on girls and women with intellectual or psychosocial disabilities, without their consent or their understanding the specific purpose of the medical operation and normally under the pretext of the wellbeing of the person with disabilities.

For many girls and women with disabilities this experience - which they are forced to undergo against their will when faced with intimidation and pressure - is a denial of their right to access appropriate services. Their fundamental human rights, including the right to safeguard body integrity and retain control over their reproductive health, are violated and removed.

Despite international human rights instruments such as the Convention on the Elimination of all Forms of Discrimination against Women, the International Covenant on Economic, Social and Cultural Rights<sup>30</sup>, and the International Convention on the Rights of Persons with Disabilities all imposing obligations on States Parties to protect their

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<sup>29</sup> Concluding observations to Spain of the United Nations Committee on the Rights of Persons with Disabilities, 6th period of sessions, September 2011.

<sup>30</sup> *International Covenant on Economic, Social and Cultural Rights*: <http://www2.ohchr.org/english/law/cescr.htm>.

citizens from any violation of the fundamental rights enshrined in them, many women and girls with disabilities all over the world are still denied their rights to found a family and to body integrity. These are unacceptable acts of violence and constitute flagrant violations of the human rights and fundamental freedoms of women and girls with disabilities.

Although the physical effects of sterilisation and abortion are well documented, the psychological and social consequences are rarely discussed. The trauma and pain can last a lifetime and there are few channels for reparation open to women and girls who fall victim to forced sterilisation and coerced abortion. This example of specific violence clearly has a gender element and it represents a case of multiple marginalisation and discrimination against women with disabilities.

The decision to sterilise a woman or girl with disabilities or to force her to have an abortion is often taken by the girl's or woman's family and, on occasions, by those in charge of the institution where she lives. It is often taken with the best intentions and under the pretext of the woman's or girl's 'wellbeing', the aim being to protect her from abuse and sexual interaction and, therefore, from pregnancy and motherhood. Research, however, has shown that a number of reasons are put forward, ranging from avoiding the need to teach women and girls about sexuality to personal hygiene or even to free her from menstrual pains.

It is worth mentioning that the idea of undergoing sterilisation or an abortion often comes from health care practitioners themselves: as a result, families and tutors treat the proposal with undue respect.

Forced sterilisation and coerced abortion are not violations just of the right of women and girls with disabilities to have children, but also of their rights to sexual development, to experiment their own sexuality, and to take their own decisions regarding sexuality. As a result, their inherent dignity as persons is undermined.

To ensure women and girls with disabilities who need assistance can enjoy their rights to motherhood, sexual development, to experiment their own sexuality and to take their own decisions regarding sexuality, suitable services must be provided. In addition, information and awareness campaigns should be organised and aimed at girls and women with disabilities themselves, their families, and above all at health sector practitioners and lawyers. The goal of these actions must be to guarantee that no decision on the reproductive health of a woman with disabilities is taken without her giving her consent and being fully aware of the consequences for her future following the intervention.

If parents and carers are offered alternatives to sterilisation - for example respite programmes, home assistance or assistance elsewhere, special programmes in hygiene

and preventive behaviour - the so called 'need' for non-therapeutic sterilisation would vanish. In this respect, the new Council of Europe *Convention on preventing and combating violence against women and domestic violence* is a major breakthrough in the fight against the human rights violations women and girls with disabilities suffer. The convention explicitly condemns forced abortion and forced sterilisation, recognises the need to make such practises illegal and urges parties to take the necessary legislative or other measures to eliminate them<sup>31</sup>. According to EDF, it is evident the potential benefits for others or for society do not justify these non-therapeutic practises<sup>32</sup>.

In 1994, the United Nations Committee on Economic, Social and Cultural Rights confirmed that in the case of a woman with disabilities, both sterilisation and abortion without the individual's prior consent constituted serious violations of the International Covenant on Economic, Social and Cultural Rights. The Committee on the Rights of the Child has also ruled along similar lines. Whether they are legal or not, the evidence shows that women continue to be subjected to forced sterilisation and coerced abortion worldwide<sup>33</sup>.

We must ask whose best interest is being considered when the decision is taken to sterilise a woman or girl with disabilities. A literature review on the matter conducted by Spicer cites several authors who call for more support for families with members who have intellectual disabilities as an alternative to non-therapeutic sterilisation. These authors suggest that many relatives would not feel forced to request sterilisation if they were offered social support, respite programmes and programmes to promote hygiene and preventive behaviour.

In testimonies from some relatives who defend their decision to put their daughters with disabilities through non-therapeutic sterilisation, it is argued that the practise improves their quality of life and frees them from mood shifts, menstrual pain and loss of blood associated with hormonal changes in the case of some fertile women. Nevertheless, one wonders if non-therapeutic sterilisation would be tolerated on a woman with no disability and the same symptoms. The answer, clearly, is that it wouldn't. Consequently, it is obvious that the presence of a disability is still being used in many legal systems as an attenuating circumstance in the decision to deprive a woman or girl of her body integrity.

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<sup>31</sup> Article 39, *Convention on preventing and combating violence against women and domestic violence*, Council of Europe: <http://conventions.coe.int/Treaty/EN/Treaties/Html/210.htm>.

<sup>32</sup> This opinion is shared by the Supreme Court of Canada. See *Eve vs. Mrs E.*, 2, SCR 388, (1986).

<sup>33</sup> *Sterilization of minors with developmental disabilities*, American Academy of Pediatrics, May 1990; *Sterilisation of Women and Girls with Disabilities* - a literature review, Cathy Spicer for WWDA (1999); *Årsberetning - for Ankenævnet i sager om svanger-skabsafbrydelse, fosterreduktion og sterilisation*, Denmark, June 2009.

Bearing in mind the provisions of the Convention on the Rights of Persons with Disabilities (article 12 - Equal recognition before the law, article 16 - Freedom from exploitation, violence and abuse, article 17 - Protecting the integrity of the person, article 23 - Respect for home and the family, and article 25 - Health), we believe forced sterilisation and coerced abortion are forms of violence that violate the rights of persons with disabilities to form a family, decide how many children they wish to have, access information on family planning and reproduction and retain their fertility on an equal basis with others.

As mentioned above, the Council of Europe *Convention on preventing and combating violence against women and domestic violence* contains a separate article on forced abortion and sterilisation (article 39 states that sterilisation shall not be performed, “*without her prior and informed consent or understanding of the procedure*”). However, the explanatory report to the convention specifically says that the convention does not aim to criminalise any medical procedure which is carried out for the purpose of assisting a woman “*who lacks capacity to consent*”. ‘Capacity to consent’ is not defined either in the convention or the explanatory report.

If a procedure is requested for an underage girl or in the case of a prior legal incapacitation, the consent of the parents or the people who represent the woman or girl with disabilities must always be based on respect for the human rights and will of the woman or girl with disabilities. It is also the responsibility of the relevant medical personnel to ensure that the woman or girl with disabilities is sufficiently informed about the fact that the surgery or medical intervention will lead to her being sterilised and the consequences of this for her future and, in the case of an abortion, the consequences for the woman or girl with disabilities and for the unborn child.

## 7. RECOMMENDATIONS FOR ACTION

1. As women and girls with disabilities still find themselves on the fringes of all human rights movements, periodic reports submitted to comply with human rights treaties must automatically include information on women with disabilities, including on their sexual and reproductive rights. This practise should also be extended to include all human rights organisations, organisations of persons with disabilities, organisations representing families, women’s organisations in general and organisations of women with disabilities.
2. Society must accept and respect the rights of women with disabilities to motherhood. All necessary measures in respect of awareness, information and training targeting both the families of girls and women with disabilities and

health sector practitioners working with them must be taken. In addition, legislative measures preventing babies and children from being removed from their mothers merely on the grounds of disability must be adopted. Where necessary, suitable support, tailored to meet particular needs in each case, should be provided to enable women with disabilities to exercise fully their right to motherhood.

3. The legal framework regarding forced sterilisation and coerced abortion requires review to address the issues of 'informed consent' and 'legal capacity' and enable legislation to be modified as required to conform to the philosophy and obligations set out in the *Convention on the Rights of Persons with Disabilities*. This treaty compels signatories to introduce those legal reforms necessary to ensure respect for the home, the family, and the personal dignity and integrity of persons with disabilities as fundamental rights that cannot be violated, so it is necessary to conduct studies to highlight forced sterilisation and coerced abortion and develop awareness-raising programmes and training programmes aimed at all stakeholders.
4. Finally, we call for reparations to be made to those women and girls whose human rights have been violated and who have been sterilised or undergone an abortion without giving their consent.

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## Chapter VIII

### EDUCATION

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## Chapter VIII

### EDUCATION

#### 1. INTRODUCTION

Education is one of the determining factors in the fight against inequalities, social exclusion and poverty, as is highlighted in the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union. Education is self-evidently one of the most effective elements in the struggle against inequalities between the sexes.

However, as studies and reports from several international organisations and specialist institutions in the field of education demonstrate, the gender gap in the enjoyment of the right to education persists worldwide. This is despite CEDAW<sup>1</sup>, a comprehensive compendium of legal obligations including the right to education and equality between women and men. CEDAW Article 10.1 specifically states that, “*States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education...*”.

Inequalities continue to exist; they are alarmingly aggravated among those social groups in situations of greatest vulnerability, and clearly and especially among women and girls with disabilities who, even now in the 21st century, are the most invisible and ignored groups in the system.

The Convention on the Rights of Persons with Disabilities, the much-needed framework and benchmark in terms of education for women and girls with disabilities, states emphatically in article 6.2 that, “*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***”, among them the right to education established in article 24.

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<sup>1</sup> Convention on the Elimination of all Forms of Discrimination against Women.

Ensuring education for girls and women with disabilities is a task for everyone in society, with each individual taking responsibility in his or her field: mothers and fathers; families; the education community; authorities; girls, young women and women with disabilities themselves; and the media. In addition, one cannot overlook the fact that education is the first step towards inclusion in the community, self-determination, furthering personal independence and social emancipation for women with disabilities. Education must be addressed, therefore, from the double perspective of gender and disability. The limited statistics we have on women with disabilities' engagement in different areas of life show this is a pressing task.

## 2. THE GENDER PERSPECTIVE IN THE RIGHT TO EDUCATION

### 2.1. General remarks

When we talk of education we need to put the right to education in historical context from its beginnings. The right to education was first set out in the Universal Declaration of Human Rights in 1948<sup>2</sup>. It was subsequently developed in several international treaties; some of these, and more specifically the Convention on the Elimination of all Forms of Discrimination against Women and the Convention on the Rights of the Child, constitute a comprehensive set of legal obligations in respect of the right to education and equality between the sexes.

In 1990 the Education for All movement was set up as a worldwide commitment to offer quality education to all girls, boys, women and men<sup>3</sup>, including six objectives aimed at meeting educational needs no later than 2015<sup>4</sup>. Importantly, two of these

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<sup>2</sup> Article 26.

<sup>3</sup> The initiative saw the light of day at the 1990 World Education for All Conference, held under the auspices of UNESCO, UNDP, UNFPA, UNICEF and the World Bank. Some years later, the 1994 Salamanca Statement, in the framework of this initiative, was an important step in recognising the needs of persons with disabilities in education.

<sup>4</sup> EFA Goals:

Goal 1: Expand and improve comprehensive early childhood care and education, especially for the most vulnerable and disadvantaged children.

Goal 2: Ensure that by 2015 all children, particularly girls, children in difficult circumstances and those belonging to ethnic minorities, have access to and complete, free and compulsory primary education of good quality.

Goal 3: Ensure that the learning needs of all young people and adults are met through equitable access to appropriate learning and life skills programmes.

Goal 4: Achieve a 50 per cent improvement in levels of adult literacy by 2015, especially for women, and equitable access to basic and continuing education for all adults.

goals, numbers four and five, are directly linked to education for girls and women and equal opportunities:

- **Goal 4:** Achieve a 50 per cent improvement in levels of adult literacy by 2015, especially for women, and equitable access to basic and continuing education for all adults.
- **Goal 5:** Eliminate gender disparities in primary and secondary education by 2005, and achieve gender equality in education by 2015, with a focus on ensuring girls' full and equal access to and achievement in basic education of good quality.

As was said above, equality is a core element in the Education For All (EFA) goals. Among the six EFA aims, achieving the goal of equality between the sexes is considered urgent, first by reaching equality between boys and girls in primary and secondary education by 2005, and then achieving full gender equality in the education system by 2015.

Reports by UNESCO<sup>5</sup> and the Commission on Human Rights of the UN Economic and Social Council<sup>6</sup> indicate clearly that excluding girls and women from access to education is akin to denying them their most basic human rights, prevents them from developing as human beings and goes against their fundamental interests.

Despite these remarks and the backing they receive from international treaties, there is persisting segregation in access to education and early dropout, mostly involving girls and young women.

It is evident that inequality between the sexes is a grave violation of the rights of women and girls and represents a major obstacle to social and economic development. It is worth remembering that paragraph 1 of CEDAW article 10 stipulates that, "*States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education...*", while article 28.1 of the Convention on the Rights of the Child

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Goal 5: Eliminate gender disparities in primary and secondary education by 2005, and achieve gender equality in education by 2015, with a focus on ensuring girls' full and equal access to and achievement in basic education of good quality.

Goal 6: Improve all aspects of the quality of education and ensure excellence of all so that recognized and measurable learning outcomes are achieved by all, especially in literacy, numeracy and essential life skills.

<sup>5</sup> EFA Global Monitoring Report - the leap to equality, 2003-2004, UNESCO: <http://www.unesco.org/new/en/education/themes/leading-the-international-agenda/efareport/reports/20034-gender/>.

<sup>6</sup> Girls' right to education, report by the Special Rapporteur on the right to education, Mr. V. Muñoz Villalobos, E/CN.4/2006/45.

recognises, “...*the right of the child to education, and with a view to achieving this right progressively and **on the basis of equal opportunity**, ...*”<sup>7</sup>.

Discrimination in education on the grounds of gender must be placed within the social model which is the result of patriarchy, whose hierarchical structure puts girls and women in a clearly disadvantageous position. This is clearly a factor that has an impact on social exclusion among girls and women in schools and, consequently, on equal relations between men and women in the education environment. Patriarchy is clearly then a cause of marginalisation for girls and women.

This is why it is important to bear in mind what CEDAW rightly says on the matter when it points out that the main challenge to identifying new education and human development policies is eliminating prejudices, customs and all types of practises based on notions of inferiority or superiority of the sexes and stereotypical roles for men and women<sup>8</sup>.

From this arises the need to strengthen, through educating girls, education for equality which respects human rights and considers diversity an enriching element. The gender perspective must be mainstreamed in education through legislation, public policies, arrangements in centres of education, research, classroom material, the role of the family and the role of the education community. Education in human rights is essential to tackle gender-based discrimination, and human rights must be put into practise in education programmes. The international reports we have referred to<sup>9</sup> rightly indicate that quality of education should be linked to the idea of citizenship

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<sup>7</sup> 1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular: (a) Make primary education compulsory and available free to all; (b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need; (c) Make higher education accessible to all on the basis of capacity by every appropriate means; (d) Make educational and vocational information and guidance available and accessible to all children; (e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates.

<sup>8</sup> CEDAW, Article 5. States Parties shall take all appropriate measures: (a) To modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women; (b) To ensure that family education includes a proper understanding of maternity as a social function and the recognition of the common responsibility of men and women in the upbringing and development of their children, it being understood that the interest of the children is the primordial consideration in all cases.

<sup>9</sup> See notes 5 and 6.

based on human rights; simply having access to a school is no guarantee that rights will be realised or needs met.

So, on the one hand girls must be educated to make them aware of their rights and teach them how to exercise their rights, while on the other boys and society in general need to be educated as it is often society itself which fails to realise it is putting in place certain differences. Consequently, a number of targeted actions should be undertaken regarding equality, such as reconciling professional and family life, the use of non-sexist language, calling for the media and advertising agencies to avoid showing sexist behaviour, eradicating sexist content from text books and other educational material, promoting women to leadership positions in the education environment, and so on.

The report by the Special Rapporteur on the right to education recalls that, *“Girls’ right to education cannot be addressed in isolation from gender issues; and these issues certainly not only affect women’s rights but also impose the need to envisage a new form of masculinity that is more sensitive, responsible and proactive towards equality, justice and solidarity.”*

Substantive equality, however, cannot be reached only through laws; economic, social and cultural inequalities, which particularly affect women, must also be kept in mind. A discriminatory socio-economic environment is often the foundation for discrimination against girls and women in educational centres.

One more sign of the invisibility of women and girls is the fact that the indicators used to gauge enrolment rates not only fail to reflect the complexities of gender-based inequalities, but also render the needs of girls and women invisible.

Experts in the field point out that no country has bridged the gender gap in all areas of life in society, so we should not inexorably link gender-based inequalities to poverty and apply the foregoing only to less developed countries. Persisting inequalities have a negative impact on the education of girls and young women worldwide, as the European Women’s Lobby points out.

Studies on education from a gender perspective stress that in order to achieve gender equality in education it is necessary to reform not only education policies as such, but economic and social policies as a whole. This is because achieving equality is not merely a question of reaching numerical parity. When we talk of equality, we should not confuse the concept of ‘parity’ (the result of quantification) with the concept of ‘gender equality’. Parity is an exclusively numerical concept - achieving gender parity means that an equal proportion of boys and girls - in relation to their respective age groups - enters the education system and takes part in all stages of primary and

secondary education. Indeed, as the aforementioned reports indicate<sup>10</sup>, education is a right whose full exercise requires equal access for all persons to quality basic education; a learning process offering girls and boys and men and women the same opportunities to develop their talents; and outcomes that lead to social and economic advantages for all and with no discrimination whatsoever. Achieving parity does not mean merely enrolling the same number of girls and boys - it means offering both sexes equal opportunities, treating them all identically and allowing them to attain similar results both in school and in society. These are core criteria for progress. As a result, parity cannot be claimed to imply real and substantial equality in terms of the opportunities given to girls and women. Exclusion and discrimination cannot be combated solely through access to education.

The discrimination women face is largely a consequence of inequalities in access and participation for girls in education systems and differences in educational attainment in respect of boys. It has been shown that reducing discrepancies between the sexes in education - whatever shape they may take - benefits everyone. Investment in education for girls leads to increased welfare for all and for society as a whole. Investing in education for girls is one of the best ways to ensure future generations are educated.

## 2.2. Relevant facts and figures

- Statistics show that even now 56% of the world's population of school age lives in countries which have not achieved gender parity in primary education. For secondary education, the figure rises to 87%;
- It is estimated that there are more than 860 million illiterate adults in the world, of whom one third are women. This figure is not expected to be reduced. In some parts of the world illiteracy rates will rise to 75% by 2015;
- The total number of children in primary school rose from 596 million in 1990 to 648 million in 2000, a global increase of 8.7%;
- In 2000 girls represented 57% of the 104 million children not in education;
- In secondary education, differences between the sexes are less pronounced than in primary education. This demonstrates that the difficulties girls face in gaining access to elementary schooling do not prevent them from obtaining the same or better results than their male peers once they have accessed education;

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<sup>10</sup> See notes 5 and 6.

- In secondary education, female adolescents face problems such as puberty, early marriage (especially in developing countries), and pregnancy, which often affect their chances of completing secondary education;
- It is estimated that between 1990 and 1997 the number of students enrolled in further education increased from 69 million to 88 million worldwide (50% in developing countries). The percentage of women matriculated in further education rose from 46% to 46.8% globally;
- In the vast majority of countries (industrialised countries) the number of women teachers falls gradually from primary education to secondary education and on to further education, where women teachers are generally in a minority;
- The countries with the lowest proportion of women primary teachers are the countries with the greatest disparities between the sexes;
- One of the EU goals for 2015 is to increase the number of graduates in mathematics, science and technologies, mainly by making these subjects more attractive to young women;
- The literacy rate among people with disabilities, according to data from the UNDP, is 3%. For girls and women it is 1%;
- UNICEF estimates that 98% of children with disabilities in developing countries do not attend school. Girls with disabilities are less likely to go to school than boys with disabilities;
- One of the aims of the Europe 2020 Strategy is to reduce the school dropout rate to below 10% (14.4% in the EU, 31.2% in Spain, 53.8% among people with disabilities in Spain). At the same time, the aim is for at least 40% of people between the ages of 30 and 40 years old to have completed higher education (32.3% in the EU, 39.4% in Spain and 19.3% among people with disabilities in Spain).

### 3. DISABILITY AS AN EXCLUSION FACTOR IN THE RIGHT TO EDUCATION FOR GIRLS AND WOMEN WITH DISABILITIES

#### 3.1. General remarks

The points made in the previous section are aggravated exponentially in the case of girls and women with disabilities, who face multiple situations of discrimination which place them in a situation of greater vulnerability. This is so because gender prejudices combine with prejudices against disability to exclude girls and young women from education. Studies suggest that little progress has been made in addressing the educational needs of girls and women with disabilities.

In this respect, paragraph 9.1 of the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union highlights the fact that, “*Girls and women with disabilities have high rates of illiteracy, school failure, absenteeism and drop-outs, all of which have major consequences as regards cohesion, involvement and social behaviour. The only way to achieve a society which is more tightly interwoven, more mature, fairer and more willing to show solidarity, and in which the values of social cohesion take precedence over obstacles hindering universal engagement, is through the effective realization of basic rights, and among them everyone’s right to high-quality, inclusive education which is free-of-charge. There is a need to promote inclusion in education for girls and teenagers with disabilities in order to mitigate the clear disadvantage they suffer in education, which in turn hinders the subsequent inclusion in the labour market and community of women with disabilities.*”

Here we must mention the inclusive approach which is needed and should guide all measures and actions aimed at realising the right to education of girls and boys, men and women with disabilities, as set out in article 24 of the Convention on the Rights of Persons with Disabilities:

*“24.1 States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning...”<sup>11</sup>.*

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<sup>11</sup> Article 24 - Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

(a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

(b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

(c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

(c) Reasonable accommodation of the individual’s requirements is provided;

(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

In this sense, inclusive education, in the full meaning of the expression, is the first step towards true and effective enjoyment of the right to education by people with disabilities and eliminating segregation on the basis of disability. The disability movement has performed a number of studies and published position papers on the need for the inclusive approach in education<sup>12</sup>. CERMI expressed its position on the subject in the National CERMI Manifesto released on the occasion of the 2010 International and European Day of People with Disabilities, ***'In favour of real and effective inclusive education'***. The document, which includes references to women and girls with disabilities, calls for *"necessary steps to be taken to foster inclusive education for girls and young women with disabilities, measures aimed at mitigating the clear disadvantage this social group encounters in education and which hinders the subsequent inclusion in the labour market and community of women with disabilities"*.

The 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union makes the case clearly in paragraph 9.2:

*"Inclusive education for girls and women with disabilities must be viewed through the paradigm of quality education, equal opportunities and universal accessibility throughout the entire life cycle, ensuring women with disabilities enjoy access to continuing education as a means to enhance their personal independence, the free development of personality, and their social inclusion, while exercising permanently the right to decide for themselves and choose their way of life."*

The Convention on the Rights of Persons with Disabilities talks about quality education, and the quality of an education can be measured using indicators on the pupil-teacher ratio, teachers' qualifications, public spending on education and educational outcomes.

### 3.2. The 2011 World Report on Disability and other relevant instruments

The 2011 World Report on Disability<sup>13</sup> includes an in-depth study on education and disability<sup>14</sup>. It demonstrates that people with disabilities have lower educational

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<sup>12</sup> Of particular interest is a 2011 study called *'The impact of the International Convention on the Rights of Persons with Disabilities on the rights of persons with education in Spanish education law'* by María José Alonso Parreño and Inés de Araoz, published as part of the *Colección Cermi.es* (number 6).

<sup>13</sup> Drawn up jointly by the World Health Organisation and the World Bank to gather data for policy formulation and programme development to implement the CRPD.

<sup>14</sup> *"Governments throughout the world can no longer overlook the hundreds of millions of people with disabilities who are denied access to...education...and never get the chance to shine"*, extract from the foreword by Stephen W Hawking.

attainment than people with no disability, the result, in part, of the obstacles that make it difficult for them to access education, above all in developing countries. This is why, as the report points out, people with disabilities must achieve full independence and obstacles that prevent them from receiving a quality education must be removed<sup>15</sup>. The report highlights the lack of financial and other incentives to encourage girls and boys with disabilities to attend school and the paucity of support services and social protection. When obstacles and inequalities are addressed in education, it is important to consider certain essential elements at all times, such as negative attitudes based on mistaken beliefs and prejudices, the need to offer disability-awareness training to those responsible for education, the need to include the rehabilitation aspect in mainstream education legislation, and create accessible and user-friendly environments which encourage people with disabilities to become engaged in education.

Going into more detail on the specific obstacles in education, the report recalls that having girls and boys with disabilities in mainstream schools, *“promotes universal primary completion, is cost-effective and contributes to the elimination of discrimination.”*<sup>16</sup>

The report includes nine cross-cutting recommendations which will require joint engagement by those involved in the fields of health, education, social protection, employment, transport and housing.

With regard to the right to education, the report points out the need to facilitate equal access to education, ensure women and men with disabilities are involved in matters related to their education<sup>17</sup>, improve human resource capacity, include pertinent information on disability and human rights, raise public awareness and understanding on disability and strengthen and support research into disability.

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<sup>15</sup> The report refers to the Fast-track Education for All scheme which has been implemented in 28 countries. It highlights that 18 of these countries provided very little information on their strategies for the inclusion of children with disabilities in schools or failed to mention disability and inclusion at all.

<sup>16</sup> *“Creating an inclusive learning environment will assist all children in learning and achieving their potential. Education systems need to adopt more learner-centred approaches with changes in curricula, teaching methods and materials, and assessment and examination systems. Many countries have adopted individual education plans as a tool to support the inclusion of children with disabilities in educational settings. Many of the physical barriers that children with disabilities face in education can easily be overcome with simple measures such as changing the layout of classrooms. Some children will require access to additional support services including specialist education teachers, classroom assistants, and therapy services.”*

<sup>17</sup> The report states that, *“Supported decision-making may be necessary to enable some individuals to communicate their needs and choices.”*

The invisibility to which women and girls are subjected can be seen once again in this report which, despite its wide-ranging scope, barely touches upon the situation faced by women and girls with disabilities.

### The Europe 2020 Strategy

The European Commission has proposed education as one of its five quantifiable targets for 2020 that will steer the process and be translated into national targets. Europe must act in the field of education, training and lifelong learning. The strategy includes various education-related flagship initiatives:

- **Innovation Union:** to promote co-operation in knowledge and strengthen the links between education, business, research and innovation;
- **Youth on the move:** to enhance the performance and international attractiveness of Europe's higher education institutions and raise the overall quality of all levels of education and training in the EU, combining excellence and equity and improving the employment situation of young people;
- **An Agenda for new skills and jobs:** strong support for the strategic co-operation framework for education and training with the involvement of all stakeholders;
- **European Platform against Poverty:** to design and implement programmes to promote social innovation for the most vulnerable, in particular by providing innovative education, training, and employment opportunities for deprived communities, to fight discrimination (**for example against persons with disabilities**), and to develop a new agenda for migrants' integration to enable them to take full advantage of their potential.

### The European Disability Strategy

The European Disability Strategy has set education and training among its eight key action areas. The Commission will support the aim of quality inclusive education and training in the framework of the *Youth on the move* initiative. In addition, it will increase knowledge on levels of education and opportunities for people with disabilities, and increase their mobility by facilitating participation in the Lifelong Learning Programme.

EU action will support national efforts, in the first place, to remove legal and organisational barriers for people with disabilities to general education and lifelong

learning systems; secondly, it shall provide timely support for inclusive education and personalised learning, and early identification of special needs; and, finally, it will provide adequate training and support for professionals working at all levels in education and report on participation rates and outcomes.

## Spanish Disability Strategy

The strategic measures for education and training are:

- Promote targeted measures for persons with disabilities to ensure compliance with the general goals in the Spanish National Reform Programme for 2011 to reduce school dropout rates and increase the number of people between the ages of 30 and 34 who have completed higher education;
- Support EU efforts towards quality inclusive education and training in the framework of the *Youth on the move* initiative;
- Boost early detection of special educational needs;
- Promote inclusive education at all stages of education, including whatever support measures are necessary;
- Enhance ongoing training for teachers;
- Make progress in the incorporation of subjects that help to guarantee the rights of persons with disabilities;
- Promote mainstreaming of the gender and disability perspectives in curricula.

As we can see, of the three instruments the Spanish Disability Strategy is the only one to include the gender perspective<sup>18</sup>.

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<sup>18</sup> In July 2011 the government adopted an inclusion plan for students with special educational needs in order to improve education for all students, and specifically for students who have special educational needs. The disability movement took part in the drafting process for the plan, which focuses on achieving the following specific aims:

1. Raise awareness among stakeholders and society of the importance of inclusive education for students who have special educational needs in terms of achieving personal development, individual wellbeing, participation in different areas in society and social cohesion.
2. Deliver quality education to students with special educational needs at all stages of education and lifelong training, based on the principles of inclusion, equal opportunities, universal accessibility and design for all and in order to facilitate his or her inclusion in the labour market.

### 3.3. Exclusion factors

To address gender inequalities in the right to education, and more specifically the inequalities girls and women with disabilities face, we must bear in mind the following three aspects: the exercise of the right to education (prejudices and stereotypes, etc.); rights within the education system (study plans and curricula, funding, teaching methods, arrangements in centres of education, training the trainers, the learning context); and rights that are acquired through education (equal opportunities in access to employment, full independence).

The main exclusion factors are stereotypes and prejudices, problems associated with sexuality and adolescence, violence and harassment to which girls and women with disabilities are subjected, child labour (in developing countries), a lack of information in society in general about disability, and gender-based discrimination. We must also remember that the confluence of other discriminatory factors contributes to aggravating exclusion. Many studies have shown that illiteracy rates are higher when multiple discriminatory factors are present in addition to gender, such as rurality, ethnic origin, immigration and poverty.

#### 3.3.1. *Stereotypes and prejudices*

Girls and women with disabilities, as we said above, are generally victims of greater invisibility and face prejudices and obstacles preventing them from enjoying their right to education. Among other reasons, this is due to the fact that diversity is not respected in education.

The prejudices and stigmatisation towards women and girls with disabilities - present in all cultures, although more so in some than in others - lead to them being denied access to schools, including by their own families, and therefore to a denial

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3. Encourage education centres to draw up and implement study plans which include measures aimed at achieving access, retention, promotion and success in education for students with special educational needs, while facilitating family participation and training and partnerships with other organisations to provide comprehensive support to these students.
  4. Enhance initial and ongoing teacher training and training for other practitioners, thus enabling them to offer quality inclusive education to students with special educational needs.
  5. Encourage partnerships among education authorities, other organisations and bodies to deliver comprehensive inclusive education to students with special educational needs.

of their right to education. In general little progress has been made in terms of meeting the educational needs of girls and women with disabilities.

Some examples are: girls and women with disabilities have low expectations about their own potential; text books and other classroom material do not feature women with disabilities; discrepancies in the availability of spaces for sports and other extracurricular activities; a tendency to use sexist language; girls and women with disabilities are more likely to suffer sexual harassment (considered at times 'normal' and which therefore goes unpunished); persistence of sexist patterns and stereotypes in the media (advertising, text books, television, etc.) which continue to promote gender differences and have a profound effect on society.

Many countries have removed all reference to any type of sexual stereotype from teaching material. However, regardless of the official curriculum, what is vitally important is how teachers interpret it. Educators are powerful behavioural role models and are capable of combating stereotypes if they are given the right support. Strong feminist movements in several industrialised countries in the seventies led to a focus on increasing female participation rates in mathematics, science and technology, as well as developing propitious environments for girls and young women in schools. Another strand of this strategy is to make schools places where stereotypes are undermined and lose their strength thanks to gender-equality awareness efforts by teachers and students through study plans and vocational training respectively.

Stereotypes and prejudices must be combated through programmes and plans that include training in human rights and respect for diversity as an enriching element. Diversity must be tied to the concept of excellence which education systems seek. Teaching material must be designed with the double gender and disability perspective, as must infrastructures in the education system: in addition to being accessible, centres of education must be built close to people's homes to avoid families being reluctant to send their daughters with disabilities to school for safety reasons.

At the same time, we must take care of the needs of mothers with disabilities, who generally use public transport more, and education centres must be easily accessible from public transport systems. As regards teachers, it is vital to increase access to further education by women with disabilities who can then train to become teachers, thus helping to increase the number of women primary and secondary school teachers. This is a major step forward as it helps to make women with disabilities more visible in the education sector. In general, it is necessary to develop comprehensive awareness-raising and training programmes in gender and disability for teachers and all others involved in the education community.

In this respect, the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - a toolkit for activists and policymakers, points out that, *“An attitude of respect for the rights of women and girls with disabilities should be fostered at all levels of the education system, including in all children from an early age. It is necessary to ensure that formal curricula in primary, secondary and tertiary education include teaching material on equality between women and men, on disability and understanding diversity, non-stereotyped sex roles, mutual respect, non-violent conflict resolution in inter-personal relationships and concepts of honour and individual self-determination, adapted to the evolving capacity of learners.”*<sup>19</sup>

Paragraph 9.5 in the manifesto adds that, *“All those involved in education must be sensitive to the reality, diversity and intrinsic value of women with disabilities, and their contribution to the society in which they live. Families and teaching staff must be given complementary training on the gender perspective applied to disability with a view to securing respect for a suitable image of girls and women with disabilities, recognizing and respecting their human rights and focusing particularly on eradicating negative stereotypes which are widely-held in society and hinder their development as people and full inclusion on equal terms as others.”*

Child labour, mainly involving girls, is an additional factor leading to girls failing to attend school, especially in developing countries. Female adolescents and women with disabilities are often in charge of caring for dependent relatives, which prevents them from continuing their education and completing their training, with serious consequences for their personal independence and active participation in society.

### 3.3.2. Education in sexual and reproductive health

Gender inequalities constitute a risk factor in contracting HIV and other sexually-transmitted diseases as a consequence of the situation of subjugation women suffer and which, on occasions, leads to violence against women. Providing information on sexuality and reproductive health to female adolescents is an issue that needs to be addressed urgently, especially in the context of the HIV/Aids pandemic. Theoretical and practical knowledge is vital for women to guide their sex lives. In many countries sex education is still a taboo subject and is held back by resistance from teachers and parents and due to insufficient training. If we add the disability factor to this, the difficulties extend to include all countries without exception.

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<sup>19</sup> Chapter 2, paragraph 2.4, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union.

As the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union points out, *“As a result of the limited access and control adolescents and women with disabilities have over their own sexuality, **they are vulnerable to sexual exploitation, violence, unwanted pregnancies and sexually-transmitted diseases.** Girls, adolescents and women with disabilities require access to emotional and sexual education to live a healthy life. They should be taught up to a level of knowledge regarding how their body works (how one becomes pregnant and how to avoid it, how to make a sexual relationship more communicative and enjoyable, how to say no to things one doesn’t wish to do, how to avoid sexually-transmitted diseases, and so on) by experts in the field, such as educators from local public social services.”*<sup>20</sup>

*“Women and girls with disabilities should be made aware of the risk of HIV and AIDS and other sexually-transmitted diseases. To achieve this, **contraceptive education and sexual education is essential** in this respect.”*<sup>21</sup>

The manifesto is also clear on the issue of education in reproductive rights: *“Reproductive rights, that is to say the freedom and independence all people have to decide freely and responsibly to have children or not, how many, when and with whom, also include **the right to information, education** and the means to exercise such rights, the right to take decisions on reproduction free from discrimination, coercion or violence, the right to access quality primary healthcare, and the right to measures to protect motherhood. All these rights must be fully ensured for adolescents and women with disabilities, on an equal footing with others and based on full consent and mutual respect.”*<sup>22</sup>

Education plans must include sexual and reproductive education programmes to promote respect for the rights of girls and female adolescents with disabilities, as the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union makes clear in the paragraphs quoted above.

Health facilities and suitable furnishings to allow the needs of female adolescents, and especially those of menstruating age, to be met are an absolute necessity. Female adolescents with disabilities must be given appropriate support during menstruation. Infrastructures must also be adapted to the needs of female adolescents with

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<sup>20</sup> Chapter 8, paragraph 8.4, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union.

<sup>21</sup> Chapter 10, paragraph 10.12, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union.

<sup>22</sup> Chapter 8, paragraph 8.6, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union.

disabilities (a lack of accessible toilet facilities will have an impact on whether female adolescents of menstruating age remain in education).

At the same time, it is important to address the problem of pregnancy among female adolescents with disabilities, which generally leads to school dropout. Adolescent mothers must be guaranteed their right to education, and female adolescents with disabilities should not be excluded from this. Furthermore, appropriate education in sexual and reproductive rights from the first years at school would undoubtedly contribute to eliminating certain violent practises to which women are subjected, such as coerced abortion and forced sterilisation.

### 3.3.3. *Violence and harassment in the school environment*

The violence to which women with disabilities are subjected in the school environment, on the way to school or in educational centres is a particularly serious impediment to the enjoyment of the right to education by girls and women with disabilities. Member of this group are far more likely to fall victim to violence than women and girls without disabilities (in the family setting, institutions or the community) and it leads to isolation and invisibility.

Protecting girls and women with disabilities from the causes of exclusion related to sexuality and violence against women in the education environment (classrooms, centres of education, etc.) is, as the Special Rapporteur points out in his report, a worldwide priority. The entire education environment should be involved in this (material, health facilities, training, hiring and raising awareness among teachers and the education community in general).

Reducing the gender difference means facing up to the reality of harassment and sexual violence that leads to low educational attainment and high dropout rates. In education policies very little attention is paid to sexual harassment and violence against girls and female adolescents with disabilities, and much firmer action involving students, parents, teachers and school administrators is needed to protect pupils from harassment, sexual abuse and human rights violations to which they are continually subjected in schools.

With regard to girls and women with disabilities, and according to the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union: “...*girls and women with disabilities may experience particular forms of violence in their homes and institutional settings which is perpetrated by family members, care-persons or strangers. All appropriate measures must be taken to avoid all types of exploitation,*

*violence and abuse against girls and women with disabilities, while ensuring adequate assistance and support catering for their specific needs is provided.”<sup>23</sup>*

Girls and female adolescents with disabilities are exposed to a greater risk of suffering sexual harassment because of their gender and disability, so it is vital to carry out research to provide relevant data and allow appropriate steps to be taken to put an end to these situations.

It is opportune at this point to make reference to the recommendation published by the Committee on the Rights of Persons with Disabilities in response to the country report from Spain on measures adopted to meet the country’s obligations under the CRPD. In its study of article 6 of the Convention, the Committee expresses its concern “*that public programmes and policies on the prevention of gender-based violence do not sufficiently take into consideration the particular situation of women with disabilities.*” The Committee recommends that Spain “*Include a more comprehensive consideration of women with disabilities in public programmes and policies on the prevention of gender-based violence*” and “*Elaborate and develop strategies, policies and programmes, especially in the fields of education...to combat violence against them.*”

In his report, the Special Rapporteur on the right to education points out that “*States continue to fail to address properly situations in which the rights of girls and female adolescents are violated...and in particular victims of...forced pregnancies, sexual assault and forced sterilization, [which] are allowed to continue without the States concerned tackling the situation head-on.*”

In the case of disability, forced sterilisation is a form of violence which is regularly performed on female adolescents and women with intellectual disabilities. “*Forced sterilisation and coerced abortion must be considered forms of violence against women. The competent European Union and Member State authorities must eradicate and strongly condemn these practises, which may amount to torture or inhuman or degrading treatment and should, therefore, be persecuted and punished.*”<sup>24</sup>

To bring this section to a close, is it vital, as article 7, paragraph 3, of the CRPD highlights, that “*States Parties shall ensure that children with disabilities have the right*

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<sup>23</sup> Chapter 6, paragraph 6.2, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union.

<sup>24</sup> Chapter 6, paragraph 6.3, 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union. On this issue, the Committee on the Rights of Persons with Disabilities urged Spain “*to abolish the administration of medical treatment, in particular sterilization, without the full and informed consent of the patient; and ensure that national law especially respects women’s rights under articles 23 and 25 of the Convention.*”

*to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.”* Girls and female adolescents must play an active role in issues affecting them and become engaged in decision-making processes and monitoring and control mechanisms.

In addition, the situation brought about by the serious world economic crisis raises fears of a regression in gender equality in all areas of life, so women’s right to education, and especially the right of women with disabilities to education, runs a higher risk of falling victim to restrictions. All sectors of society must speak out firmly against this step backwards.

#### 4. LIFE-LONG EDUCATION

As paragraph 9.4 of the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union points out, ***“Measures are needed to encourage active ageing among women with disabilities and reduce the high illiteracy rates among older women with disabilities, as well as to increase the use of new information and communication technologies by this group or women in lifelong learning programmes.”***

The role played by Information and Communication Technologies (ICTs) is particularly significant in this respect. Indeed, ICTs have emerged as a key element in strategies to democratise information, communication and participation by women in general in the knowledge age, allowing them<sup>25</sup> to play an active role in development, support and dissemination networks and enabling them to participate in interactive learning initiatives and remote training and access knowledge and information to empower and improve their lives. ICTs also contribute to combating isolation among women.

For all of the above reasons, it is essential for women with disabilities to be given the opportunity to use information and communication technologies. ICTs will help them in ongoing education, and particularly so in the case of ongoing education for older women with disabilities. In this context, we must make sure new technologies do not create new barriers and ensure they are designed and produced according to the principles of universal accessibility, design for all and social inclusion.

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<sup>25</sup> <http://www.eclac.org/socinfo/noticias/paginas/9/30389/newsletter16.pdf>

The European Union is promoting family literacy and this will boost progress towards the Education For All goals, which aim to achieve gender equality by 2015. Women are a target group and many, including a high number of women with disabilities, are keen to participate in literacy programmes to be able to help their children with their homework during the first years of school.

In addition, family literacy programmes play a crucial role in lifelong learning for women with disabilities.

## 5. VOCATIONAL TRAINING

The 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union goes into some detail in chapter 12 on the needs of women with disabilities in vocational training. It states that,

*“12.12. Women and young women with disabilities should be given accessible and relevant information on the mainstream labour market and the existing opportunities to secure employment in the public and private sectors, and offered guidance and assistance if required.*

*12.13. Women with disabilities must receive quality training enabling them to opt for employment in the labour market in both the public and private sectors, and they should be offered specific opportunities for lifelong training with a view to gaining the necessary training and qualifications in terms of responsibility, confidence-building and capabilities.*

*12.14. When specific training is required, women with disabilities should not be placed at a disadvantage in relation to others. In addition, they must be given suitable access to all training programmes, including technical and vocational guidance programmes, placement services and vocational and continuing training. Furthermore, their involvement should be actively encouraged.*

*12.15. In particular, existing vocational training programmes for women, including teletraining, should be opened up to enable women with disabilities to participate and support services should be provided where necessary.*

*12.16. Digital literacy for women with disabilities who wish to join the labour market should be secured, offering complementary funding or soft credit to purchase equipment and any support products required for access and connectivity. Particular attention should be paid to groups at risk of exclusion (older women, women living in rural areas, immigrants, women belonging to ethnic minorities, women with high*

*support needs, and so on), who should be given preference when allocating the aforementioned financial support.”*

## 6. RECOMMENDATIONS

### 6.1. Recommendations for public-sector policy makers and other public authorities

- Formulate education policies in accordance with the principles of Education For All. Draw up an Education For All Plan which mainstreams the double perspective of gender and disability, harnessing recent developments in inclusive education;
- Adopt measures to find out the needs of women and girls with disabilities in education from a mainstreaming perspective, and redistribute resources assigned to education with a view to meeting the specific needs of girls and women with disabilities through an inclusive approach and including the disability perspective. Include personalised monitoring programmes for each student as part of these measures;
- Take urgent steps to ensure girls and women with disabilities are part of decision-making processes in relation to the right to education;
- Carry out gender-sensitive research to analyse the impact of human rights instruments on the reality in classrooms, with a view to bringing to light stereotypes that keep girls and female adolescents in a subordinate position and obstacles to their participation in school life;
- Develop qualitative and quantitative human rights indicators to be able to identify and respond to the potential causes of discrimination in the exercise by girls and female adolescents with disabilities of their right to education;
- Mainstream the gender and disability perspectives in indicators used to gauge school enrolment rates;
- Adopt targeted measures to promote retention, in inclusive environments, of female adolescents with disabilities throughout the entire education system. Carry out research focusing on dropouts among female adolescents with disabilities to ensure targeted steps are taken to meet their needs;
- Put measures in place to ensure girls and women with disabilities can participate in sports and extracurricular activities on an equal footing with other students;

- Draw up training material with the double gender and disability perspective in mind, thus avoiding sexist and stereotyped content regarding males and females. Report such cases if they occur. Call for the respect required and permanently monitor content;
- Foster sex and reproductive education from the double gender and disability perspective in curricula at all levels. Monitor and supervise the implementation of these measures;
- Develop programmes to ensure adolescents with disabilities who are pregnant or mothers are in education;
- Mainstream the disability perspective in policies and programmes against sexist violence in education centres;
- Mainstream the double gender and disability perspective in teacher training programmes. Formulate specific training programmes to ensure education sector professionals receive specialised training to eliminate stereotypes that prevent equality and inclusion in society and education;
- Raise disability awareness in all parts of the education community and train practitioners in disability, gender differences and the needs of female students with disabilities. Also, raise awareness on situations which may lead to gender-based discrimination and highlight potential solutions. Deliver appropriate responses to the specific academic, personal and social needs of female students with disabilities;
- Set up support programmes for the mothers of children with disabilities, and above all carers, to provide information, support, training, etc.;
- Draft an Action Plan for Minors with Disabilities which includes the gender perspective;
- Ensure female students with disabilities are given personal, career and vocational guidance, information and access to all activities, resources and support to which they are entitled;
- Encourage businesses to take on female students with disabilities as trainees and promote protected employment for this group;
- Set up digital literacy programmes for older women with disabilities;
- Develop targeted lifelong education programmes for women with disabilities.

## 6.2. Recommendations for third-sector activists

- Further active participation by girls and female adolescents with disabilities in all issues affecting them. Introduce protocols allowing girls and women with disabilities to take part in decision-making, promote training programmes and schemes to boost access to management positions, draw up steps to ensure personal, family and work life balance in social third-sector disability organisations;
- Use educational spaces and contexts to promote women's leadership, from an early age and including the disability perspective. Without a doubt this will lead to greater equality in social, work, political, economic and cultural participation in the future;
- Put systems in place to allow acts of violence and abuse in educational environments to be reported. These mechanisms must be based on the principles of universal accessibility;
- Mainstream gender in all research carried out in the fields of education and disability;
- Carry out gender-sensitive research to analyse the impact of human rights instruments on the reality in classrooms, with a view to bringing to light stereotypes that keep girls and female adolescents in a subordinate position and obstacles to their participation in school life;
- Develop qualitative and quantitative human rights indicators to be able to identify the potential causes of exclusion, discrimination and segregation in the exercise by girls and female adolescents with disabilities of their right to education;
- Demand that public authorities formulate education policies in line with the principles of Education For All and that they draw up an Education For all Plan;
- Draft an Action Plan for Minors with Disabilities which includes the gender perspective;
- Encourage schools for mothers and fathers of girls and boys with disabilities where gender is taught;
- Raise awareness among all actors in the education community of disability issues, gender differences and the needs of female students with disabilities;
- Promote activities towards ensuring female students with disabilities are given personal, career and vocational guidance, information and access to all activities, resources and support to which they are entitled;

- Develop strategies to prevent girls and women from being socially excluded in all educational environments and leisure, free-time and sports activities;
- Report cases where the media, advertisers, television, classroom material or teachers contain or act according to sexist and stereotyped conceptions of males and females or discriminate against women with disabilities;
- Participate actively in all education-related fora to advocate for the rights of people with disabilities from a gender perspective.

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## Chapter IX

### HEALTH

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## Chapter IX

### HEALTH

#### 1. INTRODUCTION

Article 25 of the Convention on the Rights of Persons with Disabilities establishes that, “*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 43 of the 1978 Spanish Constitution recognises the, “*right to health protection, it being the responsibility of public powers to arrange and oversee public health through preventative measures and necessary provisions and services.*”

These are the regulatory cornerstones on which the right to health care is built - health care offering effective solutions to the demands of citizens and taking their characteristic diversity into account.

Historically, people with disabilities have been treated as if they were ill. The process of pathologising disability led, however, to deficient and disjointed health care focusing exclusively on the disability as the single core element on which the individual's entire state of health and wellbeing was founded, thus leading to other relevant dimensions being ignored. The social and emotional dimensions were ignored in favour of other exclusively physical elements, and as a result there has been a fragmentation and destabilising of the biopsychosocial entity that should be addressed holistically by health services.

We must bear in mind that, as the French philosopher Michel Foucault said, the concept of health contains a strong underlying discourse related to normality, a concept which also clearly carries ideological baggage requiring critical analysis. Medicine, in addition to labelling people - women and men with disabilities - as ‘sick’

or 'ill', centred its theory and praxis for many years on a body which was ostensibly neutral and valid for the whole of mankind, failing therefore to consider the specificities caused by sexual dimorphism or socialisation and culture; in short, the gender construct.

The result is the use of protocols that are uncritically applied on bodies that need 'treated', with the only justification being that biology, like natural science, acts in one single valid way for everyone, man or woman. This does not mean we should set aside procedural guidelines based on experience which ensure appropriate medical and health care; on the contrary, it means that these pathways guiding medical and health practices must become imbued with social reality.

Indeed, the definition of health used by the WHO refers to a state of complete physical, mental and social wellbeing, not merely to the absence of illness. So a social model of health is proposed which, despite ongoing obstacles to its widespread implementation, due largely to scientific progress and the mistaken idea that by implementing cutting-edge technologies we can resolve all health problems<sup>1</sup>, we must continue to champion.

There is, therefore, a human right to enjoy the highest possible standard of health with disability, sex or gender being no obstacle to that enjoyment, and a right to the best possible health care to make this right a reality. To achieve it we must move away from biology-based approaches which, on the one hand, homogenise the needs of all people with disabilities and, on the other, the needs of all women. Only if we reject explanatory models based on one single cause and offering unvarying solutions for all women with no consideration for diversity will it be possible to secure appropriate health care without running the risk of differences, which are in fact enriching, automatically becoming a factor leading to inequalities<sup>2</sup>.

Of course with the current scenario of global crisis it would not appear to be a propitious moment to consolidate a social model of health in which diversity is a key factor; in this respect professionals such as Manel Desviat - in his article *Public Health and Psychiatry* - were already indicating at the beginning of the century that World Bank findings indicated that at the end of the millennium we were far from having a social model of health for all and sustainable health, as was claimed by the WHO. On the contrary, the scene is set for regression to old paradigms based on biomedical

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<sup>1</sup> *Action on the social determinants of health: learning from prior experiences*, background paper prepared for the Commission on Social Determinants of Health, WHO, March 2005, page 9.

<sup>2</sup> For more information on this topic, see *Gender mainstreaming in the work of the WHO: WHO gender policy*, World Health Organisation, 2002: <http://www.who.int/gender/mainstreaming/strategy/en/index.html>.

thinking, posing as efficiency and through evidence-based medicine, the latest brainchild of *pensée unique* in the search for a universal vade mecum<sup>3</sup>.

## 2. MEDICAL AND HEALTH THEORY AND PRACTISE FROM THE PERSPECTIVE OF WOMEN WITH DISABILITIES

Addressing health from the woman's perspective implies, as indicated above, moving on from a model that ignores differences between women and men other than health problems linked to reproduction. Health, traditionally, and especially women's mental health, has always been linked to the vicissitudes of their reproductive functions (pregnancy, childbirth, post-partum, menopause, etc.), following a conceptualisation that regards women as mere reproductive subjects<sup>4</sup>.

However, and as we shall see in this chapter, women's reproductive functions have been systematically ignored in the case of women with disabilities or, at most, have been viewed as forbidden territory for the free exercise of rights.

In science and medical practise, the use of a supposedly neutral and universal standard, valid for all men and women, has, in reality, made more than half of humanity invisible by mistakenly homogenising the needs of the recipients of medical breakthroughs. At the same time, these ostensibly aseptic models have also ignored bodies whose diversity does not conform to the current standard<sup>5</sup>.

If we add this to the traditional medical model, which continues to consider disability as an individual pathology, we can see how women with disabilities find themselves in a situation involving double exclusion: on the one hand, disability takes absolute precedence over all other health questions and, on the other, the fact that the individual is a woman means she is subjugated to a pattern of care, prevention and rehabilitation which is not necessarily designed for her. That is why we need to revisit the premises on which many research projects and treatments are founded and mainstream other approaches such as the gender and disability perspectives.

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<sup>3</sup> DESVIAT, Manuel, *Public Health and Psychiatry, Rev. Asoc. Esp. Neuropsiq.*, 2001, volume XXI, n° 77, pages 125-133.

<sup>4</sup> GRELA, Cristina and LÓPEZ, Alejandra, *Women, mental health and gender*, Women's Commission, Montevideo City Council, Montevideo, 2000, page 5.

<sup>5</sup> An appropriate approach to situations of discrimination to which women with disabilities are subjected requires reference to normalism, the key to oppression, made up of a set of discourses and practises that discriminate people with disabilities simply because they have a disability.

In recent years battle has been fought on three fronts: the lack of studies on female health; the differentiated treatment women receive (a 1987 study published in the *Annals of Internal Medicine* showed how men generally found it easier to gain access to a certain heart treatment than women)<sup>6</sup>; and, finally, a lack of women in leadership positions in the field of science<sup>7</sup>. Also, from the pages of the *Journal of Women's Health*, there has been a call for a new speciality addressing female health.

As women have gradually become more prominent an 'alternative point of view' - evaded in academic and professional circles - has become more evident. Medicine is one of those disciplines where sexism has always existed, and it is only in recent years that the andocentric nature of research and medical practises has been a topic for debate<sup>8</sup>.

As Teresa Ortiz Gómez, Professor of the History of Science, points out, "*in recent years the interaction between health, history and feminism has led to developments in areas of research that include new and multifarious lines of questioning born out of women's social experience in modern times. The two major areas that arose over the course of the 20th century with the aim of studying women's health practises and discourses on the female body have been maintained in the last decade, with the incorporation of major theoretical novelties.*"<sup>9</sup>

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<sup>6</sup> Doctor Carme VALLS-LLOBET, on this subject, states that, "*in the eighties and nineties women weren't included in studies on heart attacks. That's why nobody knew women have different symptoms in cases of heart attacks and angina, for instance. We also didn't know that some treatments affect men's and women's bodies in a different way, such as the potassium pump or the aspirin*". Interview published in *Mi Estrella de Mar*: <http://mi-estrella-de-mar.blogspot.com/2008/10/enfermedad-y-mujer-el-punto-de-vista-de.html>.

<sup>7</sup> M.<sup>a</sup> Ángeles DURÁN, Professor of Sociology, states that, "*science has been built up from positions of power and power has placed science at its disposal; we also believe science has always turned its back on women and has often developed in the face of women...if science hasn't built itself, but instead has been built by groups of human beings who have given it its physical basis and organisational structures, through the same social intervention it can be thought of as a project towards freedom, a new call with no prohibitions or exclusions. That is why, as one of the groups historically excluded from science, today's women should confront old school science to make their own the potential science of the future, science that should be, the utopia-like science of the future*", DURÁN, M.<sup>a</sup> Ángeles, *Liberation and utopia: women and science*, E-mujeres.net.

<http://www.e-mujeres.net/ateneo/maria-angeles-duran/textos/liberacion-y-utopia-mujer-ciencia>.

<sup>8</sup> Of particular interest in this respect is the study *The history of medicine and the history of women*, by Teresa Ortiz Gómez: [http://www.ugr.es/~esmujer/pdf/tortiz\\_h\\_medicina\\_h\\_mujeres.pdf](http://www.ugr.es/~esmujer/pdf/tortiz_h_medicina_h_mujeres.pdf).

<sup>9</sup> ORTIZ GÓMEZ, Teresa, *Interactions between health, history and feminism: a historiographic review*, *Diálogo Filosófico*, number 59, 2004, page 234.

If we analyse medicine from this viewpoint and we add the disability perspective, we find that many gaps still exist and these lead to unsuitable treatments being used - if they exist - and negligent practises.

Two examples will suffice at this point to demonstrate how the gender bias impregnates current medical and health practise and discourse. Fibromyalgia and chronic fatigue syndrome remain invisible and overlooked<sup>10</sup>. The word fibromyalgia refers to muscular pain and the tissues connecting the bones, ligaments and tendons. The causes of these pathologies are unknown and they cannot be diagnosed by means of laboratory testing. As a result, diagnosis is based on a clinical examination of the patient's symptom. The fact that an extremely high percentage of the people affected are women, and above all middle-aged women<sup>11</sup>, along with persisting sexist views of medicine, means that in many cases the presence of pain has been denied and hundreds of thousands of women have been deprived of appropriate treatment. Organisations representing women with fibromyalgia and chronic fatigue syndrome condemn the fact that they are still labelled as 'moaners' or 'dissatisfied' people who simply want to kick up a fuss. Doctor Javier Rivera, a rheumatologist at the Gregorio Marañón Hospital in Madrid, has this to say on the subject: "*the dominant sexism in many societies has pigeonholed women patients as neurasthenics and blamed the female mind for the cause of the symptoms*"<sup>12</sup>.

Another example is how orthopaedic devices and technical aids are designed and function. *Self-diagnosis of the situation of women with disabilities in Andalusia*, published in 2011, reports how many women with disabilities are forced to use external prostheses which are too heavy and aesthetically unpleasant, for no reason other than economic motives. A standard - normally male - body model is used to design these aids with no consideration whatsoever for the person who is going to use it or thought of prevention criteria. One remark from a woman with disabilities illustrates the point well:

*"I have to wear this orthopaedic device. Have you seen how ugly all the shoes are? Always black, ugly things...we should get ourselves organised to change this. It's not because they are very heavy and they end up ruining*

<sup>10</sup> Since 1992 the WHO has considered fibromyalgia as a separate diagnosis and classified it as a type of soft tissue rheumatism. It is the most common cause of general osteoarticular pain.

<sup>11</sup> YUSTE GRIJALBA, Francisco Javier; YUSTE ECHARREN, Francisco Javier y VIDAL, A., *Fibromyalgia: a real illness under suspicion*, page 5:  
<http://www.afigranca.org/docs/La-FM-Dr-Yuste-Grijalba.pdf>.

<sup>12</sup> IBARRA, Rafael, *Fibromyalgia: between pain and scepticism*, ABC, health section, 6th June 2011.

*your body - I'd like to know what prevention criteria they use when they design and approve these things...in the [ortho-prosthetic] catalogue the only thing they have is the standard and cheapest model - to make it more economical..." (M.G., 57 years old)<sup>13</sup>.*

### 3. PRIMARY HEALTH CARE

According to the WHO definition, primary health care is essential health care which is universally accessible to all individuals and families in the community through means which are acceptable to them, involve their full participation and are delivered at affordable cost to the community and the country. It is the very heart of the health system and is an integral part of overall socio-economic development in the community.

Article 12.1 of Law 16/2003, dated 28th May, on National Health Service cohesion and quality, recognises that, *"primary health care is the basic and initial level of care; it guarantees nationwide coverage and continuity in care for patients during their entire lives, acting as a manager and coordinator for cases and regulating flows. It shall include activities aimed at promoting health, health education, disease prevention, health care, health maintenance and recovery, as well as physical rehabilitation and social work."*

In our country, due to major differences between primary health care systems in each of our Autonomous Communities, carrying out a detailed study on what care women with disabilities receive is complicated. However, we would not be wrong in stating that in general there is a certain level of ignorance among health practitioners (as also occurs in specialist health care) as to what specific factors have a bearing on the health of women with disabilities. The medical and health professions still generally believe them to be genderless and their health status is linked solely and exclusively to their disability. Furthermore, prejudices seem to grow in direct proportion to the degree of disability, and this has caused many women with disabilities to seek other sources of information, such as for instance internet, where the sheer amount of information on medical questions and lack of expertise on the subject matter lead more to confusion and alarm than to solutions.

Disability is still, therefore, viewed as the core factor on which all treatment or clinical analysis to be prescribed should be founded. This is why many typically female ailments, many with potentially serious consequences - osteoporosis, the causes of which are not linked only to the menopause, is one example - are not dealt with appropriately when there is a pre-existing disability. As a result, many women with

disabilities in our country are often left untreated and do not receive the medical attention they require.

Organisations of women with disabilities report numerous cases where primary health care services have failed to apply early detection protocols and refer women with disabilities to specialist services for treatment for breast cancer, cancer of the uterus, ovarian cancer and birth control, among other cases, with the consequent risk to the patient of developing cancer or a serious illness, given the lack of preventative guidelines, and unwanted pregnancies. Moreover, the practise of so called opportunistic screening (routine testing performed on members of at risk populations) does not appear to have the same impact on women with disabilities as on the female population as a whole precisely because, out of habits which are generally unacknowledged by health care practitioners, they continue to view them as 'non-women'.

Breaking down these myths should be precisely one of the main aims of training curricula for any health care specialist, given the diversity in the population he or she will treat and the key factors influencing their state of health, moving beyond strictly biomedical factors for which they are properly trained. Steps to achieve this would help to meet the requirements set out in article 6.1 of Law 33/2011, dated 4th October, on Public Health, which recognises the right to equality and establishes that, *“all persons enjoy the right for public health interventions to be performed under equal conditions; there shall be no discrimination on the grounds of birth, racial or ethnic origin, sex, religion, belief or opinion, age, disability, sexual orientation or identity, illness or any other factor or personal and social circumstance.”*

We must also remember that the life experiences of many women with disabilities are closely linked to the health system, bringing about relations of power with the specialist (in fact not all disabilities require constant medical examinations and check-ups, but some do require closer medical and health monitoring). The traditional imbalance in power between health care practitioners and the general public is aggravated in the case of people with disabilities, and particularly women with disabilities, who have historically been pathologised and disempowered in all areas relating to health. Not being able to question any specialised decision regarding their health has had a particular bearing on them, and they are often forced to construct their own individual identity through medical discourses. That is why it is necessary to put in place a primary health care model based on approachability, equality, participation and respect for diversity, and develop actions aimed at empowering citizens in health, and more specifically men and women with disabilities, with a view to ensuring everyone can effectively exercise their freedom of choice and have greater control over the decisions and actions affecting their health.

Linked to this we have the call by organisations of women with disabilities for the right to privacy in health care. According to the 2011 *Self-diagnosis of the situation of women with disabilities in Andalusia*, out of a total of 1 115 women who were asked the question, 87% responded that at some point in their lives they had felt their privacy was encroached upon by the health system. This clearly reflects how they are objectified as patients; despite being rights holders they are unable to exercise them.

The need to leave behind the medical model is deeply-felt and clearly expressed, as we can see, by the vast majority of women with disabilities<sup>14</sup>. The right to privacy is recognised in our legal system in article 7 of Law 41/2002, dated 14th November, concerning regulations for patient independence and their rights and duties regarding information.

#### 4. SPECIALIST HEALTH CARE

Article 13 of Law 16/2003, dated 28th May, on National Health Service cohesion and quality, states that, “*specialist health care includes activities related to welfare, diagnosis, therapy, rehabilitation and care, as well as actions to promote good health, health education and disease prevention which, by their nature, should be performed at this level. Specialist health care shall ensure continuity in the overall health care delivered to the patient once the options at primary health care have been exhausted and until he or she can be referred back to that level.*”

Due to the wide range of issues that could be addressed in this section, remarks will focus fundamentally on four key areas: sexual health, reproductive health, mental health and gender-based violence.

##### 4.1. Sexual health and women with disabilities

The WHO defines sexual health as a state of physical, emotional, mental and social wellbeing related to sexuality: it is not merely the absence of illness, dysfunction or disability. Sexual health requires a positive and respectful approach to sexuality and sexual relations, and the opportunity to obtain pleasure and enjoy safe sexual experiences free of coercion, discrimination and violence. To achieve and maintain sexual health the sexual rights of all persons must be respected, protected and honoured.

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<sup>14</sup> CÓZAR GUTIÉRREZ, M<sup>a</sup> Ángeles (Coordinator), *Self-diagnosis of the situation of women with disabilities in Andalusia*, Consejería para la Igualdad y Bienestar Social de la Junta de Andalucía, 2011, page 100.

Sexual and reproductive rights have been recognised by the international community as human rights in United Nations declarations, conventions and covenants and in other internationally-adopted instruments. In particular, since the Fourth World Conference on Women and through the Platform for Action, women's human rights include the right to exercise control and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free from coercion, discrimination and violence<sup>15</sup>.

In our country, the 2011 National Strategy for Sexual and Reproductive Health, published by the Ministry for Health, Social Policy and Equality, addresses and includes people with disabilities as a group in the context of vulnerability. It does so recognising and stating that groups are mentioned merely for ease of understanding and should not be considered exclusive as contexts of vulnerability may intertwine and be shared. The document, as it says itself, has been drafted with the gender perspective in mind. Having said this, there are few initiatives and practises in this field which manage to see beyond a dichotomic viewpoint and approach the subject from an intersectional perspective<sup>16</sup>.

The *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union - a toolkit for activists and policymakers* also includes a section on sexual and reproductive rights for women with disabilities. The manifesto highlight social and structural barriers that make it difficult to access specialist health services in this field, and we will now go on to look at these in further detail.

As we can see, there are references to the sexual rights of women with disabilities in many statutory requirements and advocacy documents. Nevertheless, the key is not only to recognise that women with disabilities have the right to freely enjoy their sexuality in official discourse; it is to realise that in fact women with disabilities in real life are sexually active in many different ways. The implication is that specialist sexual health services must respond to this reality, and consequently they must be informed by two fundamental cross-cutting issues: gender and disability.

Accessibility is one of the prerequisites for medical and health care in sexual health to be delivered appropriately. Paragraph 14 in chapter 3 of the 2nd manifesto holds that, "*It is necessary to ensure universal accessibility, design for all and a gender*

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<sup>15</sup> CÓZAR GUTIÉRREZ, M<sup>a</sup> Ángeles (Coordinator), *op. cit.*, page 101.

<sup>16</sup> The intersectionality theory can be defined as one which enables us to analyse how power is produced focusing mainly on minorities and bearing in mind the different causes of discrimination, such as disability, race, ethnicity, gender, social class, etc. For more information, see CRENSHAW, Kimberlé, *Mapping the Margins - Intersectionality, Identity Politics, and Violence against Women of Color*, in *Stanford Law Review* 43.

*perspective in products, objects, instruments, tools and devices, in order to ensure that those used regularly by women and girls are also accessible for women and girls with disabilities, can be used safely and comfortably and as independently and naturally as possible. Special attention should be paid to those related to the sexual health of women with disabilities (contraceptives, gynaecologist's examination bed, mammography equipment, and so on), and to motherhood (babies' bottles with handles, prams designed to be clipped on to wheelchairs or pushed with one hand, wheelchair-accessible nappy changers, and so on), and should be included in publicly-available catalogues at affordable cost."*

We mustn't forget that alongside the world of ideas, the material world is built on the same cultural processes that feed our symbolic imaginary. In this sense, what is thought is brought to life in material reality and, at the same time and in a continuous process of feedback, thoughts are constructed. Breaking this dynamic occurs when there is a paradigm shift, through slow transformation processes, which in the case at hand involve destigmatising human reproduction and deconstructing the maternal ideal which is built from the patriarchal model.

This is how, by invisibilising the sexual and reproductive right of women with disabilities, gynaecology and obstetrics services ignore universal accessibility and design for all men and women. Health spaces and resources still seem to be designed to suit consultants and not the beneficiary population. So gynaecology examination beds are normally not equipped with a hydraulic system to enable a woman with reduced mobility, for instance, to sit and lie down by herself, either by transferring from her wheelchair or with assistance from another person, but without risk of falling and injury, as can happen easily with the old-fashioned examination bed widely used in gynaecology. The same occurs with other diagnostic examination equipment, such as for instance mammography units, which cannot be used by all women, with the consequent risk this involves for women's health<sup>17</sup>.

Paragraph 14 in chapter 3 of the 2nd Manifesto is a summary of the key demands which organisations of women with disabilities have been putting forward for years. It includes generic accessibility problems that continue to exist even today in the majority of specialist health care services, including symbolic barriers which continue to abound in the minds of many male and female health practitioners, built on myths surrounding asexuality - when it's not uncontrolled hyper sexuality - of women with disabilities, part of the dominant ruling discourse excluding those on

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<sup>17</sup> An example of good practise in this area are the gynaecology units set up in the Andalusia region, which are equipped with the ideal infrastructure and staffed by trained professionals.

the margins<sup>18</sup>. This is a good example of how the ideational world feeds off the material world and vice versa.

The *Convention on the Rights of Persons with Disabilities* recognises the importance of accessibility to the built, social, economic and cultural environment, to health and education and to information and communication to enable people with disabilities to enjoy all their human rights and fundamental freedoms. Accessibility, therefore, must be viewed as an essential component in the right to health. Along the same lines, article 25 section d) of the Convention imposes an obligation on health sector practitioners to deliver health care of the same quality to people with disabilities as to others, on the basis of free and informed consent, including by raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.

As mentioned above, paragraph 14 in chapter 3 of the 2nd Manifesto refers, *inter alia*, to the important issue of birth control. Planned and urgent contraception, in addition to preconception control, require further study in the case of women with disabilities. In this respect, the study on *Contraception in Andalusia - representations, discourses and practise among adolescents and adults with and without disabilities*, published in 2011, highlights the fact that the distinct additional barriers affecting women with disabilities in terms of contraception are unknown to most people, and this helps to sustain them. For people with disabilities the main obstacle is awareness. One of the women interviewed for the study said that,

*“I also think there is no information for women with disabilities, because nobody thinks we have sex or sexual desires, or partners...they don’t think you’re attractive because you have a disability, whatever kind of disability it is, and they don’t believe someone else could find you attractive...plus, if you’re a woman, they don’t believe you have sex” (GD8:1/5).*<sup>19</sup>

<sup>18</sup> The analysis of the French philosopher Michel Foucault regarding sexuality among those subjects who subvert the dominant model and are constructed from, for instance, disability itself, as sexed and sexual human beings, is well-known. Foucault, in his book *The history of sexuality*, refers to biopower, the set of disciplinary and control measures expressed on the body. Biopower is expressed through two techniques: on the one hand anatomopolitical techniques, which focus on the individual and control of the body through institutions such as prisons, asylums, hospitals and schools, with the aim of anatomising, that is to say to produce docile and fragmented bodies; and biopolitics, which regulates the ‘body-species’ or the population through birth control, fertility, morbidity, etc.. The meeting point between the two techniques lies in controlling sexuality as a mechanism for disciplinary control of the body and population control.

<sup>19</sup> GÓMEZ BUENO, Carmuca (lead researcher), *Contraception in Andalusia - representations, discourses and practise among adolescents and adults with and without disabilities*, Junta de Andalucía, Consejería de Salud, 2011, pages 73-74.

While on the subject of studies on birth control, to the myths expressed above we have to add the organisational diversity in sexual and reproductive health services which are confusing for the public and make them difficult to use, and even more so if the user happens to be a female adolescent or adult woman with disabilities. Another relevant point is that the vast majority of campaigns on contraception ignore female adolescent or adult woman with disabilities and use formats which are not accessible for all women and men. As a result of all of the above, it is easy to understand why information does not reach these women.

#### **4.2. Reproductive health and women with disabilities**

Paragraph 6 in chapter 8 of the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union* recognises that “*Reproductive rights, that is to say the freedom and independence all people have to decide freely and responsibly to have children or not, how many, when and with whom, also include the right to information, education and the means to exercise such rights, the right to take decisions on reproduction free from discrimination, coercion or violence, the right to access quality primary healthcare, and the right to measures to protect motherhood. All these rights must be fully ensured for adolescents and women with disabilities, on an equal footing with others and based on full consent and mutual respect.*”

These demands seek to achieve full recognition of the reproductive rights of women with disabilities and safeguards to ensure they can exercise them. Rights are made effective precisely when they become everyday practises, as a sign of day-to-day progress, and may experience progression or setbacks. In the specific case of women with disabilities and their reproductive rights, it is only possible to take stock of shortcomings and progress through reference, on the one hand, to the myths and prejudices used to construct the maternal ideal in our societies, and, on the other, to the strategies used by women with disabilities themselves to deconstruct this exclusive maternal model in western culture.

Women with disabilities, and especially those with more severe disabilities, normally face particular difficulties when they attempt to exercise their reproductive rights. Often these difficulties arise precisely in relation to health. Debunking the myth that women with disabilities are forever children who are incapable of looking after themselves, far less care for others, is an attainable goal if we show health care practitioners the reality these women face. We do have some examples of good practise, including the experience from the *Humanising Perinatal Care in Andalusia* project conducted over the past few years by the health department of the Andalusia

regional government in line with the guidelines set out in the *National Care for Normal Birth Strategy*.

Through this project dozens of health sector professionals have received training in these matters. Moreover, a diversity-sensitive public health sector cannot make the mistake of medicalising pregnancy and childbirth in women with disabilities, who are often subjected to numerous tests and unnecessary caesarean sections.

It is hardly surprising that health services covering pregnancy, childbirth and the post-natal period reflect precisely preconceived ideas regarding reproduction, and that these notions are, in turn, reflected in designs, spaces, instruments and services used to deliver this type of service.

Among the main obstacles limiting the right to appropriate reproductive health care is a certain level of mistrust among health sector practitioners because they lack knowledge, experience and specific references when dealing with a woman with disabilities who wants to become a mother or is already pregnant. Often they spout arguments which have no theoretical or medical basis in order to dissuade the woman from disabilities from becoming a mother. In this respect we have the medical discourse that stresses how the woman's disability, viewed as a health condition, may become worse as a result, or the possibility that the disability will be passed on to the foetus, often expressed as a fact and with reproach. The woman is not given the opportunity to take a decision that is fully free and informed on the matter.

This all leads to excessive interventionism during pregnancy, childbirth and the post-partum period which should not be addressed as if they were illnesses but as life stages and part of a natural process (although culturally constructed obviously and, as such, charged with meaning) where the woman's opinion must be considered, in the framework of a new person-centred health model. In recent years there has been an increasing and general trend to overuse technologies and perform unnecessary, unpleasant and even unadvisable interventions in normal childbirth.

There is a noticeable trend towards inducing labour and depriving women with disabilities of the chance to give birth naturally. Although induction of labour is justified in cases where there are potential complications during childbirth, using it systematically makes one believe it is a way to avoid problems due to a lack of expertise among medical staff involved. In our country the National Health Service's *National Care for Normal Birth Strategy*<sup>20</sup>, adopted in plenary session by the National Health Service Interregional Council and published by the Ministry for Health and

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<sup>20</sup> *National Care for Normal Birth Strategy in the National Health Service:*  
<http://www.msc.es/organizacion/sns/planCalidadSNS/pdf/equidad/estrategiaPartoEnero2008.pdf>.

Consumer Affairs in 2007, includes an interesting study on the need to seek common ground between the opinions held by professionals and the scientific community and those of women and reach a critical consensus on the differences that may exist regarding pregnancy and childbirth.

The document also stresses the need to find linkages between the different conceptualisations of health, a particularly significant issue if we consider that the subjectivity of a woman with disabilities has often been constructed through medical discourses that help to create a somatic body model for use by eugenic-like policies, and therefore a body incompatible with reproduction.

On this point we must make reference to the *Organic Law dated 3rd March 2010 on sexual and reproductive health and voluntary interruption of pregnancy*, which regulates this right and brings an end to a long period of legal uncertainty surrounding its exercise in our country. The law has a particularly significant impact on disability: while it offers a system involving time limits which allows women to choose freely whether to go ahead with a pregnancy or not and without the need to allude to specific circumstances or suppositions, as was the case with the previous law, it has added concrete circumstances to the time limits - and herein lies the problem - which allow a woman to have an abortion even when the legally-established time period to exercise the right has expired.

More specifically, article 14 regulates interruption of pregnancy based on a request by the pregnant woman. It allows interruption during the first fourteen weeks of gestation subject to a request by the pregnant woman, provided she has been informed of her rights, services and public support measures for motherhood and a period of at least three days has passed since she received this information and the time the intervention is performed.

Article 15 provides for interruptions for medical reasons and due to exceptional circumstances. For this to happen a number of conditions must be met; for instance, the period of gestation cannot exceed twenty-two weeks. The provisions in paragraph b) are particularly relevant to the case at hand as they allow interruption of pregnancy during the first twenty-two weeks of gestation when there is a serious risk of foetal anomalies and this risk is confirmed in a medical report issued prior to the intervention by two medical specialists other than the one performing or in charge of the intervention.

The disability movement must make society aware that by establishing a specific provision allowing abortion to be performed on foetuses with disabilities is an implicit endorsement in our country of eugenic abortion. If interruption of pregnancy for any foetus not affected by disability is prohibited beyond 14 weeks, *a sensu contrario* the

option to do so in exceptional cases implies that those fetuses which have an anomaly are not considered part of 'humanity' in the same way, and therefore the legal time limit stipulated in law does not apply to them. If these provisions are accepted, does this not mean that people with disabilities are considered not to have the same humanity as their fellow human beings?

The law as put forth considers there to be a legal interest which merits greater protection than the potential life of an unborn child with disabilities. This establishes a dangerous doctrine concerning which lives are worth living and which are not. A law setting time limits, providing all possible guarantees and excluding indications of serious foetal anomalies would not violate any fundamental rights. In a democratic country, all women should have the opportunity to avail themselves of a law safeguarding their right to abort, but abortion must be regulated in such a way that it does not lead to establishing a method to expedite getting rid of life with a disability.

The right to interrupt pregnancy has been mentioned in this chapter although it is addressed elsewhere in more detail in the chapter on reproductive rights and women with disabilities. This point must also be linked with non-consensual contraceptive sterilisation and women. On this matter, we refer to the guidelines and recommendations issued by the International Federation of Gynecology and Obstetrics in June 2011:

*"Evidence exists, including by governmental admission and apology, of a long history of forced and otherwise non-consensual sterilizations of women, including Roma women in Europe and women with disabilities. Reports have documented the coerced sterilization of women living with HIV/AIDS in Africa and Latin America. Fears remain that ethnic and racial minority, HIV-positive, low-income and drug-using women, women with disabilities and other vulnerable women around the world, are still being sterilized without their own freely-given, adequately informed consent."*<sup>21</sup>

The possibility of performing sterilisations exists in our Penal Code. Article 156 of the Spanish code allows medical personnel to carry out sterilisation without incurring any legal liability provided the individual involved has given valid, free, conscious and explicit consent. However, the law also stipulates that sterilisation in the case of an 'incapacitated' person with a severe mental deficiency shall not be punishable if, based on the guiding principle of the best interest of the individual under guardianship, it is authorised by a judge, either during the incapacitation process or as part of a subsequent voluntary legal proceeding initiated by the legal representative of the

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<sup>21</sup> *Female Contraceptive Sterilization*, International Federation of Gynecology and Obstetrics, meeting of the Executive Board, June 2011, page 1.

incapacitated individual, having considered reports from two specialists and the Ministry for Fiscal Affairs and following a medical examination of the individual who is to be sterilised.

There is, therefore, an established legal procedure that delimits cases in which sterilisation can be performed when the individual has been declared 'incapable'. The procedure does contain some grey areas - for example it does not state what type of specialists should issue reports or define 'serious mental deficiency'.

Particularly alarming is the information provided in the article *Sterilisation of Women and Girls with Disabilities. An update on the issue in Australia*, published in December 2010 by *Women with Disabilities Australia* (WWDA). It highlights how women and female adolescents with disabilities in Australia face a serious threat of forced sterilisation. WWDA points out that the Australian government views sterilisation as a medical issue unrelated to the exercise of a human right, and even considers it acceptable to perform sterilisation on minors with disabilities. This is just one example from among many, and it underlines how reproductive health can come under the influence of biopolitical measures which are imposed in issues related to right to life and reproduction even in countries considered democracies.

## 5. MENTAL HEALTH AND WOMEN WITH DISABILITIES

As the executive summary of the 2009 WHO report *Women and Health: today's evidence, tomorrow's agenda*<sup>22</sup> points out, mental health problems, and particularly depression, are major causes of disability for women of all ages. While the causes of mental ill-health may vary from one individual to another, women's low status in society, their burden of work and the violence they experience are all contributing factors.

Paragraph 10.21 of the 2nd Manifesto recalls that gender is a critical determinant in mental health as it influences the differential power and control men and women have over the socio-economic determinants of their lives, their social position, status and treatment in society and their susceptibility and exposure to specific mental health risks.

In our country there are no figures specifically detailing the prevalence of situations of psychological malaise among women. The most information we have comes from the National Health Service Mental Health Strategy 2009-2013, which reports that the

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<sup>22</sup> *Women and Health: today's evidence, tomorrow's agenda, 2009*, executive summary: [http://whqlibdoc.who.int/hq/2009/WHO\\_IER\\_MHI\\_STM.09.1\\_eng.pdf](http://whqlibdoc.who.int/hq/2009/WHO_IER_MHI_STM.09.1_eng.pdf).

prevalence of mental ill health is greater among women from disadvantaged social classes<sup>23</sup>. The strategy only mentions disability in cases where this is caused by a mental illness.

When we talk about mental health in women with disabilities we are not necessarily referring to the existence of an illness, but rather the presence of a malaise which may be caused precisely by the discriminatory situations these women have to confront on a daily basis. Clearly exclusive models of female corporeality, closed doors in terms of access to services and resources, denial of sexual and reproductive rights, violence that goes unnoticed in society, and so on...are realities that have helped to shape a feminine subjectivity placing them in liminal spaces where multiple mechanisms for disciplining and social repressions operate. They may all have a negative impact on how women with disabilities perceive themselves and trigger feelings of confusion and dissatisfaction.

GRELA and LÓPEZ GÓMEZ point out the need to “*consider mental health in the general population and, in particular, among women, as a product of different interwoven factors: socio-economic position, the outcomes of masculinity and femininity in history, value systems and beliefs in relation to mental health and mental illness, scientific interpretation and technical intervention models; and an analysis of social norms and everyday lives, among others*”<sup>24</sup>. To this we must add the historical and cultural construct surrounding people with disabilities, and specifically women with disabilities, which has developed in our societies since time immemorial.

In relation to mental health and girls and women with disabilities, mental health services must not only be instructed in how to respond to post-traumatic stress, cognitive distortions, sex-related difficulties, phobias, culpability, low self-esteem, and so on, but must also intervene from a critical perspective and look beyond roles constructed by a patriarchal and normalist system.

In truth, this comprehensive approach should be standard practise in individual and group therapies in mental health services as it would enable women to improve their health and become more empowered at the same time<sup>25</sup>. It would be the ideal

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<sup>23</sup> *National Health Service Mental Health Strategy 2009-2013*, Health 2011, Ministry for Health, Social Policy and Equality, page 17.

<sup>24</sup> GRELA, Cristina and LÓPEZ GÓMEZ, Alejandra, op. cit., page 31.

<sup>25</sup> Empowerment is a term coined at the Beijing World Conference on Women in 1995. It refers to the full and equal participation by women in all spheres of society, including participation in decision-making processes and access to power. It also includes raising awareness of the power women wield individually and collectively, which is related to recovering the dignity of women as human beings.

method for women with disabilities to become aware of the power they have to lead and transform their life projects and condemn the biomedical discourses and practises which have labelled them as pathological. This would obviously require major efforts in training and raising awareness by mental health practitioners, with a view to their including this critical and emancipating viewpoint in their everyday work. At the same time, we must get rid of technocratic mental health models which believe knowledge is held only by professionals and in order to further more participatory models where the voices of women can be heard and taken into account. Of course this approach to the mental health of women with disabilities does not mean we must start to overlook clinical and epidemiological aspects, but neither is it about seeking the prescribed tranquillity mentioned by Mabel Burín, in a clear reference to the trend towards abusive prescription of psychotropic drugs and excessive consumption of tranquilizers by women<sup>26</sup>.

On this matter, paragraph 22, chapter 10 of the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union* recognises that mental health professionals must be given suitable training in the human rights and fundamental freedoms enjoyed by women with disabilities in order to ensure the treatment they receive is based on absolute respect for their dignity and independence, according to the principles enshrined in the Convention on the Rights of Persons with Disabilities.

The manifesto also highlights the need to offer professional support to mothers with disabilities and the mothers of girls or boys with disabilities to resolve cases of anxiety and depression which may arise due to this situation.

## 6. GENDER-BASED VIOLENCE AGAINST WOMEN WITH DISABILITIES: A HEALTH SERVICES APPROACH

Chapter 3, paragraph 16 of the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union* calls for, “*All care services for women (and especially those related to health, motherhood, violence against women and childcare)...[to be]...fully accessible for women and girls with disabilities.*”

Organic Law 1/2004, dated 28th December, on comprehensive protection measures against gender-based violence, among its guiding principles, highlights the need to “*ensure measures are mainstreamed so that, when implemented, the specific*

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<sup>26</sup> BURIN, Mabel, MONCARZ, Esther and VELÁZQUEZ, Susana, *Women's malaise and prescribed tranquillity*, Paidós, Buenos Aires, 1998.

*needs and demands of all women who are victims of gender-based violence are considered.”*

In section III (rationale), the law stipulates that *“in the field of health, early detection and welfare support systems for victims will be delivered, in addition to health protocols to tackle the aggressions caused by gender-based violence as covered by this Law. These shall be referred to the corresponding courts of law with the aim of expediting legal proceedings. Moreover, in the framework of the Interregional National Health Service Council, a Commission shall be set up to provide technical support and co-ordinate and assess health measures initiated under this Law.”*

Spain has developed a set of nationwide indicators for gender-based violence which enable us to gauge the scale and consequences of this kind of violence for health and on the health system. The indicators were developed on the basis of proposals drawn up and agreed upon in the Commission to Combat Gender-based Violence in the Interregional National Health Service Council. Among many others, the system includes indicators related to the personal characteristics of victims of violence, including women with disabilities, the level of assistance and the source of the referral (for cases detected in primary or specialist health care). Furthermore, the *Common protocol for health care in cases of gender-based violence* refers to the particular situation faced by women with disabilities without, however, drawing up precise recommendations to guide prevention, detection and treatment by health service practitioners for women with disabilities.

This means that even though mechanisms are in place to prevent and address gender-based violence against any woman, there is still a serious lack of knowledge on the characteristics and implications of gender-based violence against women with disabilities, to the point where reality is denied as cases of mistreatment are systematically put down to a type of violence carried out on the basis of situations of vulnerability in which a woman may find herself simply because she has a disability.

It is apparent then that despite efforts to visibilise the situation, in the specific case of gender-based violence there is still widespread reluctance to acknowledge that, in addition to the processes and cycles at play and the ways gender-based violence occurs generally, there are other specific ways and processes resulting from the confluence of various factors leading to discrimination, such as gender and disability, gender and place of birth and, even more so, gender, ethnicity and disability, to cite some examples.

One noteworthy example of good practise in the field is the *Protocol addressing gender-based violence in health in Catalonia: a working document for women with disabilities*, drawn up by the regional government in Catalonia, which contains detailed instructions and covers three areas: prevention, detection, and care and recovery.

For prevention, the protocol proposes awareness-raising activities aimed at the general public, training on gender-based violence for health sector practitioners, and training courses on prevention and awareness for teachers, with an eye to health education. In addition, primary health care staff should keep a record of all visits by women with disabilities in their case records and monitor them proactively.

The protocol puts forward a wide range of methods to detect violence. Primary health services would seem to be the most direct way of carrying out detection as they are in contact with women with disabilities. As the protocol points out, sexual and reproductive health centres and hospital-based services are well placed to detect cases, without overlooking social organisations, whose co-operation on-line with health services should be strengthened. In this respect, many European Union countries have organised networks of women with disabilities which are in contact with other likeminded social organisations and, working together, many cases are referred to specialist public health services.

Indeed, chapter 10 of the 2nd Manifesto covers health care to address violence against women, and paragraph 17 recognises that health services can play a crucial role in assisting women and girls with disabilities who are victims of violence as most will be in contact with these services at some time in their lives. Moreover, abuse affects women's health and as a result women use health services more often, in particular primary health services, emergency services, obstetrics, gynaecology and mental health services. Consequently, health policies must ensure women and girls with disabilities are provided with adequate healthcare throughout all stages of the process (prevention, early diagnosis and patient recovery).

It goes without saying that sexual violence is one type of violent situation many girls and women with disabilities experience. Although no official figures exist, organisations of women with disabilities constantly report repeated cases of violence, and it is thought the incidence rate among women with mental illness and intellectual disabilities is higher.

Accessibility as a cross-cutting theme must be secured, as paragraph 3.16 of the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union recalls: *"All care services for women (and especially those related to health, motherhood, violence against women and childcare) must be fully accessible for women and girls with disabilities."*

The way to move forward would be to ensure compliance with universal design criteria in health services so that they can be used by everyone without impediment due to disability or any other personal circumstance.

## 7. RECOMMENDATIONS FOR POLICY MAKERS AND THIRD-SECTOR ACTIVISTS

On the basis of the analysis carried out above on the main shortcomings and potential the medical health model offers women with disabilities, a series of experience-based recommendations are now put forward for social agents as well as those in charge of formulating and delivering public policies.

<b>GENERAL HEALTH CARE</b>	
	Foster research on the health needs of women with disabilities, mainstreaming the double gender and disability perspective.
	Develop health prevention and promotion programmes to teach women with disabilities about their rights in this area and about existing health resources.
	Train health sector practitioners on the reality of women with disabilities, with a view to ensuring they are treated decently and appropriately.
	Medical and health staff should inform patients about their state of health so that patients themselves can take conscious and informed decisions on the most suitable treatment.
	Promote research on the ailments and discomfort which affect women in particular, with gender and disability mainstreamed in these studies. Epidemiologic research involving disability must contemplate the differences between men and women.
	Ensure medical data on the health of women with disabilities is confidential and prohibit access to data without legally-sanctioned authorisation.
	Strengthen public health citizens' networks and social partnerships and encourage women with disabilities to participate actively. Partnership between citizens and civil society is a necessity and should form part of any truly democratic and participative public health model, while in no way acting to the detriment of the professionalization of those services public powers are mandated to deliver to citizens. Volunteering and mutual support should also be encouraged and strengthened.
<b>PRIMARY HEALTH CARE AND SPECIALIST HEALTH CARE (birth control, sexual health and reproductive health)</b>	
	Monitor women with disabilities closely through health review protocols. Suitable treatment in each case must be provided as medical practitioners often misdiagnose by systematically attributing women's complaints to the fact they have a disability.
	Promote campaigns to disseminate information on women and disability in hospital-based patient care services.
	Draw up and conduct plans to remove architectural, communication and information-based barriers in health services and equip them with accessible examination instruments and equipment.

	Avoid excessive and unnecessary medical intervention in pregnancy, childbirth and postnatal services when the patient has a disability.
	Develop specific protocols for sexual health and family planning, including the disability perspective, to foster self-responsibility in sexual and reproductive health among women.
	Acknowledge the right to freely-chosen motherhood and to natural childbirth, avoiding systematic recourse to induction methods and surgical procedures.
	Ensure women with disabilities and sterility problems enjoy full and equal access, on an equal basis with other women, to fertility programmes.
	Set up counselling services in maternity hospitals for women who have had or are going to have a daughter or son with a disability, in order to provide them with full information and tackle taboos and prejudices surrounding disability.
	Carry out campaigns on sexual and reproductive health involving women with disabilities and ensure accessible formats are used.
	Make available in accessible formats material on preparation for labour, pregnancy and care for the newborn child.
	Put in place social awareness campaigns on the sexual and reproductive rights women with disabilities enjoy, including in accessible formats.
	<b>GENDER-BASED VIOLENCE AGAINST WOMEN WITH DISABILITIES AND HEALTH CARE</b>
	Draw up and implement protocols addressing gender-based violence in the health sector.
	Carry out cross-cutting awareness programmes on gender-based violence aimed at health sector staff.
	Foster mainstreamed information and awareness programmes on gender-based violence aimed at health sector personnel, with a view to facilitating detection and effective treatment. Focus particularly on the specific characteristics which may be present when the victim is a woman with disabilities.
	<b>MENTAL HEALTH AND WOMEN WITH DISABILITIES</b>
	Set up psychological care services with participatory and mutual support methods, not based solely on clinical aspects but with gender and disability mainstreamed and considering the cultural, economic and social factors affecting the mental health of women with disabilities.
	Broaden mental health services for those women with disabilities who need them, with special focus on women who are victims of gender-based violence (including sexual violence and forced sterilisation) and mothers of girls and boys with disabilities.

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## Chapter X

### WORK AND EMPLOYMENT

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1. WOMEN WITH DISABILITIES AND EMPLOYMENT
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6. RECOMMENDATIONS FOR THIRD-SECTOR ACTIVISTS

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## Chapter X

### WORK AND EMPLOYMENT

#### 1. WOMEN WITH DISABILITIES AND EMPLOYMENT

##### 1.1. Engagement in the labour market: still a utopian dream

Employment is an essential factor in guaranteeing equal opportunities for all. It is a decisive factor in full participation by citizens in economic, social and cultural life. Nevertheless, there are still many cases of discrimination in the labour market affecting, above all, people who are vulnerable or find themselves in a position of social vulnerability.

In the case of women, their struggle and efforts to join the labour market on equal terms has, in the last few decades, generated growing political and social interest. Efforts have been made to intervene to safeguard equality between men and women and attempt to eliminate existing discrimination on the basis of gender, particularly in the labour market and in labour relations.

In the case of persons with disabilities, even nowadays and despite progress in recent years —mainly in legal instruments promoting equal opportunities and combating discrimination<sup>1</sup>— the use and enjoyment of social and economic rights is still limited.

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<sup>1</sup> Convention on the Rights of Persons with Disabilities, 13th December 2006, New York; Article 19 (previously article 13) of the Treaty on the Functioning of the European Union, which entitles the Council to ‘take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation’. In developing this power a number of directives have been adopted, including Directive 2000/43/EC on the principle of equal treatment and non-discrimination on the basis of racial or ethnic origin, Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation and addressing discrimination based on religion or belief, disability, age or sexual orientation, and Directive 2002/73/EC on the implementation of the principle of equal treatment for men and women as regards access to employment, vocational training and promotion, and working conditions. In Spain, Law 51/2003, dated 2nd December, on equal opportunities, non-discrimination and universal accessibility for persons with disabilities.

As the '*European Disability Strategy 2010-2020: a renewed commitment to a barrier-free Europe*' so pertinently points out, quality jobs ensure economic independence, further personal achievement and offer better protection from the threat of poverty.

For women with disabilities, the intersection of two factors —disability and sex— has led to a clear violation of their rights, curbed their wishes, shaped their desires, limited their options and condemned them to invisibility and, consequently, to non-existence.

Women with disabilities continue to fall victim to situations of multiple discrimination in terms of their participation in social and economic life. Disability and sex interact to place women with disabilities in an unequal position in the labour market in relation not only to the population in general, but also to men with disabilities and women in general. Furthermore, in addition to the discrimination they suffer due to the double condition of being a woman and a person with disabilities, they are subjected to additional types of discrimination due to other personal or social circumstances: age, ethnic origin, place of residence, socio-economic position, level of culture, etc. These further entrench the socially unequal position they hold and limit their chances of enjoying equal access to employment.

It is worth acknowledging that in the fight to achieve equality significant progress has been made both in sexual equality and in the struggle by persons with disabilities to attain full citizenship. However, the scarce data we have highlights the inequity women with disabilities face in respect of participating in the labour market: women with disabilities have lower activity rates<sup>2</sup>, lower employment rates<sup>3</sup>, and, at the same time, a higher unemployment rate<sup>4</sup>.

The following facts and figures should serve to illustrate the statements made above:

- Global figures from the *World Health Survey*<sup>5</sup> indicate that employment rates are lower among men and women with disabilities (53% and 20% respectively) than among men and women without disabilities (65% and 30% respectively);

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<sup>2</sup> *Activity rate* is the quotient between the total number of active persons (population in employment + unemployed population) and working age population.

<sup>3</sup> *Employment rate* is the quotient between the population in employment and the population of people of legal working age.

<sup>4</sup> *Unemployment rate* is the quotient between unemployed population and active population.

<sup>5</sup> World Report on Disability, World Health Organisation and the World Bank.

- In the European Union<sup>6</sup>, 49% of women with disabilities have a job and 61% of men with disabilities are in employment, compared to 64% of women without disabilities and 89% of men without disabilities;
- In Spain, according to data from EDAD-2008<sup>7</sup>, the activity rate among men and women with disabilities (40.3% and 31.2% respectively) is lower than that of men and women without disabilities (84.7% and 65.3% respectively). The pattern is reproduced in employment rates: men and women with disabilities have lower employment rates (33.4% and 23.7% respectively) than men and women without disabilities (77.4% and 56.6% respectively). On the other hand, the unemployment rate among men and women with disabilities (17.2% and 24% respectively) is higher than the equivalent statistics for men and women without disabilities (8.6% y 13.4% respectively). More recently, a report from the National Institute for Statistics, ‘Employment among persons with disabilities’<sup>8</sup> confirmed the situation. According to data from 2010, activity rates among men and women with disabilities (40.4% and 31%) remain lower than activity rates among men and women without disabilities (83.6% and 68.1%). In respect of employment rates, they are also lower among men and women with disabilities (31.4% and 23.3% respectively) than among men and women without disabilities (67.1% and 54.1% respectively). Men and women with disabilities have a higher unemployment rate (22.3% and 24.9% respectively) than men and women without disabilities (19.8% and 20.5% respectively).

Inactivity is one of the consequences for people with disabilities and, above all, for women with disabilities. Taking full responsibility for household tasks and care duties, a lack of guidance and focus on working life in education and training, performing duties traditionally assigned to the female role —fortunately now in disuse— continue to have an extremely negative effect on women by generating discrimination and limiting their opportunities.

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<sup>6</sup> Eurostat: *Employment of people with disabilities* (ad hoc module of the Labour Force Survey 2002), <http://ec.europa.eu/eurostat> (28.10.2009).

<sup>7</sup> Survey on Disability, Personal Autonomy and Dependence, 2008. National Institute for Statistics.

<sup>8</sup> ‘*Employment among persons with disabilities*’ (people holding a disability certificate or who have a legally-recognised disability and a degree of disability equal to or above 33%). Statistics extracted from the Active Population Survey and the National Database of Persons with Disabilities, 2009 and 2010. Provisional data. National Institute for Statistics, 2011.

As well as discrimination in participation in employment, women with disabilities are also more likely to fall victim to other types of inequality in relation to the labour market:

- Difficulties in accessing career guidance services and the unsuitability of services to their needs, leading to a lack of fit between women with disabilities' capabilities, skills and expectations and expectations, needs and trends in the labour market;
- Traditions and stereotypes influencing choices in education and greater 'over-protection', lack of motivation caused by accepting or being resigned to inactivity, lack of independence in decision making, etc.;
- Horizontal segregation: jobs held by women with disabilities tend to belong to a very limited range of sectors and professions. In addition, the jobs they perform are generally less valued socially;
- Vertical segregation: women with disabilities generally perform lower-paid jobs with less responsibility. Furthermore, they face greater obstacles in career development and advancement;
- Poorer working conditions: lower salaries, jobs which are unadapted to their needs, involuntary part-time work, etc.;
- Difficulties balancing private lives with professional careers, often leading to involuntary part-time work and gaps in careers which hinder career development;
- Lack of sensitivity among employers.

This reality devalues the social position of women with disabilities and forces them into a weak and precarious position in the labour market which, in turn, leads inexorably to situations of dependence and inequity.

## **1.2. Training for employment: an indispensable tool**

It is evident that whether one enjoys greater opportunities to access, retain and gain promotion in a job is determined largely by the training one has; the higher the qualifications, the greater opportunities the individual has.

An economy which is ever more competitive and technology-based demands greater complexity, leading to ever higher requirements in terms of professional qualifications regardless of the professional level of the post (this affects both highly-qualified jobs and low —skilled jobs).

Women with disabilities generally have basic qualifications, and this has been a major obstacle to their chances of accessing employment and developing a career, although the situation is improving among younger generations.

In the near future, dramatic changes in the labour market and the introduction of new technologies will lead to the disappearance of thousands of low-skilled jobs while, on the other hand, available jobs will require ever higher qualifications and professional skills in line with a new job culture.

Training for employment plays a decisive role in acquiring and adapting professional skills. In this context, women with disabilities must be guaranteed equal access to training for employment programmes and lifelong training programmes with safeguards to prevent discrimination or segregation due to their being women with disabilities.

### **1.3. The social construction of gender and disability: jointly fuelling discrimination for women with disabilities**

In order to understand the reasons why women with disabilities find themselves in a position of inequality in the labour market and attain lower qualifications, it is necessary to understand how disability and gender act together.

Some socio-cultural factors, such as stereotypes and prejudices about women, and specifically women with disabilities, make it easier for discrimination to occur and may fuel social exclusion or limited opportunities.

The construction of gender<sup>9</sup> and disability is based on the existence of deeply-held social and cultural stereotypes at different moments in history. These stereotypes cause prejudices and discriminatory attitudes.

The standard gender roles in our socio-economic and cultural context have assigned women to the domestic sphere and assigned to them —and only them— the role of mothers, carers, housewives and spouses. As a result, feminine subjectivity has developed on a limited and stereotyped basis and women are excluded from the possibility of fully enjoying their social, economic and political rights and equal access to all aspects of full citizenship, including access to the labour market.

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<sup>9</sup> Construct of gender refers to the process by which people are linked to characteristics, expectations, roles and opportunities according to their sex, and the way in which each individual structures his or her identity.

The traditional social construct of disability has also excluded persons with disabilities. It has stigmatised them and viewed them as without abilities, faulty and useless for production, unusable and inefficient in terms of performing a job, for reproduction and for forming their own families and developing their own lives, incapable of taking decisions for themselves and unable to lead an independent life.

As the 'Manifesto by Disabled Women in Europe'<sup>10</sup> rightly pointed out, the roles attributed by society to women with disabilities are more restricted than those assigned to other women, causing discriminations to occur which are not merely the sum of discrimination due to being a woman plus discrimination due to having a disability, but new discriminations, fewer opportunities and differentiated treatment.

These social constructions mean women have been victims of multiple discrimination and have even encountered barriers and difficulties in identifying themselves and performing their traditional role. There is a general trend that considers women with disabilities to be dependent, incapable of taking decisions for themselves and unskilled for participation in society and economic productivity.

Often these social barriers have led women with disabilities to hold a negative image of themselves and lack self-esteem; they accept the social role assigned to them, and this leads to social exclusion.

Among the reasons why women with disabilities may find themselves in situations of greater vulnerability are the following personal and social factors:

- Low educational and training attainment levels and unsuitable qualifications to meet the demands of the labour market;
- Low expectations of their own career possibilities;
- Difficulties in accessing job-seeking resources and using job placement systems;
- Difficulties in accessing the labour market and developing a professional career;
- Difficulties in accessing information, guidance and career training services;
- Companies rarely engage in developing reasonable accommodations and seeking reconciliation, etc.;
- Lower self-esteem and the influence of social stereotypes on the image they have of themselves;

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<sup>10</sup> European Disability Forum, 22<sup>nd</sup> February 1997.

- Conflict between the traditional role assigned due to being a woman and denial on the part of society for her to perform it in practise;
- Overprotection by the family;
- Greater social isolation leading to a lack of opportunities;
- Lack of social and work-related skills;
- Greater dependence on assistance and care provided by other people;
- Living in environments where dependence thrives;
- Persisting negative self-perception —women with disabilities sometimes feel inferior and less valued than other women.

These factors make it difficult for women with disabilities to access employment. They can be pooled together in two groups:

- Barriers associated with social acceptance of women with disabilities, linked to a lack of information, lack of access to services, ignorance, social prejudices, overprotection and a persistent negative image regarding their capacity and labour skills;
- Barriers associated with women with disabilities' own self-perception of their capacities and potential.

#### **1.4. Legal instruments and policy guidelines: a step in the right direction**

The last few decades have seen growing interest in improving labour market participation levels among women and people with disabilities. The more targeted commitment to increasing the number of women with disabilities in employment is a much more recent one.

Many international and national legal instruments and policy guidelines have been adopted in recent years<sup>11</sup> with a view to protecting and promoting the rights of persons with disabilities and remedying historical inequality in, among others, the field of employment.

The United Nations Convention on the Rights of Persons with Disabilities<sup>12</sup> is a new international human rights tool for the protection and promotion of the rights and

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<sup>11</sup> In this section we refer only to the most significant legal instruments and policy guidelines.

<sup>12</sup> New York, 13th December 2006.

dignity of persons with disabilities. The Convention is a pivotal instrument in the fight against violations of the human rights of persons with disabilities and ignorance of their rights, and against social indifference regarding full social mainstreaming.

In the preamble to the Convention, paragraph e) acknowledges that disability is an evolving concept that, “...results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others...” Among persons with disabilities it includes people who have, “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (article 1, paragraph 2 of the Convention).

This means that disability is now not viewed as an individual characteristic or feature, but as a product of the interaction of an individual who has particular personal circumstances with an environment that places obstacles in his or her way and prevents the individual from effectively exercising his or her rights<sup>13</sup>. The Convention therefore adopts the so-called *social model* which, to summarise, holds that the disability is in society and not in the individual. The contribution people with disabilities can make to society is closely linked to inclusion and accepting differences. This model is a goal for persons with disabilities to aim for as, despite having these precepts in legal systems, in the social sphere these postulates are not the norm.

The Convention includes a specific article addressing women with disabilities — article 6<sup>14</sup>— while article 27<sup>15</sup> deals with work and employment. In contrast to other issues covered by the Convention, the gender dimension is not specifically mentioned in the area of employment, although we must consider the preamble and the general principles if we are to interpret the Convention correctly, especially in terms of gender.

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<sup>13</sup> PÉREZ BUENO, L. C., ‘Incorporating the UN Convention in the Spanish legal system: necessary accommodations’, in ‘*Legal capacity and disability*’, a comparative study of private law in the light of the UN Convention on the Rights of Persons with Disabilities, edited by Soto Ruiz, J. J., volume I, Common law, workbook 7, Spain (López Sosa, L., updated 2009), page 10.

<sup>14</sup> CRPD, 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.

<sup>15</sup> CRPD, Article 27, Work and employment: 1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.

In this respect and with regard to gender, the preamble includes two paragraphs which refer to sex as one of the bases for multiple discrimination suffered by persons with disabilities, and to the need to include the gender perspective in all efforts to achieve the full enjoyment by persons with disabilities of human rights and fundamental freedoms. Article 3, General Principles, explicitly mentions gender equality as one of the principles of the Convention. Finally, article 8 on awareness-raising includes, among other provisions, an obligation on States Parties to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas.

Article 10 of the Treaty on the Functioning of the European Union states that “In defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.” Article 19 (formerly article 13) allows the Council to adopt appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

Directive 200/78/EC<sup>16</sup> aims to establish a general framework to combat discrimination on the grounds of religion or beliefs, disability, age or sexual orientation in the fields of employment and occupation.

The European Disability Strategy 2010-2020: a renewed commitment to a barrier-free Europe<sup>17</sup> seeks, in general terms, to enable people with disabilities to enjoy all their rights and benefit fully from participating in the European economy and society, especially through the single market. The strategy focuses on removing barriers, and the European Commission identifies eight key action areas, including equality and employment. In terms of equality, the strategy states that particular attention will be given to the cumulative impact of discrimination that people with disabilities may experience on other grounds, including sex. In employment, the strategy makes reference to the fact that in order to achieve the EU’s growth targets, more people with disabilities need to be in paid employment on the ‘open’ labour market. The only

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<sup>16</sup> Transposed into Spanish law by virtue of Law 63/2003, dated 30th December, on fiscal, administrative and social order measures.

<sup>17</sup> Resolution adopted by the European Parliament on 25th September 2011 on mobility and inclusion of persons with disabilities and the European Disability Strategy 2010-2020. The European Parliament states that it, “Regrets that the Commission Communication on the European Disability Strategy does not include an integrated gender perspective or a separate chapter on gender-specific disability policies, despite the fact that women with disabilities are often in a more disadvantaged position than men with disabilities and are more often victims of poverty and social exclusion; calls on the Commission and the Member States to take gender aspects into account throughout the European Disability Strategy (EDS) 2010-2020.”

reference to women states that the strategy seeks to “*improve knowledge of the employment situation of women and men with disabilities, identify challenges and propose remedies.*”

There is no explicit reference to women with disabilities in the latest European Union legal instrument on gender equality, while employment is included (European Commission Strategy for equality between women and men 2010-2015 and Council conclusions of 7 March 2011 on the European Pact for Gender Equality 2011-2020).

In Spain, the Spanish Disability Strategy 2012-2020<sup>18</sup> is the framework for future public disability policies. Among its guiding principles is “*(non-discrimination, equal treatment before the law and equal opportunities)*”. The strategy follows the objectives of the European Disability Strategy, so it specifically addresses employment; one of the aims of the 2020 strategy is to increase the percentage of people in employment. One of the concrete actions it puts forward in employment is to, “*promote actions specifically aimed at furthering access to the labour market by women with disabilities, on an equal basis with others*”. In addition, among the more general actions it proposes is to “*draw up a Global Action Strategy to combat multiple discrimination in gender policies.*”

Finally, the Spanish Employment Strategy 2012-2014<sup>19</sup> seeks to set out a regulatory framework for co-ordinating and delivering active policies in employment nationwide. Actions and measures included in these active employment policies address the following areas: career guidance, training and retraining, job opportunities and boosting recruitment, furthering equal opportunities in employment, opportunities for groups with particular difficulties (including persons with disabilities), self-employment and business start-up, promoting regional development and economic activity, improving mobility (both geographical and between sectors) and integrated projects.

The principal goal of the strategy is to “*boost employment among the active population and increase participation by men and women in the labour market, improve productivity and the quality of posts in a sustainable labour market, based on equal opportunities and social and territorial cohesion.*”

As regards targeted measures in the Spanish Employment Strategy to promote access to jobs in the open market among people with disabilities, there is an explicit reference to women with disabilities. The strategy includes financial incentives for companies that hire women with disabilities.

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<sup>18</sup> Adopted by the Council of Ministers on 14th October 2011.

<sup>19</sup> Adopted by the Council of Ministers on 28th October 2011. Royal Decree 1542/2011, dated 31<sup>st</sup> October, adopting the Spanish Employment Strategy 2012-2014.

In conclusion, despite the progress being made, gender mainstreaming in employment policies in general, and in particular in policies targeting women with disabilities, has still not been achieved.

## 2. RECONCILIATION AND SOCIAL CARE ARRANGEMENTS

### 2.1. Interpretive framework: the sexual division of labour and gender inequality

Over the past decades it is undeniable that huge numbers of women have entered the labour market. Women's presence in employment is not now a contingent diversity, nor can it be put down to a precarious financial situation in the family, as occurred in the past<sup>20</sup>. Gender roles in the field of employment have undeniably been transformed and, at present and in western countries, one of the hallmarks of women's identity is, more and more, liberation from masculine modernity.

Female employment has become an essential component of families' economies, personal independence and full citizenship<sup>21</sup>.

Without a doubt we live in different times, but they are not entirely different. Work in the home continues to be performed according to the old rules. The changes we see in women's lives have been accompanied by resistance to change both in arranging public spaces and in men's attitudes to domestic tasks. Both continue to follow the old rules governing the sexual division of work in private spaces and the invisibility of unpaid housework.

Public spaces continue to be designed as if an 'invisible hand' were gratuitously resolving social care arrangement problems. The logic associated with production continues to transfer reproduction costs and workforce maintenance to private spaces, and the sexual division of labour in private spaces passes on this task to women. So a redistribution of financial responsibility in the family —it is not now exclusively a

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<sup>20</sup> Employment outside the home by women in the past was unwelcomed and viewed as a 'lesser evil' in the face of family financial difficulties. This explains why only women from the most disadvantaged social classes were active in the labour market. However, patterns began to change during the second half of the 20th century.

<sup>21</sup> As Victoria Camps has rightly pointed out, "*In olden days, what gave citizens rights was the fact that they were owners. Thanks to the fact that we now acknowledge equality through social rights, it is now work that grants citizens rights that are not merely formal. Being a full citizen implies having an income, and income, with the exception of a small privileged group, comes through work.*" Camps, 1998, page 44.

task for men— has not been backed up by an equivalent redistribution in household tasks.

Caring and housework remain ‘women’s business’, as does the juggling act associated with reconciling work and family responsibilities. Consequently, it is women who must seek to resolve the reconciliation dilemma in their daily lives, and this affects and limits their employability, autonomy and career advancement.

The move towards precarious employment in the labour market has done little to help. These changes have a greater impact on the most vulnerable groups, such as women, and particularly if they have some type of disability and family responsibilities.

Public or collective guidance on social care arrangements is neither public nor collective. Women put their own resources to use in order to balance domestic and professional responsibilities, and this includes strategies involving presence-absence from work, racing against the clock, giving up personal desires and, consequently, a precarious position in what is an ostensibly independent public space. Paradoxically, we call rushing around, doing without and precariousness ‘reconciliation’.

As a result, the sexual division of labour in private spaces and gender stereotypes determine the degree of personal autonomy and the position women occupy in the labour market, causing new gender inequalities to emerge which are more serious and deeper when the woman has a disability and when other variables such as rurality or low educational attainment interact with disability.

## **2.2. Developments in European Union policies addressing work-family reconciliation**

From the nineties on, legislating in the field of balancing working life and family life has gradually become more important in European Union countries. The turning point was the adoption of the agreement on social policy (an annex to the Treaty on European Union) and the Treaty of Amsterdam. From then on, EU regulations were not only binding but a major part of EU social policy development.

Since the adoption of the Treaty on European Union, a wide range of regulations and binding agreements governing reconciliation have been approved. The most significant ones, due to their impact and content, are the White Paper on Growth, Competitiveness and Employment (1993) and Directive 96/34/EC (3<sup>rd</sup> June 1996).

The White Paper on Growth, Competitiveness and Employment introduced the first strategies and mechanisms for specifically addressing work-family reconciliation in a

growing and competitive marketplace. Reconciliation policies would no longer be considered voluntary actions aiming to promote employability among women; they began to be viewed as measures for increasing companies' competitiveness<sup>22</sup>.

Directive 96/34/EC on a framework agreement for parental leave was the first instrument to specifically address conciliation between work and family. It acknowledged parents' individual and non-transferable entitlement to leave lasting at least three months following birth or adoption of a son or daughter<sup>23</sup>.

However, the general trend is for transposition into national legislation to be more nominal than substantive because, in accordance with the new approach at EU level, action should have been transferred from specific policies on co-responsibility in care in the family setting (private sphere) to focus on a wider perspective and include the public-private dimension. This, however, wasn't the case.

The adoption of the Treaty of Amsterdam in October 1997 brought about a qualitative shift as it tied together gender equality in employment and furthering work-family reconciliation as inseparable. Its entry into force two years later meant that equal opportunities and mainstreaming the gender perspective at EU level were constitutionalised and, in addition, it established an interdependent link between productive and reproductive work.

European Employment Summits, held by virtue of the new title on employment in the Amsterdam Treaty, would convert the programme proposals in the treaty into concrete actions. So, at the European Council on Employment held in November 1997 in Luxembourg, it was agreed that equal opportunities represented one of the goals in the guidelines for the European Employment Strategy. This acknowledgement would turn out to be decisive as it means the EU can force member states to link employment policies with budgeting and transfer financial and personal resources with a view to meeting the goals set out.

Among the proposals was an initiative to expand infrastructures and services for childcare and care for dependent persons<sup>24</sup>, and a proposal to introduce more flexible working hours and promote the sharing of professional and family responsibilities.

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<sup>22</sup> According to the conclusions of a meeting of the World Economic Forum in Davos in January 2009, having women in positions of responsibility in a company increases its productivity.

<sup>23</sup> This recognition would turn out to be particularly significant because although legislation in some countries provided for partial transfer of leave from the mother to the father, it was not standard practise. Normally the mother took the entire leave.

<sup>24</sup> In terms of care, people who are dependent have been completely ignored in reconciliation policies. These policies focus on care for minors as they are more numerous. The key to EU legislation is if these rights are linked to social security, in which case at least 'co-ordination' be-

But it was at the special meeting of the European Council in Lisbon on March 23rd and 24th 2000 where a strategy was adopted that went beyond the pragmatic voluntary nature of previous policies and set concrete targets in the employability of women. This strategic volte-face occurred due to a heightened awareness of the poor medium-term outlook fuelled by falls in birth rates, the resulting ageing of the population and the difficulties this would cause modern day social protection systems in terms of sustainability.

For the first time, gender inequalities in employment were not considered solely as a question of social justice, women's rights or even competitiveness, but as a matter that could have an impact on the medium-and long-term sustainability of public finances and the maintenance of the European social model<sup>25</sup>. To this end, the Council and Commission were mandated to adopt measures to promote work-family reconciliation<sup>26</sup> and there was a basic agreement, including on timelines and specific goals, on female occupation rates<sup>27</sup>.

European Union legislative initiatives would, from this moment on, have a bearing on the development of strategies to effectively safeguard reconciliation of working and family lives<sup>28</sup> as a means to promote the employability of women. New employment

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tween member states is an EU power, or if they form part of welfare or social protection systems, distinct from social security, which are addressed exclusively at national level and where the EU does not even have norms to co-ordinate actions. Co-ordinating efforts for minimum levels of care for dependent people were agreed in the European Social Agenda (2005-2010), which included a commitment to establish a common basic agenda in health and long-term care.

<sup>25</sup> Paragraph 23, Presidency Conclusions, Lisbon European Council.

<sup>26</sup> Paragraph 29, Presidency Conclusions, Lisbon European Council.

<sup>27</sup> It was agreed that, "...the overall aim of these measures should be, on the basis of the available statistics, to raise the employment rate from an average of 61% today to as close as possible to 70% by 2010 and to increase the number of women in employment from an average of 51% today to more than 60% by 2010." Paragraph 30, Presidency Conclusions, Lisbon European Council.

<sup>28</sup> In the European Union Charter of Fundamental Rights, proclaimed on the occasion of the Council meeting held in Nice on 7th December 2000, and in the following regulations: Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin; Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation; Directive 2002/73/EC regulating the switch in the burden of proof in cases of dismissal of pregnant employees (which was not considered in Directive 92/85/EEC) and setting out specific safeguards for care of descendants, proposing infrastructures and services aimed at facilitating reconciliation. Decision 2000/228/EC of 13th March 2000 on guidelines for employment policies in Europe for the year 2000 also influenced European strategy. This Decision includes the need to introduce measures to further work-family conciliation as a means to strengthen equal opportunities policies, although as it is non-binding it is less effective.

directives adopted by the European Commission in January 2002 would strengthen this trend<sup>29</sup>.

### **2.3. Study of the general approach in addressing reconciliation and social care arrangements: critical aspects in intervention**

While it is true that in recent years we have witnessed a radical transformation in how gender equality is addressed by public authorities, it is also true that attention has focused principally on equality in public spheres. The need to rationalise how public and private responsibilities are arranged (the source and origin of inequalities in public spaces) has been dealt lip-service —little practical progress has been made.

The binding nature of relevant European Union treaties and directives has led to active policies in member states, but regulations in the field are far from homogeneous. Differences have arisen because of different approaches to the welfare state (or the relationship between the state, the markets and families —the three welfare providers)<sup>30</sup> and, more specifically, to state involvement in managing care and existing gender relations.

Although member states have assumed direct responsibility for work-family reconciliation (by providing services, in fiscal policies and in financial transfers to families) and indirect responsibility (through time management in parental leave, reduced working hours and leave of absence), public policies have proven to be clearly insufficient and social care arrangements —above all with family models such as the Spanish one— continue to depend on family support networks which are made up almost exclusively of female family members.

For this reason, and although EU initiatives were groundbreaking in defining and promoting measures for reconciliation, the approach taken has brought to the fore some critical aspects in intervention, some of which we will go on to discuss.

Institutionally, reconciliation is being addressed as if the problem at hand were a specifically female question or merely the outcome of women accessing the labour market. And, while it is true that the latter has made visible the conflict represented

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<sup>29</sup> In the case of Spain these recommendations were included in successive National Employment Action Plans (PNAE in Spanish) and the Kingdom of Spain National Plan for Social Inclusion.

<sup>30</sup> As Moreno points out, “A welfare state requires an institutional structure that combines legal, material and organisational resources from its three principal producers: the state, markets and families”, Moreno, L., 2003, page 41.

by dealing separately with realities which are co-dependent (the public and the private), as long as it is considered a problem for women it will continue to be so.

The conflict is not always approached from the gender perspective. A neutral approach —disregarding the gender perspective— ensures that traditional gender roles will prevail and will inertially push women's work into the private sphere and men's towards the public, thus excluding or penalising women in the labour market. That is why the gender perspective and the introduction of positive action measures promoting shared responsibility in care by men are essential tools in drawing up proposals and public policies for reconciliation<sup>31</sup>.

Furthermore, EU policies have focused on specific aspects related to caring by people engaged in formal employment and have ignored those who are unemployed, inactive or in atypical or precarious employment<sup>32</sup>.

At the same time, people with disabilities who are forced to take on responsibilities for caring (mostly women) notice how their particular circumstances are lost in the overall framework. What this means is that there are reconciliation policies for the general public and policies to promote the employability of women with disabilities, but there is no common, joint or co-ordinated intervention.

Action in this area is taken from an individual perspective and the conflict is addressed one-sidedly, forcing one party into (total or partial) renunciation in terms of taking on employment-related and family responsibilities. The most propitious age for career advancement clashes with the most advisable age for biological reproduction, and this causes women themselves to react: they either put off having children or renounce motherhood (the so-called 'birth strike' which is causing an alarming ageing process in the population), or give up labour activity (thus making it difficult to meet the target employment rate set as a minimum by the European Council in Lisbon).

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<sup>31</sup> Positive action measures implemented for decades to promote women or persons with disabilities have been shown to be highly effective, but this effectiveness will always have a limited impact unless men are encouraged to participate in domestic tasks and we reach a balanced position in responsibilities related to work and caring.

<sup>32</sup> In Spain, for instance, where people with disabilities have a much lower occupation rate than the European Union average, this approach has undeniable consequences. While the average occupation rate among persons with disabilities in Europe is 70.5%, the figure falls to 28.8% in Spain, with a gender difference of over 10 percentage points. So this approach fails to cover three out of four women with disabilities who are either unemployed or inactive (23.9%). Figures taken from the Global Action Strategy for Action in Employment and Persons with Disabilities 2008-2012 (Statistics sourced from the interim report on the study "Persons with disabilities: contribution to achieving the goals of the Europe 2020 strategy", EDAD 2008 and Eurostat).

In addition, reconciliation policies have tended to focus on a particular type of woman, and this invisibilises and ignores groups who do not fit into this approach or are excluded from official policies. Personal circumstances, for instance if one has a particular disability, are viewed as dissenting voices that diverge from the hegemonic order and are dealt with as differing contingent diversities that deviate from what is predefined or expected as neutral, natural or the norm. This approach views intervention from a welfare and sectoral perspective and tends to pigeonhole the beneficiary population in the context of political or social dependence and positive discrimination to achieve balance.

The underlying problem is that abstract rationalist universalism not only ignores situations or identities which fail to conform to the hegemonic pattern, but also constructs this pattern as 'the norm', 'the natural thing' and neutral. Specificities are therefore thought of as 'differences' belonging to the sphere of the particular, the subordinate to the hegemonic order<sup>33</sup>. And, although it is true that the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) highlights and condemns the consequences of this false categorisation of what is 'normal'<sup>34</sup>, in reconciliation policies its impact has been minimal.

So in general terms reconciliation policies reflect this hegemonic pattern and ignore the specific needs of those groups who do not conform to the cultural, political and social construct of what is 'normal'.

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<sup>33</sup> The origin of this phenomenon lies precisely in the trap in the process of constructing citizenship. Universalising citizenship began as a formal means of condemning prevailing naturalist exclusion, according to which participation in decision-making processes on public issues — the state — was conditional upon possessing certain merits, attributes or personal characteristics. The historical struggle for formal equality removed prior exclusion but brought with it an identifying standardisation of those groups which were traditionally excluded. The mechanism used was to deny or ignore diversity and the identifying mark which was the object of prior exclusion, thus silencing and overshadowing the specificities of the groups 'to be included'. As Marcuse points out, it was an 'as if' mechanism, that is to say as if she wasn't a woman, as if she didn't have a particular disability... This historical and political process projected a fictitious and abstract concept of citizenship that denies specificity and promotes a more subtle type of exclusion and repression. Chomsky, 1996.

<sup>34</sup> The Convention is a turning point in how disability is addressed; it leaves behind the welfare approach and embraces a model for protection against discrimination based on human rights. The European Disability Strategy 2010-2020 subsequently established the complementary provisions and action required at national level to implement the Convention and put it into practise. In Spain this is also recognised in Law 26/2011, dated 1st August, introducing modifications to ensure compliance with the Convention, and in the Spanish Disability Strategy 2012-2020, which includes disability mainstreaming as one of its underlying principles.

The labour market is slowly beginning to incorporate conciliation. There is a growing awareness of the need to make employment compatible with family responsibilities. Nevertheless, integrating in its dynamics and functioning the reality of women who have a job, a disability and family responsibilities is an exercise in inclusion which goes beyond the imagination of the labour market<sup>35</sup>.

Regulations governing equality between men and women, conciliation and non-discrimination for persons with disabilities focus their attention on issues such as safeguarding the right to maternity, marriage or employment but approach conciliation, a crucial aspect for effectively exercising these rights, from a very sectoral point of view. They include few corrective and protective measures to address the reasons for this triple exclusion.

United Nations, for instance, both in the CRPD and the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW), fails to address both questions comprehensively. Paragraph 2 of article 23 holds that, “*States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities*”, while paragraph 1.c in article 27 establishes the obligation to “*Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others*”. A joint interpretation of both statements should lead to special measures in reconciliation, but this has yet to happen.

Article 11.2 of CEDAW recognises that, “*In order to prevent discrimination against women on the grounds of marriage or maternity and to ensure their effective right to work, States Parties shall take appropriate measures... (c) To encourage the provision of the necessary supporting social services to enable parents to combine family obligations with work responsibilities and participation in public life, in particular through promoting the establishment and development of a network of child-care facilities*”, while article 16.1 affirms that, “*States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and*

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<sup>35</sup> One exception to this rule is the 14th ONCE collective bargaining agreement. As we will see when we study it in detail in the following section, it extends legally-recognised leave in the case of death of the spouse if the employee has children under 18, maternal and paternal leave (at the same time allowing leave for breastfeeding to be added up to fifteen days), reduced working hours (from a minimum of one eighth to a maximum of 50%), flexitime up to thirty minutes (extendable to one hour in demonstrated cases involving personal or family needs), and extended leave of absence for three years to care for a son, daughter or relative, with the right to return to the same position. Source: 14th ONCE collective bargaining agreement and labour relations memorandum 17/2009.

*family relations...*”, recognising the same rights and responsibilities during marriage and at its dissolution.

Nothing, however, is established in relation to the particular approach people with disabilities may require to take on responsibilities for caring, or in relation to those who are responsible for a dependent person.

However, at European Union level, the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union*<sup>36</sup> does take into account these special requirements and recommends both the implementation of “effective measures based on their specific demands” and the need to give women with some type of disability and women who have a son or daughter with disabilities priority in access to childcare services.

In Spain the ‘Global action strategy for employment and persons with disabilities 2008-2012’<sup>37</sup> contains no specific measures in this area. As regards people with disabilities in the ‘Spanish employment strategy 2012-2014’, the document mentions promoting conciliation and co-responsibility in very general terms, but does not set out any initiatives or specific measures to achieve this.

In the framework of the ‘Action plan for women with disabilities 2007’<sup>38</sup> there is a small step towards furthering conciliation and persons with disabilities. Objective 6 in section II, recognising the right of women with disabilities to motherhood, sets out as one of the action points, “*promote outreach services offering support and care for the sons and daughters of women with disabilities*”. Objective 4 in the section on employment (dealing with furthering access by women with disabilities to employment in the public sector) proposes, “*to encourage actions aimed at adapting the measures contained in the Concilia Plan to take into account the needs of women with disabilities*”. Nevertheless and despite the importance of these initiatives, regulating to deal with the complex situation in employment among women with disabilities and family responsibilities must address labour relations in detail, not just in the public sector but in the private sector also.

Finally, although the feminist movement has been the main driver in raising awareness on the importance of reconciliation policies, the movement’s discourse has at times contained a homogenising component.

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<sup>36</sup> Adopted in Budapest on 28th-29th May 2011 by the General Assembly of the European Disability Forum following a proposal by the EDF Women’s Committee.

<sup>37</sup> Adopted to give effect to Law 43/2006, dated 29th November, to enhance growth and employment.

<sup>38</sup> Adopted by the Council of Ministers on 1st December 2006.

Historically feminism built its discourse around a cultural identity, an 'us'<sup>39</sup> or 'project identity'<sup>40</sup>, and put its demands to society as a united group subjected to the same oppression or discrimination. Perversely, within this supposedly homogeneous group the contextual specificities of each individual were denied.

There is little similarity between the types and degrees of discrimination suffered by women due to variables such as educational level, social class, place of residence, race or disability (and especially if two or more of these discriminating factors are present simultaneously). For this reason, during the eighties some Afro-American theorists<sup>41</sup> criticised the monolithic use of the term 'woman' and the aggravated underlying types of discrimination present when double discrimination occurs. This not only sophisticates discrimination, but also takes place in invisibilised contexts on the fringes of equality policies, leading to a new type of discrimination against the group in question.

However, the idea of double discrimination was soon found to be wanting; exclusion caused by deviation from the hegemonic identity model was multiple and complex as the concurrence and intersection of discriminating elements sophisticated discrimination. That is why the intersectionality approach<sup>42</sup> allows us to introduce a more accurate portrayal of existing practises in discrimination, for instance due to sex, disability, social class, rurality or education<sup>43</sup>.

In the United Nations, multiple discrimination was included in international anti-discrimination instruments as of 1995, when the Fourth World Conference on Women was held in Beijing. Subsequently, the UNCRPD preamble acknowledges concerns

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<sup>39</sup> According to Valcárcel, *"Any movement which aims to change particular features of political and social reality must promote an 'us' to which legitimacy and excellence can be added"*, VALCARCEL, A., 1997, page 80.

<sup>40</sup> The term 'project identity' is used in line with the definition given by Castells: *"when social actors, based on the cultural material they have at their disposal, construct a new identity which redefines their position in society and, by doing this, seek to transform the entire social structure"*, CASTELLS, M., 1997, page 30.

<sup>41</sup> Among others Patricia Hill Collins and Bell Hooks.

<sup>42</sup> Term coined in 1989 by Kimberlé Williams Crenshaw, WILLIAMS CRENSHAW, K, 2005.

<sup>43</sup> Multiple discrimination was included in international anti-discrimination instruments as of 1995, when the Fourth World Conference on Women was held in Beijing. Over the past few years, the concept of multiple discrimination or intersectionality, that is to say discrimination caused by the intersection of two or more factors, has taken on greater importance. This anti-discrimination approach was incorporated into European law in the racial equality directive (Directive 2000/43/EC), which included the term 'multiple discriminations' in recital 14. Although it is not common practise, North American jurisprudence has begun to apply the theory of 'sex-plus' discrimination: multiple discrimination to which women are subjected.

regarding, *“the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status”*, while article 6 includes a commitment to adopt measures to ensure, *“the full and equal enjoyment... of all human rights and fundamental freedoms”* by girls and women with disabilities.

The intersectionality approach was incorporated into European law in the racial equality directive (Directive 2000/43/EC), which included multiple discriminations in recital 14. Years later and in keeping with the UNCRPD, the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union explicitly denounces the multiple discrimination girls and women with disabilities suffer and calls for a commitment to make this phenomenon more visible and adopt measures to allow girls and women with disabilities to enjoy their human rights and freedoms fully and equally, and to ensure their full development, advancement and empowerment.

Nevertheless, effective freedom from multiple discrimination is closely linked to flexibility in legal proceedings (which on occasions only allow anti-discrimination cases on one ground: race or sex) and a current reluctance to accept what may amount to a super-safeguard for alleged victims of discrimination<sup>44</sup> (REY, F., 2008, page 7).

The underlying problem lies precisely in the broadness of the approach and the political commitment needed to address this reality. For instance, in Spain it would not be the same to work on the basis of a new criteria in legal interpretations of article 14 of the Spanish constitution as on the basis of an open or intersectional list of factors in the Universal Declaration of Human Rights and international treaties if, in addition, there is an intention to introduce specific policies in the fields of equality or reconciliation aimed at what could be understood to be ‘target groups’ (such as women with disabilities) or ‘target contexts’ (for instance rural environments).

Undoubtedly legal instruments play a pivotal role in protecting people who are victims of discrimination effectively, but there is a need for a more complex engagement which does not merely focus on redress or individual protection through legal channels, but also leads, at the same time, to comprehensive prevention policies to eradicate discrimination and eliminate the concept of ‘neutral’, ‘natural’ or ‘the norm’ from the symbolic order.

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<sup>44</sup> Although it is not common practise, North American jurisprudence has begun to apply the theory of ‘sex-plus’ discrimination: multiple discrimination to which women are subjected.

### 3. INITIATIVES FROM THE TRADE UNIONS: AGREEMENTS, COLLECTIVE BARGAINING AND WOMEN'S ENGAGEMENT IN TRADE UNIONS

We must not forget collective bargaining and social dialogue as we seek to change the current state of play regarding discrimination and inequality due to gender and disability. But this requires at least a three-pronged framework for action. On the one hand, there is a need to adopt overarching framework agreements enabling discrimination on both grounds to be reduced. This is a prerequisite, but is insufficient as the working conditions of women with disabilities are determined at the same time by agreements specifically governing each sector of the economy and, as a result, collective bargaining in centres and sectors is a key element in furthering equality and non-discrimination. However, we should also not ignore the fact that having women with disabilities in positions of power within the trade union movement carries huge potential for transformation, empowerment and visibilisation.

Participation by social agents is a key factor in drawing up, guiding and carrying out employment, training and conciliation policies. In recent years trade unions have sought to reach agreements to combat gender-and disability-based discrimination. Nevertheless, few documents contemplate both and, while it is true that there are several European<sup>45</sup> and national<sup>46</sup> documents, it is also true that the framework for action can be described as weak and sectoral.

Engagement in the field of discrimination on the basis of sex or gender takes place mainly in collective bargaining processes<sup>47</sup>. Nationally, inter-confederation agreements have served to lay the foundations; they are the main instruments for agreements between employers' organisations and unions<sup>48</sup>.

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<sup>45</sup> For instance the European Declaration on employment and persons with disabilities, adopted in 1999 by the European Trade Union Confederation.

<sup>46</sup> Such as the report published by the Economic and Social Council in 1995 on the situation regarding employment for persons with disabilities.

<sup>47</sup> In its Action Programme 2008-2012, *Comisiones Obreras* set a goal to increase membership among persons with disabilities in ordinary employment and further their involvement in union elections. To this end the union rolled out a targeted plan for union membership in Special Employment Centres and guidance for union representation in such centres.

<sup>48</sup> The Interconfederal Agreement for stable employment, signed in 1999 by CCOO, UGT, CEOE and CEPYME, included the principle of working to promote the signing of indefinite contracts by employees with disabilities and the removal of age limits on training contracts for persons with disabilities. The agreements for the years 2002-2003 included a commitment to incorporate general clauses to promote equal treatment in collective bargaining agreements, with the aim of facilitating access to employment by persons with disabilities. In 2006, when the Agreement on Collective Bargaining was renewed, the signatories —CCOO, UGT, CEOE and CEPYME— adopted a specific report on 'Collective bargaining and workers with disabilities'

A good example which should be replicated in this area is the ONCE Collective Agreement, which goes beyond the coverage provided in national legislation and relevant framework agreements<sup>49</sup>.

However, as was stated at the outset, it is not enough to facilitate access to jobs, job retention and career advancement for women with disabilities. The fight to overcome the exclusion and discrimination they face must shy clear of meaningless paternalistic policies and promote their full participation in all areas of working life, including trade unions. This engagement will not only enable them to defend their own rights first hand; it will, at the same time, visibilise and empower women with disabilities as a group.

In this respect, article 29 of the UNCRPD establishes that the exercise of political rights on an equal basis with others must be guaranteed, thus actively promoting their involvement. In addition, article 27 includes the duty of governments to “*Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others*”<sup>50</sup>.

As a result, governments and government institutions are obliged to promote conditions favouring full participation, and social agents also have a direct responsibility in this area, because if women’s participation in public life is meagre, then participation by women with disabilities could be said to be derisory: in the eyes of society they are practically invisible.

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which included a range of new clauses to be applied in the negotiating process for the new collective agreement. Nevertheless, the key interconfederal agreement is undoubtedly the 2006 agreement, which for the first time includes a commitment to meet the requirements of the quota or reserved positions (2%) for persons with disabilities in large companies (in line with the provisions of Law 13/1982, dated 7th April, for the social integration of persons with disabilities). This agreement also includes a series of measures aimed at enhancing access to jobs for persons with disabilities on the basis of equal treatment, a commitment to ensure work enclaves and jobs are adapted to the needs of employees in special employment centres (to comply with current legislation in health and safety at work), and an agreement to make accommodations in recruitment processes and public sector recruitment. Source: Arroyo, L., ‘Collective bargaining and persons with disabilities’, internal report by the 1 de Mayo Foundation, 2011.

<sup>49</sup> 14th ONCE collective bargaining agreement and labour relations memorandum 17/2009.

<sup>50</sup> Chapter 14 of the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union*, in the same spirit as articles 27 and 29 of the UNCRPD, includes a call to ensure the full and effective participation of women with disabilities and, to this end, it points out that, “*Periodic reports produced by the relevant European Union and Member States human rights treaty bodies must automatically include information on women with disabilities in relation to each right, ... and difficulties and obstacles encountered, especially in rural areas.*” In Spain, the 2007 Action plan for women with disabilities puts forward a proposal to study, “*the possibility of setting participation quotas for women with disabilities in decision-making bodies in different area of public life*”, (Objective 1, Chapter V).

Consequently, having women with disabilities engaged in the trade union movement is an empowering element that makes them visible and, in addition, brings a specialised dimension to the collective bargaining negotiating table.

The 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union explicitly includes the goal of furthering both aims —empowerment and visibilisation— and enhancing the possibility of playing an active part in social development and participatory or consultative mechanisms, above all in those issues that directly affect women with disabilities such as collective bargaining<sup>51</sup>.

## 4. CORPORATE SOCIAL RESPONSIBILITY

### 4.1. CSR: an overview

Corporate Social Responsibility (CSR) has taken on particular relevance in the past decade thanks to efforts by various international and domestic organisations from the public and private sectors and an economic and social context in which an ever-growing demand for information and transparency has become a priority for all stakeholders in the economy.

In its Green Paper on promoting a European framework for Corporate Social Responsibility<sup>52</sup>, the European Commission defines CSR as “*a concept whereby companies decide voluntarily to include social and environmental dimensions in their business operations and in their relations with interest groups*”.

The definition of CSR was expanded upon in Spain by the Ministry for Employment Expert Forum: “*...in addition to complying strictly with the legal obligations in force, voluntarily including in its governance, management, strategies, policies and procedures issues related to social, labour, environmental and human rights concerns which arise from transparent relations and dialogue with interest groups, thus taking responsibility for the consequences and impact of the company's actions*”.

*“A company is socially responsible when it meets in a satisfactory manner the expectations regarding its functioning held by different interest groups. CSR refers to how companies are governed in respect of the interests of its employees, clients, suppliers and shareholders and its environmental and social impact on society in gen-*

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<sup>51</sup> Paragraphs 14.5 and 16.4 of the 2<sup>nd</sup> Manifesto on the Rights of Women and Girls with Disabilities in the European Union.

<sup>52</sup> Commission of the European Communities, 18<sup>th</sup> July 2001, COM (2001) 366 final.

*eral; that is to say company management that respects all interest groups and includes a strategic approach which should be part of its day-to-day management in decision-making and all business operations, adding value in the long term and significantly contributing to gaining a lasting competitive advantage. This is why it is vitally important that companies' governing bodies and management integrate a CSR perspective."*

CSR seeks to reconcile growth, competitiveness and sustainability, while also adding a commitment to social development and environmental protection. There is a requirement nowadays for companies to include their commitments in their strategies and manage them across the board. These commitments should bring about qualitative improvements in human capital, generate opportunities for groups traditionally excluded from the labour market, consider the needs of its clients and partners, enhance good governance, increase transparency in information, etc.

A social commitment by a company should not merely be a statement of intent; it must promote the generation of social and economic value<sup>53</sup>.

#### **4.2. CSR: an opportunity to enhance access to employment for women with disabilities**

En effective realisation of equal opportunities is one of the long-standing demands put forward by persons with disabilities and one of the key elements in social commitments by companies in their CSR strategies<sup>54</sup>.

Women with disabilities form one of the groups that suffers most from inequality and discrimination in the labour market, as we have seen in previous sections in this book. Companies must take advantage of the talent and capacities women with disa-

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<sup>53</sup> "Creating Shared Value", Harvard Business Review, 2011, Michael Porter and Mark Kramer. The authors hold that business and society should unite efforts in order to reach a common benefit. The principle of shared value involves creating economic value in such a way that value is also generated for society.

<sup>54</sup> Worthy of mention here is the resolution adopted by the European Parliament on 25th October 2011 on mobility and inclusion of persons with disabilities and the European Disability Strategy 2010-2020. The European Parliament, "Stresses that voluntary social corporate responsibility could also be an important impetus to the situation of people with disabilities; calls for the introduction of aid and subsidies with special regard to EU funds and programming, which would vary according to the type of contract, for companies and individuals hiring workers with disabilities; calls on actors and stakeholders to support and apply good practice in this field, with special regard to women who have children with disabilities."

bilities can bring to their businesses and, in this process, CSR (both its internal and external aspects) can be a very efficient tool to achieve this.

#### INTERNALLY

- CSR can contribute to career diversification and help to overcome the pronounced 'horizontal and vertical segregation' to which women with disabilities who are part of the labour market are subjected. Positive actions to enable women with disabilities to access jobs in sectors and positions where they are under-represented;
- It can help to guarantee equal pay for jobs of equal value by establishing suitable remuneration structures and job assessment processes;
- It can help to avoid direct and indirect discrimination and harassment;
- It can make it easier for reasonable accommodations<sup>55</sup> —required to perform jobs properly— to be introduced;
- It can further participation by women with disabilities in life-long learning (indispensable for job retention and career advancement) by meeting their accessibility needs, accommodating training processes to account for specific needs caused by different disabilities, allowing more flexible working hours to be able to take part, etc.;
- It can promote conciliation by introducing flexibility in working hours, introducing non-stop working days, improve access to tele-working options (provided accessibility to ICTs is suitably addressed), etc.;
- It can help to increase the almost non-existent engagement by women with disabilities in decision-making positions by drawing up specific and accessible programmes (training, career planning, learning executive skills and abilities, etc.) to allow women with disabilities to be promoted to positions of responsibility.

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<sup>55</sup> "Reasonable accommodations: adjustments in the physical, social and attitudinal environment to take into account the specific needs of persons with disabilities. Accommodations shall efficiently and practically facilitate access and participation by a person with disabilities on an equal basis with all other citizens without imposing a disproportionate burden." Article 7, Law 51/2003, dated 2nd December, on equal opportunities, non-discrimination and universal accessibility for persons with disabilities.

EXTERNALLY

- CSR can boost access to the labour market by women with disabilities, thus helping to increase the number in employment, through targeted strategies in job seeking, design and implementation of non-exclusive and non-discriminatory recruitment processes, positive action measures to enable women with disabilities to find employment with or without quota systems;
- It can assist in developing products and services aimed at women with disabilities or responding to their needs (women with disabilities as consumers should not be underestimated);
- It can improve the company's reputation. CSR strategies promoting real equality of opportunities are viewed very positively by society;
- Finally, any initiative by a company to further equality will help to progress towards a fairer and more cohesive society in which everyone, regardless of whether they have a disability or not, gender, age, ethnic origin or any other diversity factor, enjoys the same opportunities for personal and work-related development.

## 5. RECOMMENDATIONS FOR POLICY MAKERS AND SOCIAL AND ECONOMIC STAKEHOLDERS

### 5.1. Employment

While recognising that progress has been made in recent decades thanks to a new relationship between women and the labour market, inequality for women with disabilities in terms of access to employment continues to exist. Furthermore, there are continuing inequalities in other parts of the labour market: poorer working conditions; horizontal and vertical segregation; barriers to reconciliation; persistent stereotypes and prejudices; precarious employment and underemployment, etc.

In order to overcome these inequalities, concerted action involving all stakeholders is required. Furthermore, this action must include mainstreaming.

Chapter 12 of the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union* contains a range of recommendations for activists and policymakers in the field of work and employment for women with disabilities. We recommend they are implemented immediately as they are of great interest and could potentially contribute to achieving significant and positive results.

We believe it is essential to adopt cross-cutting and positive action policies, actions and measures to combat high inactivity rates among women with disabilities, promote recruitment, improve working conditions, enhance career development and promotion in the workplace, eliminate the segregation of women with disabilities in sectors and positions requiring lower qualifications, combat precarious employment and grapple with underemployment.

This also requires career guidance and job placement services delivering personalised support to women with disabilities based on their needs. In addition, practitioners working in these services must be given targeted and specialised training in the realities and needs of women with disabilities.

Awareness-raising campaigns are a necessity. These should target the business world with a view to overcoming prejudices and stereotypes regarding the capabilities, skills and professional competences of women with disabilities, and women with disabilities and their families, with the goal of overcoming existing negative and limiting self-perceptions.

In education and training the approach must be to ‘activate’ women with disabilities and dispel protectionist and welfare-based ideas.

Training programmes which are adapted to the specific needs of women with different types of disabilities should be designed and provided in order to raise training, competence and/or qualification levels among women with disabilities. It is vital to raise these levels if we are to increase activity levels, as has happened in the case of women without disabilities.

Measures to motivate women with disabilities and their families are to be encouraged so that they engage in training schemes for employment and in training in the use of information and communication technologies.

Full access to training and workplaces —environments, resources, personal support and technologies— must be guaranteed while taking into account individual needs.

We support new methods to personalise learning and make systems more flexible, to adapt training to the diversity of aptitudes, interests, expectations and needs women with disabilities have.

## **5.2. Reconciliation and social care arrangements**

Women’s engagement in the labour market is not just an objective of equal opportunities policies —no small achievement— but also a necessity for the financial

and human sustainability of our societies. However, engagement is limited and influenced by the sexual division of labour in private spaces and the assumption of responsibility for caring. For these reasons measures in the field of reconciliation are vital if we are to increase activity rates among women with disabilities and curb the gradual ageing of our population.

To date, however, reconciliation has not been approached in a manner which is accurate, comprehensive or co-ordinated. In this respect, policies combining disability and reconciliation are conspicuous by their absence.

Strategies must seek not only to increase shared responsibility by men and women, promote flexible working hours or offer sufficient provision and public services to cover care requirements, but also to address reconciliation, social responsibility for caring and disability precisely in its social dimension. All sectors and social agents in a position to influence how housework and salaried work are arranged —trade unions, business, public authorities and society in general— should be encouraged to play an active role in concerted actions.

We must address the diversity, complexity and social changes which have taken place in recent decades in such a way that conciliation and care are not treated as strictly family issues and, more precisely, women's issues. This challenge necessarily involves assuming collective responsibility for so-called social care arrangements.

Sufficient, wide-ranging and accessible public services must be provided to offset the impact of care responsibilities on employability and career advancement in workers. Such services must also meet the special needs and requirements women with disabilities have<sup>56</sup>.

It is also time to review sensibly how working arrangements are regulated to develop norms which leave behind the traditional idea of the *male breadwinner* with no mobility restrictions or disability and who is fully available for the market thanks to the hidden work being done behind the scenes by women in the private sphere. This supposed scenario not only does little to promote inclusion —it also fails to guarantee productivity<sup>57</sup>. We must challenge the culture that values being present at work

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<sup>56</sup> For instance, according to the 2008 survey on disabilities, personal autonomy and dependence, the proportion of women with disabilities is higher than that of men with disabilities, and three out of four women with disabilities (73%) claim mobility problems to be the main obstacle restricting their activity in the job market. It is necessary, therefore, to modify and adapt working arrangements and public care services to this proven reality.

<sup>57</sup> According to a report by the Spanish Parliament Sub-commission on conciliation and working hours, marginal production by employees falls considerably after the first six hours. As it turns

above all else and measures work in terms of putting in one's working hours instead of objectives achieved.

This new approach must go hand-in-hand with a study to gauge the viability of measures such as flexitime, the so-called 'lights out' policy<sup>58</sup>, non-stop working days or shorter working days<sup>59</sup>, calculating working hours on a weekly basis instead of daily, partial tele-work<sup>60</sup>, extending hours for assistance services and setting up care services for older people and people with high support needs, community-based services providing treatment and care for the sons and daughters of women with disabilities<sup>61</sup>, or new solutions such as personal assistance to support younger women with disabilities who access the labour market and those with family responsibilities.

In addition, we must raise awareness of how important it is to introduce individual, paid and non-transferable paternity leave which is of a similar length to maternity leave (in Spain this is constantly being put off), focus on promoting family policies that take into consideration the special needs of persons with disabilities, and set up more public nursery schools<sup>62</sup> or introduce incentives for companies that provide childcare services on their premises<sup>63</sup> and prioritise access

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out, Spain is one of the European Union countries with the lowest productivity per hour in the workplace. Source: report published in the Official State Bulletin, number 480, 14th December 2006.

<sup>58</sup> This policy forces centres of employment to close at a certain time.

<sup>59</sup> Shorter working hours is a more flexible solution than part-time employment as the salary and time on the job can be reduced proportionally in line with the reduction in hours requested by the employee. However, when implementing schemes like this some safeguards must be put in place to enable the employee to return to the same position.

<sup>60</sup> However, to ensure tele-work does not lead to precarious employment for employees, it would be advisable to develop the European Framework Agreement on Tele-work (signed on July 16th 2002 in Brussels by the ETUC, UNICE/UEAPME and CEEP following the adoption of Council Directive 91/533/EEC, dated 14th October 1991, on an employer's obligation to inform employees of the conditions applicable to the contract or employment relationship) in order to establish a specific legal framework regulating tele-work and avoid situations of domestic isolation among tele-workers, uninterrupted working hours and lower salaries.

<sup>61</sup> As set out in the 2007 Action Plan for Women with Disabilities.

<sup>62</sup> Paragraph 12.20 of the aforementioned 2nd Manifesto states that, "Structural Funds, and in particular the European Social Fund, should be used as key tools to help European Union countries develop the greatest possible number of care facilities for children, older people and people with high support needs, including by testing new forms of public-private organisational and financial cooperation and new arrangements for such cooperation."

<sup>63</sup> This measure must be considered 'complementary' because, if there is insufficient public coverage, promoting in-company nurseries once again excludes women with disabilities who are inactive, unemployed or work in small and medium-sized companies which cannot offer these services, not to mention temporary contracts which force the child to adapt to different centres, with the consequent uprooting from his or her peer groups.

to employment by women with some type of disability or a son or daughter with a disability<sup>64</sup>.

It is worth pointing out that support for women with disabilities to join the labour market or reconcile care responsibilities should not result in paternalistic overprotection brought on by homogenising universalism; this would have the perverse effect of reducing, both symbolically and materially, the woman's autonomy and status as a citizen. Support should be based on an acknowledgement of her rights as a citizen and, as a result and in addition to the strategies set out herein, legal systems in member states should include and recognise the particular impact, dimension and complexity of multiple discrimination.

Given the lack of multi-pronged and co-ordinated initiatives in policies related to conciliation and dependence, it is immaterial to what extent gender equality policies attempt to seek equilibrium in the position women and men hold in public space or how disability policies seek to promote employability and financial and personal independence among women. These goals are implausible if there are no efforts to modify the sexual division of labour in private spaces, reformulate the public-private relationship and revisit how conciliation policies, which continue to ignore the specific needs of women with disabilities, are arranged.

### **5.3. Trade union initiatives: agreements, collective bargaining and women's engagement in trade unions**

Social agents should encourage scenarios in which there is real and effective participation by everyone, and this involves furthering the adoption of global framework agreements to reduce gender- and disability-based discrimination.

When negotiating, trade unions should prioritise working conditions that allow women with disabilities to take on employment-related, family, training and personal responsibilities and should promote non-discriminatory employment scenarios. A strong commitment is needed to mainstream protection against discrimination on the basis of sex or disability in collective bargaining. In addition, women with disabilities should have greater representation and be more involved as they can bring their experience and expertise to these processes, and this will enable a more accurate reading of their needs and demands and the resources required to fight against discrimination and exclusion from the labour market.

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<sup>64</sup> As recommended in the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union.

There is, therefore, a need to strengthen incentives to increase engagement by women with disabilities, support training schemes aimed at promoting active participation, leadership and empowerment, implement awareness-raising strategies involving informative guides and manuals or workshops and seminars to study progress and setbacks, disseminate good practises and provide a common framework for action.

#### **5.4. Corporate Social Responsibility**

CSR can play an important role in achieving goals in equal opportunities. It can raise the minimum legal standards and incorporate this key social concern in its arrangements. When including the disability dimension and the gender approach in their CSR strategies, policies and activities, businesses and the public sector must realise that a commitment to equal opportunities and non-discrimination must cover all levels in the organisation and be mainstreamed in all its activities.

When drawing up CSR strategies and activities, it is highly recommended to take into account the particular aspects related to women with disabilities and their needs among all interest groups —as female employees, clients, partners or stakeholders— and in all their dimensions —governance, employment, working conditions, work arrangements, training, career development, conciliation, internal and external communication, social action programmes, sponsorship, etc.

Furthermore, it is highly advisable to include specific indicators on targeted activities for women with disabilities in CSR policies and plans and in reporting (on sustainability, CSR, etc.), as well as promoting benchmarking in this area.

### **6. RECOMMENDATIONS FOR THIRD-SECTOR ACTIVISTS**

The social action third sector has a pivotal capacity to enhance employment, training, conciliation and trade union activism among women with disabilities. In its external activities, space and visibility must be given to associations representing the interests of women with disabilities, not just in order to empower them but also because if they are absent their interests will be unheard. For this reason networks, partnerships, collaborating associations and activities and programmes must give the floor to these doubly-silenced voices, because it will be difficult to intervene to eliminate inequalities if there is discrimination due to equalisation and the needs and interests of women with disabilities are ignored.

Action areas for direct action, communication or awareness-raising must always be founded on citizens' rights and a critique of the construct of the neutral as an all-embracing, false and exclusive category. The challenge is to empower women with disabilities as a group and avoid situations which amount almost to false paternalism or overprotection and which disempower women with disabilities collectively and individually.

The third sector must also take a leading role in this issue by promoting and proposing targeted campaigns, training and awareness-raising programmes to eradicate certain prevalent stereotypes and prejudices in our societies which are based on the belief that disability *per se* incapacitates a person for employment.

Logically and for reasons of consistency, internal plans must be put in place to incorporate the measures outlined in the previous section in the running of each organisation and include them in the core documents by which they are governed and their collective bargaining processes. Social action organisations must be consistent and act in accordance with their ultimate aim and purpose; they must lead the way in advocating for citizens' rights, but this will not happen if, by failing to act, they allow situations to occur in which the citizens' rights of the most unprotected and vulnerable groups are denied.



## Chapter XI

# CO-OPERATION AND DEVELOPMENT

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2. WOMEN AND GIRLS WITH DISABILITIES AND POVERTY, MULTIPLE DISCRIMINATION AND EXCLUSION: AN OVERVIEW
3. GENDER AND DISABILITY IN RELATION TO DEVELOPMENT AND HUMANITARIAN AID: THE CONCEPTUAL THEORETICAL FRAMEWORK
4. LEGAL FRAMEWORK AND KEY POLICIES IN DEVELOPMENT AND GIRLS AND WOMEN WITH DISABILITIES
5. CASE STUDIES: GENDER- AND DISABILITY-SENSITIVE DEVELOPMENT INITIATIVES
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## Chapter XI

# CO-OPERATION AND DEVELOPMENT

### 1. INTRODUCTION

#### WHY IS THIS AN IMPORTANT ISSUE?

- The inclusion and participation in decision-making (or empowerment) of girls and women with disabilities in international co-operation politics, programmes and projects is essential to make progress in human development<sup>1</sup> and achieve poverty-reduction goals;
- Inclusive and accessible services and facilities benefit the entire community;
- Cost effectiveness: inclusion costs less than exclusion;
- Women and girls participating actively in decision-making is vital if their practical and strategic needs are to be met; in addition, it furthers equal development for all.

The aim of this chapter is to provide activists, policymakers and other stakeholders in development with a useful tool for including girls and women with disabilities in development co-operation and humanitarian aid actions from a human rights-based approach (HRBA). These actions should bring about real changes in life quality, empowerment and engagement, including among those who are in situations of greater vulnerability such as women and girls with disabilities. This chapter addresses the following:

- The overall situation regarding poverty, multiple discrimination and exclusion among girls and women with disabilities;

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<sup>1</sup> Human development is currently defined as a four-step process: meeting basic needs, developing the capacity of each human being, the right and duty to take part in social life, and attaining independence and freedom to choose the lifestyle one thinks is best. Each of these stages influences the reality of persons with disabilities (See Sen, 2000).

- An approach to the conceptual theoretical framework in gender and disability in relation to development and humanitarian action;
- Key regulations and legislation to be considered in including girls and women with disabilities in international co-operation and humanitarian action;
- A number of practical examples from the field of development where gender and disability are taken into account. These provide experiences for learning, positive outcomes and good practises to be considered.
- A range of recommendations including the gender and disability perspective and aimed at national, European and international stakeholders.

## 2. WOMEN AND GIRLS WITH DISABILITIES AND POVERTY, MULTIPLE DISCRIMINATION AND EXCLUSION: AN OVERVIEW

The aim of this section is to present an overview of the worldwide situation regarding girls and women with disabilities while bearing in mind the serious shortcomings and fragmented nature of data gathering in many low-income countries. In 90% of developing countries there are no statistics disaggregated by sex and, in many cases, gender- and disability-based discrimination is neither identified nor reported —or reporting does not reflect gender— related problems in issues such as gender-based violence, ‘femicide’, sexual harassment, feminisation of poverty, etc.<sup>2</sup>, or disability-related problems such as lack of accessibility, paucity of reasonable accommodations, additional costs, etc.

Given the invisibility of girls and women with disabilities in available statistics, one could conclude they are not part of the problem as, on many occasions, there is little reliable data on their identity or location. However, women with disabilities represent three quarters of all persons with disabilities in middle- and low-income countries (USAID), and 10% of the total population of women (WHO). It is estimated that between 65% and 70% lives in rural areas<sup>3</sup>.

Some statistics<sup>4</sup> on the situation faced by girls and women with disabilities speak for themselves:

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<sup>2</sup> Source: United Nations Department of Economic and Social Affairs (DESA): [http://unstats.un.org/unsd/demographic/products/indwmm/ww2005\\_pub/English/WW2005\\_text\\_complete\\_BW.pdf](http://unstats.un.org/unsd/demographic/products/indwmm/ww2005_pub/English/WW2005_text_complete_BW.pdf)

<sup>3</sup> Ortoleva, S. (2011): “Right Now! - Women with Disabilities Build Peace Post-Conflict.” *Barbara Faye Waxman Fiduccia Papers on Women and Girls with Disabilities*. Center for Women Policy Studies.

<sup>4</sup> These statistics are available on the United Nations web site in the section on statistics regarding women with disabilities: <http://www.un.org/disabilities/default.asp?navid=37&pid=1514>

- The mortality rate among girls with disabilities is much higher than that of boys with disabilities (USAID, UNICEF);
- While the literacy rate for adult males with disabilities in low-income countries is 3%, the rate for women with disabilities in these countries is, overall, just 1% (UNDP, 1998);
- Women with disabilities have fewer opportunities to access vocational training (UNDP);
- Women with disabilities are half as likely to find a job as men with disabilities. Although the majority of women with disabilities contribute significantly in the family environment by cooking, cleaning and caring for children and older relatives, 75% of all women with disabilities worldwide, and up to 100% in some poorer countries, are excluded from the workforce (UN);
- Poverty does not only affect persons with disabilities, but extends to include relatives and other people close to them who are responsible for their care, mostly women. This means having to relinquish other activities such as employment, attending training programmes, or simply having an active social life, and results in additional costs and loss of income;
- A study of the results from the World Health Survey for 51 countries indicates an employment rate of 52.8% among men with disabilities and 19.6% for women, compared to 64.9% for men without disabilities and 29.9% among women without disabilities (WHO, 2011);
- Women with disabilities are discriminated against in employment and promotion and do not receive the same salary as men for the same work. They are often forced to work in segregated occupations for lower pay (WHO, 2011);
- Women with non-severe disabilities earn less than their peers, while women with severe disabilities receive less than any other group, both in countries with higher economic development and in less developed countries (World Bank);
- Women with disabilities are often denied access to credit and other productive resources (World Bank);
- Inaccessible health services are a serious barrier for women with disabilities, in respect of facilities and lack of staff properly trained to communicate with women with different types of disabilities, or staff who consider women with disabilities to be asexual in relation to sexual and reproductive health provision. Women with disabilities face a greater risk of contracting HIV due to high rates of gender-based violence against them and a lack of access to health services (World Bank, WHO, 2011);

- Among all women with disabilities, 80% fall victim to violence. Women with disabilities are four times more likely to suffer sexual violence than other women (UN, 2011)<sup>5</sup>;
- Despite legal prohibitions, there are still many cases of forced sterilisation to render some people with disabilities infertile; almost all are women, and particularly women with intellectual disabilities (WHO, 2011).

All of the above are aggravated in situations of risk or humanitarian emergency, where there is a deterioration in safety and protection for women and girls with disabilities and they have a noticeably slimmer chance of survival. Women and girls with disabilities find themselves in situations of greater vulnerability than the rest of the population before, during and after risk situations such as armed conflict, territorial occupation, natural disasters and humanitarian emergencies.

In emergency situations, a poor woman or girl with a disability may not have her specific needs met when the family must use its scarce resources for survival. In these circumstances and as a result of structural discrimination in the productive system in many cultures - which do not consider women to be 'profitable' in economic terms, and women with disabilities even less so - there is evidence that this can lead to an increase in abuse and/or neglect of women and girls with disabilities by the family and community.

Women and girls with disabilities who are refugees, reside in areas of armed conflict or occupied territories, or are survivors of natural disasters, are at increased risk of suffering violence and sexual abuse. Humanitarian aid efforts must prevent such situations from happening and address them when they do occur.

Disability, gender and poverty are inter-related concepts. Disability and poverty are said to be feminine<sup>6</sup>; this is no coincidence — it is because these concepts are largely

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<sup>5</sup> UN, 2011: Report of the Special Rapporteur on violence against women, its causes and consequences (A-HRC-17-26).

<sup>6</sup> The feminisation of poverty is a generally accepted maxim in gender-sensitive development policies when women's organisations study the results of policies aimed at structural readjustment of the lives of men and women in countries where they are implemented. Statistics on woman worldwide have, for some decades now, shown that women and girls are over-represented among those living in poverty. This situation is caused by the different types of discrimination they suffer and a lack of equal access to human rights and, consequently, lack of access to participation in economic, social, political and cultural spaces worldwide. Women in situations of poverty, low income or economic crisis assume more responsibility than men for production and reproduction to ensure family subsistence (for instance food, firewood, caring for dependent person and/or children, health care), and this implies taking on more

related to girls and women<sup>7</sup>. Girls and women with disabilities are over-represented in the poor population. They are the poorest of the poor.

Nevertheless, despite the large number of women and girls with disabilities in poverty and the vital role women, and particularly women with disabilities, play in traditional economies as carers, breadwinners and homekeepers, women in general and women with disabilities in particular are 'invisible' and absent in terms of formulating and implementing the political agenda and in the context of development co-operation.

### 3. GENDER AND DISABILITY IN RELATION TO DEVELOPMENT AND HUMANITARIAN AID: THE CONCEPTUAL THEORETICAL FRAMEWORK

The main and central goal of development co-operation is to eliminate poverty within the context of sustainable human development<sup>8</sup>. Poverty, however, must be seen not only as a lack of income or financial resources, but also as the notion of inequality in access to material and non-material benefits in any particular society, and inequalities in control over these benefits.

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unremunerated and unrecognised tasks. In short, the feminisation of poverty means working double or triple shifts, reduced access to education, nutrition, health services, difficulties and exclusion from access to economic rights and the regulated labour market and, of course, to fora where power is exercised. In short —no human rights. This all means that it is very difficult to overcome and escape from the poverty and exclusion women suffer as a gender (Ministry for Foreign Affairs and Co-operation, 2007, page 42).

<sup>7</sup> "Gender is one of the most important categories of social organization, and patterns of disadvantage are often associated with the differences in social position of women and men. These gendered differences are reflected in the different life experiences of women with disabilities and men with disabilities. While women with disabilities have much in common with men with disabilities, women with disabilities have to face multiple discrimination in many cases, so that they are often more disadvantaged than men with disabilities in similar circumstances." Arnade, S. And Haefner, S. (2006): Gendering the Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Available at: [http://v1.dpi.org/lang-en/resources/topics\\_detail?page=446](http://v1.dpi.org/lang-en/resources/topics_detail?page=446) (Consulted 27.12. 2011).

<sup>8</sup> The actions and recommendations suggested are based on the Beijing Declaration, which states that, "We are firmly convinced that economic development, social development and environmental protection are interdependent and synergic elements in sustainable development, the framework for our efforts to achieve a higher quality of life for all persons. Equal social development, recognising the empowerment of poor people, and in particular of women living in poverty, in order to use environmental resources sustainably, is the necessary basis for sustainable development."

Disability, gender and poverty influence the capacities of a person and have an impact on that person's engagement in society. Disability and poverty occur when there is a situation where a person is deprived of habilitation or his or her capacities or human rights are denied.

When a person does not have the habilitation needed to function equally, this leads to that person being viewed as less capable than others. The same happens with gender, which places women in a disadvantageous position for taking on traditional roles in unequal power relationships between men and women and a socialisation process which assigns different tasks and behavioural norms to men and women, thus perpetuating discrimination against women in social, political, economic, cultural and civil circles in each society. In addition, when gender and disability combine multiple discrimination occurs, causing poverty and social exclusion.

This is why development co-operation must be addressed inclusively and from a human rights-based approach, which means that people have the same rights to participate in and benefit from development processes; *"...poverty reduction and human rights are not two projects, but two mutually reinforcing approaches to the same project."*<sup>9</sup>

The women's human rights approach must be included as a way to combat poverty. More specifically, article 18 of the Programme of Action adopted by the World Conference on Human Rights in Vienna in 1993 states that, *"The human rights of women and of the girl-child are an inalienable, integral and indivisible part of universal human rights. The full and equal participation of women in political, civil, economic, social and cultural life, at the national, regional and international levels, and the eradication of all forms of discrimination on grounds of sex are priority objectives of the international community."* Here we see a fundamental shift in human rights theory in accepting that these rights can be enjoyed both in the public and in the private sphere and can therefore be violated in both with, for the first time, states being held responsible.

Ideas taken up in Cairo (1994) and Beijing (1995) form the backbone of this move towards consolidated acknowledgement of the universal and specific rights of women.

In addition, the principles of the Convention on the Rights of Persons with Disabilities must be incorporated. The entry into force of this convention has brought about a shift in how disability is conceived; persons with disabilities are not 'objects' of charity or welfare policies, but 'subjects' holding human rights. As a result, the

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<sup>9</sup> UN, 2004, Human Rights and Poverty Reduction - A Conceptual Framework, Office of the High Commissioner for Human Rights, New York and Geneva, page 3.

social disadvantages they endure should not be eliminated because of other people's or government's 'goodwill', but because these disadvantages violate the enjoyment and exercise of their human rights.

In practise, however, development policies and policies for the advancement of human rights have developed separately and have not been part of the same project. This has happened with the concept of inclusive development, which is used only in the field of promoting the development of persons with disabilities. These concepts need to be brought together in actions including them in all aspects of development co-operation to make it sustainable and effective.

A human rights approach to international co-operation could potentially help to tackle the different dimensions in poverty more efficiently. To achieve this it will be necessary to consider not only needs and resources, but above all the development of capacities to be able to lead a free life<sup>10</sup> (freedom to be healthy, well housed and educated, freedom to eat properly, etc.) and fully exercise human rights and the consequent legal obligations generated towards third parties.

Although there is no single set definition for HRBA, United Nations bodies<sup>11</sup> have agreed on a number of key characteristics:

- All development co-operation programmes, policies and technical assistance should further the realisation of human rights as laid down in the Universal Declaration of Human Rights and other international human rights instruments.
- Human rights standards contained in, and principles derived from, the Universal Declaration of Human Rights and other international human rights instruments guide all development cooperation and programming in all sectors and in all phases of the programming process.
- Development cooperation contributes to the development of the capacities of 'duty-bearers' to meet their obligations and/or of 'rights-holders' to claim their rights.

Based on these three principles, the following were agreed as elements of co-operation programming under an HRBA:

- People are recognized as key actors in their own development, rather than passive recipients of commodities and services;

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<sup>10</sup> Sen, 2000, *'Development as Freedom'*.

<sup>11</sup> UN, 2003, *'The Human Rights Based Approach to Development Cooperation: Towards a Common Understanding among UN Agencies'*, Report from the Second Interagency Workshop on Implementing a Human Rights-based Approach in the Context of UN Reform, Stamford, USA.

- Participation is both a means and a goal;
- Strategies are empowering, not disempowering;
- Both outcomes and processes are monitored and evaluated;
- Analysis includes all stakeholders;
- Programmes focus on marginalized, disadvantaged, and excluded groups;
- The development process is locally owned;
- Programmes aim to reduce disparity;
- Both top-down and bottom-up approaches are used in synergy;
- Situation analysis is used to identify immediate, underlying, and basic causes of development problems;
- Measurable goals and targets are important in programming;
- Strategic partnerships are developed and sustained;
- Programmes support accountability to all direct stakeholders.

Source: Methodological guide for the inclusion of human rights in development co-operation, page 20.

As also mentioned previously, development must be inclusive<sup>12</sup>, and by this is meant a process to achieve a non-exclusive global community<sup>13</sup>. It is defined

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<sup>12</sup> The concepts of gender mainstreaming and inclusion of disability form the main framework when discussing the inclusion of girls and women, including girls and women with disabilities, in development activities. This refers to the process of assessing the implications for women and men with and without disabilities of any planned action, including legislation, policies or programmes, in all areas and at all levels. Bearing in mind article 6 of the Convention on the Rights of Persons with Disabilities, including women with disabilities in international development and emergency situations helps “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.”

<sup>13</sup> An inclusive rights-based approach means efforts towards generating means for participative development where the voice of excluded people effectively influences decision-making. The right to have a voice and be heard is, therefore, a prerequisite for exercising other rights and to transform power relations. The essence of participation involves opening up spaces for this to happen and strengthening and promoting the consolidation and institutionalisation of structures to facilitate association and participation for those most excluded at community, local, regional and national level. By doing this, their voices can be taken into account in decision-making processes affecting them and in setting the agenda on what issues are to be decided. (Ministry for Foreign Affairs and Co-operation, 2009, pages 34-35).

according to an understanding of two concepts: inclusion and development. Inclusion is both a process and an objective. Diversity must be incorporated as a fact of life and differences accepted as normal. However some people, like girls and women with disabilities, are excluded from society due to their differences, and this may be the result of a number of factors. Some may be universal while others may be culture- or context-specific. Inclusion is the process whereby society changes to accommodate difference and combat discrimination. Inclusion does not place responsibility for the problem on the person, but rather on society.

Nevertheless, the concept of inclusive development is not truly applied when implementing general development policies. As regards persons with disabilities, often the concept has been confined to development projects focusing exclusively on persons with disabilities. The concept of disability must be mainstreamed in development policies from an HRBA so that it plays a part in every action area - including gender policies —and the policies can be truly effective.

In order to achieve this, a twin-track approach is needed:

- Focus on society and eliminating the barriers that cause people with disabilities to be excluded from all areas (mainstreaming/cross-cutting horizontal action);
- Act directly with excluded women and girls with disabilities to strengthen and support their capacities so that they can fight for inclusion (sectoral action). The aim is to empower people to bridge the discrimination and inequality gaps they suffer.

Including girls and women with disabilities means they participate in society at all levels. Empowerment<sup>14</sup>, co-operation and networking are key strategies to achieve this goal.

Development, however, has often created new obstacles preventing their participation: new buildings with architectural barriers; designs that fail to consider the specific characteristics of women with disabilities, their greater vulnerability to violence and their reduced purchasing power; and their particular needs in relation to access to information, communication and new technologies, among others. The first step towards achieving a more inclusive approach is to link up with general development

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<sup>14</sup> The definition agreed in the 1996 Beijing Declaration is used here. The key to empowering women is social and political engagement, and this means modifying traditional power structures and fostering relationships that allow women to control their own lives. Investing in education for women and girls, reproductive health and economic rights are, at the same time, fundamental pillars in empowerment, UNFPA, 2005.

frameworks and include disability as an element to be addressed immediately in order to foster active participation by persons with disabilities.

Mainstreaming the rights of persons with disabilities in development policies is essential as their rights can not be safeguarded through targeted actions for several reasons:

- Disability is present in all population groups regardless of age, geographical location and socio-economic capacity, among other factors. It is estimated that 15% of the world's population<sup>15</sup> has a disability, so basic services must be accessible for everyone, including persons with disabilities;
- Sustainability requires a systemic shift. One-off projects can have positive outcomes, but they do not normally have a sustainable and systemic impact. What is needed, therefore, is an inclusive approach to modify the system and involve all actors —both public and private— at all relevant levels and both horizontally and vertically;
- The strategy should make basic resources available to everyone equally. Segregated or separate services can only be justified in rare cases;
- Awareness-raising processes and training in the HRBA and targeted empowerment programmes must be provided to further the engagement of persons with disabilities in all areas.

#### 4. LEGAL FRAMEWORK AND KEY POLICIES IN DEVELOPMENT AND GIRLS AND WOMEN WITH DISABILITIES

The key legal instruments in relation to girls and women with disabilities and development are the United Nations Charter (1945), commitments entered into by virtue of ratifying international conventions adopted at United Nations international conferences, in particular the *Convention on the Rights of Persons with Disabilities* (CRPD) and the *Convention for the Elimination of all Forms of Violence against Women* (CEDAW), European Union legislation which is binding upon its member states, guidelines and recommendations from the OECD DAC, and national legislation.

A brief study of legislation indicates that people with disabilities are largely invisible in most general regulations, while references to gender are more common.

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<sup>15</sup> WHO, 2011, World Report on Disability, Geneva.

To enable the gender and disability perspectives to be mainstreamed in all areas, we must put forward well-founded ethical and legal arguments. To do so, this section is very helpful in facilitating the inclusion of these perspectives in all relevant actions and policies.

The recommendations put forward in this chapter are in line with the provisions of the regulatory framework for the inclusion of girls and women with disabilities, as summarised in the following table:

<b>PRINCIPAL REGULATORY FRAMEWORK FOR THE INCLUSION OF GIRLS AND WOMEN WITH DISABILITIES IN DEVELOPMENT</b>
<b>INTERNATIONAL REGULATORY FRAMEWORK</b>
<b>1966 - International Covenant on Civil and Political Rights</b>
Article 26 stipulates that all persons are equal and entitled to protection against all types of discrimination.
<b>1966 - International Covenant on Economic, Social and Cultural Rights</b>
Article 3 recognises that men and women are equal in the implementation of economic, social and cultural rights.
<b>1979 - Convention on the Elimination of all Forms of Discrimination against Women (CEDAW)</b>
Although reference is made in this convention to ALL women, girls and women with disabilities are not specifically mentioned. The convention sets out the general principle of non-discrimination.
<b>1989 - Convention on the Rights of the Child</b>
Article 2 contains references to sex and disability. Article 23 recognises the specific situation of children with disabilities and calls on States Parties to make the necessary accommodations for them to be included in society and enjoy a full and decent life.
<b>1995 - Beijing Platform for Action</b>
Article 32 mentions girls and women with disabilities and refers to the need for them to be included in decision-making processes.
<b>2006 Convention on the Rights of Persons with Disabilities</b>
Contains a specific article —article 6— addressing women and girls with disabilities. Article 11 refers to situations of risk and humanitarian emergencies. Article 32 refers to the importance of international co-operation in advancing the realisation of the human rights of persons with disabilities. Gender was mainstreamed throughout the convention and the rights of women with disabilities in all spheres of life are mentioned.

<b>REGULATORY FRAMEWORK - COUNCIL OF EUROPE</b>
<b>1953 - Convention for the Protection of Human Rights and Protocol 12 outlawing discrimination</b>
Article 14 prohibits discrimination.
<b>REGULATORY FRAMEWORK - EUROPEAN UNION</b>
<b>1993 - Treaty on European Union, amended by the Treaty of Amsterdam (1997)</b>
Article 2 of the Treaty on European Union states that promoting equality between men and women is part of the European Union's mission. Article 3 paragraph 2 of the Treaty states that the Community shall seek to eliminate inequalities and promote equality between men and women in all its activities. (gender perspective included)
Article 13 includes an explicit reference to eliminating discrimination on the grounds of sex and disability.
<b>Council Directive 2000/78/EC</b> , dated 27th November 2000, establishing a general framework for equal treatment in employment and occupation.
<b>Council and Parliament Regulation 806/2004/EC</b> , promoting equality between men and women in cooperation and development policies.
<b>Directive 2006/54/EC</b> . This directive amends Directives 75/117/EEC, 76/207/EEC, 86/378/EEC, 96/97/EC, 97/80/EC and 2002/73/EC. The purpose of the directive is the implementation of the principle of equal opportunities and equal treatment of men and women in matters of employment and occupation. To achieve this, it includes provisions to implement the principle of equal treatment in a) access to employment, including promotion, and to vocational training, b) working conditions, including remuneration, and c) occupational social security schemes.

<b>REGULATORY FRAMEWORK IN SPAIN</b>
<b>1978 Spanish Constitution</b>
Article 1 states that one of the guiding principles of the Spanish legal system is equality. Article 14 establishes the principle of non-discrimination, although disability is not explicitly mentioned.
<b>Law 23/1998</b> , dated 7th July, on international development co-operation. Article 2 prohibits discrimination on the grounds of sex, race, culture and religion and includes respect for diversity. Among the specific priorities set out in article 7 is protection and respect for human rights, equal opportunities, non-discrimination, universal accessibility for persons with disabilities, and social participation and integration of women.
<b>Law 51/2003</b> , dated 2nd December, on equal opportunities, non-discrimination and universal accessibility for persons with disabilities.

**Organic Law 1/2004**, dated 28th December, on comprehensive protection measures against gender-based violence, and its enabling regulations.

**Organic Law 3/2007**, dated 22nd March, for effective equality between men and women.

**Law 26/2011**, dated 1st August, adapting regulations to the International Convention on the Rights of Persons with Disabilities.

## Internationally

Mainstreaming disability in development co-operation programmes and projects is a relatively new concept for most actors involved. It is a new process which has been bolstered by the entry into force of the Convention on the Rights of Persons with Disabilities (CRPD), which has become the key instrument for the inclusion of disability in development policies, situations of risk and humanitarian emergencies<sup>16</sup>.

The United Nations system has begun to mainstream disability, although the process is still far from comparable with the level of gender mainstreaming.

One experience in this respect is provided by UNICEF, the United Nations Children's Fund, which has engaged an advisor on persons with disabilities. Providing

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<sup>16</sup> CRPD article 32 on international co-operation stipulates that:

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

(a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;

(b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;

(c) Facilitating cooperation in research and access to scientific and technical knowledge;

(d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

CRPD article 11 on situations of risk and humanitarian emergencies stipulates that:

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

a focal point for disability has significantly raised the visibility of disability and enhanced actions in general programmes for girls and boys. A resolution on the rights of the child has been adopted<sup>17</sup> which includes a section containing an explicit reference to girls with disabilities and the important role international co-operation plays in rights. Furthermore, a resolution on the girl child has also been adopted<sup>18</sup>. In addition, the upcoming annual report by UNICEF on the State of the World's Children will focus on children with disabilities.

Setting up focal points for disability in international bodies, UN agencies and other organisations is proving to be an effective way to manage resources towards achieving inclusion and visibilisation for disability in mainstream actions and programmes.

Disability is absent from the 2000 **Millennium Declaration**<sup>19</sup>. The outcome document from the September 2010 World Summit to review the Millennium Goals contains a number of references to people with disabilities, although none explicitly mentions girls and women with disabilities. As regards gender, the MDG do include references to gender, and for instance there is MDG 3 on promoting gender equality and MDG 5 on sexual and reproductive health.

Less significant is Human Rights Council resolution HRC/16/15 from March 2011 on the role of international co-operation; however, it is notable in that it contains a reference to gender and disability:

*“6. Encourages all actors, when taking appropriate and effective international co-operation measures in support of national efforts for the realization of the rights of persons with disabilities, to ensure:*

*(a) That appropriate attention be given to all persons with disabilities, including those with disabilities relating to physical, mental, intellectual and sensory impairments, and that appropriate attention be given also to gender issues, including the connection between gender and disability;*

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<sup>17</sup> General Assembly of the United Nations, *Rights of the Child*, GA resolution 62/141.

<sup>18</sup> General Assembly of the United Nations, *The girl child*, GA resolution 66/140.

<sup>19</sup> The following are some of the key resolutions related to the MDG: United Nations Millennium Declaration, Resolution A/55/L.2, 55/248 (2000); Resolution adopted by the General Assembly of the United Nations (60/1), World Summit 2005 Outcome (to review the Millennium Summit, MDG+5, New York, September 2005); Resolution A/RES/65.1, adopted by the General Assembly of the United Nations on 19th October 2010: Keeping the promise: united to achieve the Millennium Development Goals; General Assembly Resolution A/C.3/65/L.12/Rev.1, dated 3rd November 2010: Realizing the Millennium Development Goals for persons with disabilities towards 2015 and beyond.

*(b) Adequate coordination between and among actors involved in international cooperation;”*

As regards situations of risk, the adoption by the Security Council of Resolution 1325 on *Women, peace and security* in 2000 was a milestone in terms of acknowledging that women are active agents in promoting peace and security.

In addition, in October 2010 the UNHCR (United Nations agency for refugees) Executive Committee adopted a conclusion on refugees with disabilities which calls for respect for women and men with disabilities by UNHCR staff and organisations working with the agency. The conclusion contains several references to women and girls with disabilities<sup>20</sup>.

The Development Assistance Committee (OECD - DAC)<sup>21</sup> plays a vital role in setting development aid policy in OECD countries. At its high level forum in Paris in 2005 the Paris Declaration<sup>22</sup> on aid effectiveness was adopted, while in 2008 the Accra Agenda for Action was approved. The Agenda includes a reference to disability in a paragraph alongside references to human rights, decent employment, environmental sustainability and gender equality.

The Committee’s work in aid effectiveness has resulted in four high level meetings, the last of which was held in Busan, South Korea, from 28th November to 1st December 2011. The meeting adopted an outcome document containing the same formula as the Accra Agenda for Action:

*“11. As we embrace the diversity that underpins our partnership and the catalytic role of development co-operation, we share common principles which - consistent with our agreed international commitments on human rights, decent work, gender*

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<sup>20</sup> General conclusion 110 on international protection: Conclusion on refugees with disabilities and other persons with disabilities protected and assisted by UNHCR. See <http://www.acnur.org/t3/a-quien-ayuda/personas-con-discapacidad/>.

See also the work carried out by the Women’s Refugee Commission in gathering data on the situation faced by men and women with disabilities in refugee camps, in emergency aid for persons with disabilities in Haiti, and tools for including people with disabilities, including women, in aid programmes in refugee camps: <http://www.womensrefugeecommission.org/programs/disabilities>. See also the 2008 UNHCR guide to protecting women and girls.

<sup>21</sup> The Working Party on Aid Effectiveness is composed of key policy advisors from 23 DAC countries, as well as 22 representatives from developing countries and 11 multilateral organisations.

<sup>22</sup> The principles set out in the Paris Declaration should be made viable. These are: ownership, alignment, harmonisation, mutual accountability and results.

*equality, environmental sustainability and disability - form the foundation of our co-operation for effective development”<sup>23</sup>*

The paper contains few references to human rights, demonstrating that human-rights based development is still in its infancy. Whatever the case, sections of the Busan conclusions are relevant, such as the recognition of the need to assist groups in situations of greater vulnerability and the role of civil society.

The Busan partnership contains the following section on gender:

*“20. We must accelerate our efforts to achieve gender equality and the empowerment of women through development programmes grounded in country priorities, recognising that gender equality and women’s empowerment are critical to achieving development results. Reducing gender inequality is both an end in its own right and a prerequisite for sustainable and inclusive growth. As we redouble our efforts to implement existing commitments we will:*

*a) Accelerate and deepen efforts to collect, disseminate, harmonise and make full use of data disaggregated by sex to inform policy decisions and guide investments, ensuring in turn that public expenditures are targeted appropriately to benefit both women and men.*

*b) Integrate targets for gender equality and women’s empowerment in accountability mechanisms, grounded in international and regional commitments.*

*c) Address gender equality and women’s empowerment in all aspects of our development efforts, including peacebuilding and statebuilding.”*

Alongside the Busan declaration, a Gender Action Plan put forward by the Parallel Civil Society Forum in the framework of the Political Statement from the Busan Global Women’s Forum is still on the table for approval.

Gender is present in the work performed by the OECD - DAC: the Development Co-operation Directorate (DCD-DAC) has a Department for Gender Equality and Development and a Network on Gender Equality (GENDERNET). This is the only international forum where those responsible for gender in government ministries and development agencies from DAC member countries meet to set out common projects to achieve gender equality<sup>24</sup>. There is no such forum for disability. OECD - DAC guidelines do not focus on disability as such, but they do include a multi-dimensional

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<sup>23</sup> High Level Forum on Aid Effectiveness (28th Nov. - 1st Dec. 2011): Busan Partnership for Effective Development Cooperation.

<sup>24</sup> See the thematic summaries drawn up in recent years by GENDERNET on implementing effectiveness principles in gender equality.

approach to poverty which is reflected in OECD and World Bank policies. These dimensions provide a conceptual framework which can easily be adapted to analyse poverty among women with disabilities.

The United Nations Development Group (UNDG) and the Inter-Agency Support Group for the CRPD Task Team (IASG/TT) have set up the Inter-Agency Support Group for the CRPD (IASG), which is made up of more than 20 United Nations agencies. The *International Disability Alliance (IDA)*<sup>25</sup> attends its meetings. The IASG helps to mainstream disability in the work of United Nations agencies and promote sustainable inclusive development. In July 2010 the group adopted a guidance note<sup>26</sup> for UN country teams on how to include the rights of people with disabilities in their work while also considering the gender perspective.

In December 2011 the Multi-donor Trust Fund was established. The fund works to mainstream the rights of persons with disabilities in UN work at national level, and it includes an obligation to guarantee the rights of women and girls with disabilities are promoted equally.

## The European Union

European Union co-operation policies<sup>27</sup> are based on its international development objectives as they are set out by the Organisation for Economic Co-operation and

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<sup>25</sup> The International Disability Alliance (IDA) is a network of global and regional disabled people's organizations. Its aim is to promote the effective implementation of the UN Convention on the Rights of Persons with Disabilities. It is composed of eight international organisations of persons with disabilities and four regional organisations, and has two regional organisations with observer status. IDA represents the interests of the estimated 700 million persons with disabilities worldwide.

<sup>26</sup> United Nations Development Group (UNDG)/Inter-Agency Support Group for the CRPD Task Team (IASG/TT), 2010: '*Including the rights of persons with disabilities in United Nations programming at country level. A guidance note for country teams and implementing partners*': [http://www.un.org/disabilities/documents/iasg/undg\\_guidance\\_note.pdf](http://www.un.org/disabilities/documents/iasg/undg_guidance_note.pdf).

<sup>27</sup> The European Union is the world's biggest donor of Official Development Assistance (ODA). It donates 8 000 million Euros. Europe donates half of the world's public co-operation aid and, for many countries, is the biggest trading partner.

The following is relevant EU legislation on women with disabilities and development co-operation: Regulation 806/2004 of the European Parliament and the Council, on promoting gender equality in development cooperation (2004); COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT AND THE COUNCIL on Gender Equality and Women Empowerment in Development Cooperation, 7257/07 COM(2007) 100 final; Outcome document from the Council and government representatives from Member States (MD number 677/07 REV7 DEVGEN. 04.05.2007); European Parliament (2006) Resolution on disability and development; 7th meeting of the Special Committee (RSP/2005/2623).

Development's Development Assistance Committee (DAC), in major international conferences, and in line with the principles enshrined in the Treaty establishing the European Economic Community. In addition, the 2005 European Consensus on Development<sup>28</sup> sets the foundations for European co-operation based on the aid efficiency agenda and the MDG. It is of relevance because for the first time a framework of common principles was defined within which the EU and its Member States each implement their development policies in a spirit of complementarity.

The *Cotonou Agreement* proposes a European Union co-operation framework for economic, social and cultural development in the African, Caribbean and Pacific Group of States (ACP countries). All ACP and EU countries must respect the non-discrimination clause introduced in the 2010 Cotonou Agreement, according to which political dialogue between EU and ACP countries, “shall focus, *inter alia*, on... discrimination on any grounds, such as race, skin colour, gender, language, religion, political opinion or any other type of opinion, national or social origin, property, birth or other status” (article 8, paragraph 4).

The report by the Joint ACP-EU Parliamentary Assembly on including people with disabilities in developing countries refers to disability as a development issue. Furthermore, it points out that the EU must respect article 32 of the Convention on the Rights of Persons with Disabilities on international co-operation, and highlights the need to consider people with disabilities as a priority. It reports that a high number of people with disabilities face multiple discrimination and suggests special focus is given to the specific situation faced by women with disabilities.

The EU has also adopted the *European Disability Strategy 2010-2020: a Renewed Commitment to a Barrier-free Europe*. The strategy identifies eight essential areas for action, and one of these is promoting the rights of persons with disabilities in EU external actions. Among other action items, it states that,

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<sup>28</sup> The consensus holds that the fundamental aim, which is poverty reduction, also includes complementary goals such as fostering good governance and respect for human rights, common values which form the foundation of the EU. The fight to combat poverty also involves seeking a balance between activities linked to human development, protecting natural resources, economic growth and wealth creation to favour poor populations. The common principles governing development co-operation actions are: ownership, partnership, in-depth political dialogue, participation of civil society, gender equality and an ongoing commitment to preventing state fragility. Developing countries bear the primary responsibility for their own development, but the EU accepts its share of responsibility and accountability for the joint efforts undertaken in partnership. See [http://europa.eu/legislation\\_summaries/development/general\\_development\\_framework/r12544\\_es.htm](http://europa.eu/legislation_summaries/development/general_development_framework/r12544_es.htm) (consulted on 19th January 2012).

*“The EU and the Member States should promote the rights of people with disabilities in their external action, including EU enlargement, neighbourhood and development programmes. The Commission will work where appropriate within a broader framework of non discrimination to highlight disability as a human rights issue in the EU’s external action; ...including accessibility, in the area of emergency and humanitarian aid;”*

The *Action Plan on Gender Equality and Women’s Empowerment in Development (2010-2015)* was put forward and adopted in June 2010 by the EU during the Spanish Presidency. The plan refers to the need to develop targeted actions for women who suffer the worst types of discrimination. The *2007 Communication on Gender Equality and Women’s Empowerment in Development Cooperation* is a higher ranking document which sets out gender provisions in EU development policies.

## **Regulatory and policy framework in Spain**

Law 26/2011, dated 1st August, containing regulatory modifications in light of the International Convention on the Rights of Persons with Disabilities, introduces those modifications in regulations and timelines required to comply with the obligations arising from ratification of the Convention. It amends Law 23/1998, dated 7th July, on international development co-operation in the following terms:

1 Paragraph c) in article 7 is amended to read:

*“c) Protect and respect human rights, equal opportunities, non-discrimination and universal accessibility for persons with disabilities, participation and social integration for women and protect the most vulnerable groups in the population (minors, paying particular attention to eradicating child labour, refugees, displaced persons, returning persons, indigenous persons and minorities).”*

2 Second section added to article 9, to read as follows:

*“2 These instruments shall be inclusive and accessible for persons with disabilities.”*

The Master Plan for International Co-operation 2009-2012<sup>29</sup> includes provisions for disability in several sections and establishes social inclusion and poverty reduction as cross-cutting horizontal priorities. Nevertheless, it does not mainstream disability horizontally, as we would have wished, in order to deliver inclusive development

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<sup>29</sup> Master Plan for International Co-operation 2009-2012: cross-cutting priorities, social inclusion and combating poverty. Guidelines Document, Council of Ministers, 2009.

projects effectively, with an HRBA and in line with article 32 of the CRPD; instead, inclusion is addressed in certain specific areas, and above all in social services, social protection provisions and dependent persons with disabilities.

As regards women with disabilities, the plan confirms,

*“Support for targeted empowerment actions for women who suffer the worst types of gender-based discrimination when exercising their rights, as well as women citizens who suffer multiple discrimination (on the basis of ethnic origin, race, culture, age, disability, illness, HIV/Aids, worse labour conditions and situations of extreme hardship).”*

Another key document is the 2007 ‘Gender in development’ Spanish Co-operation Strategy, adopted by consensus by all actors in the field of co-operation through their representation on the Co-operation Council. The defining principles of the strategy are equality and non-discrimination, with the latter defined as,

*“Putting an end to all barriers involving differentiated treatment (exclusion, preference or distinction) on the grounds of personal characteristics such as sex, race, religion, disability, class, age, sexual orientation, etc., that lead to infringements or denial of equal treatment and equal opportunities for people.”<sup>30</sup>*

In developing projects and implementing instruments, the strategy prioritises efforts to empower groups of women who are in greatest need of aid. The strategy acknowledges that women with disabilities (*disabled women*) and girls (*who may suffer additional discrimination due to race, ethnic origin or disability*)<sup>31</sup> are victims of the worst types of discrimination, and that they should be prioritised when implementing positive actions.

As regards real equality, and in the priority action items set out in order to realise social rights, women with disabilities are included in efforts to strengthen national and local public policies in gender and social rights. One of the targeted short-term actions is to:

*“Strengthen indispensable national and local social policies with a view to minimising the worst forms of discrimination against women (for instance policies and programmes targeting disabled women or which deliver positive actions for integrating disabled women and girls or gender-sensitive child protection programmes)”<sup>32</sup>.*

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<sup>30</sup> ‘Gender in development’ Spanish Co-operation Strategy, Guidelines, page 31.

<sup>31</sup> ‘Gender in development’ Spanish Co-operation Strategy, page 65.

<sup>32</sup> ‘Gender in development’ Spanish Co-operation Strategy, page 70.

The schema showing gender intersectionality with other priority areas also takes into account the situation women with disabilities find themselves in with regard to social rights and, in particular, education. The need is noted to deliver *“targeted education programmes to further integration and positive action for girls and women who suffer the worst types of discrimination: indigenous girls and women, women with diverse cultural backgrounds, women with disabilities, etc.”*

In protective measures aimed at vulnerable groups, there is mention of *“women who suffer double and triple discrimination due to race or ethnic origin (indigenous women and women of African descent), age (girls, young women and older women who suffer exclusion), sexual orientation, disability or illness.”*

Other important documents are the *Equal Opportunities Strategic Plan 2008-2011* (Core theme 11, ‘Foreign and development co-operation policies’) and the *Gender Action Plan in Development in the AECID (2007)* which, although it does not include specific references to disability, is a key document for gender and development co-operation.

In addition we have the *Women and Peacebuilding Plan for Spanish Development Co-operation* (Ministry for Foreign Affairs and Co-operation, 2009) pursuant to *Resolution 1325 on Women, peace and security*. This plan recognises the need to provide targeted support to women who suffer the worst types of discrimination.

The *Spanish Disability Strategy 2012-2020*<sup>33</sup> sets forth a number of measures in the field of foreign activities to include people with disabilities in all actions carried out abroad by Spain. More precisely, it includes the following strategic measure:

1. *Include the disability factor and the gender perspective in projects related to emergencies, humanitarian aid and programmes and international co-operation instruments developed by the Ministry for Foreign Affairs and Co-operation and the Spanish Agency for International Development Co-operation.*

According to the latest peer report from the CAD on official aid given by Spain (2011), *“Spain has put gender equality high on its political agenda, built a reputation as a champion of gender equality and women’s organisations, and put in place multiple tools to live up to this commitment. Spain has backed this political commitment with significant contributions to NGOs and multilateral agencies to support gender equality. It should continue to do so. We particularly commend Spain*

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<sup>33</sup> Based on the *European Disability Strategy 2010-2020: a Renewed Commitment to a Barrier-Free Europe* and its first action plan. List of tasks 2010-2015 and the 2011 World Report on Disability published by the World Health Organisation and World Bank. Recommendation three of the report highlights the need to “adopt a national disability strategy and plan of action”.

*for covering important gaps where other donors have withdrawn their support despite severe and persisting gender inequalities. This is the case in Latin American middle-income countries with regard to indigenous women, rural women, women with disabilities and lesbians.”<sup>34</sup>*

The review also highlights the need to increase Spain’s development impact by focusing on fewer countries and on the poorest sectors.<sup>35</sup>

## 5. CASE STUDIES: GENDER- AND DISABILITY-SENSITIVE DEVELOPMENT INITIATIVES

Despite the fact that girls and women with disabilities have become part of the regulatory and political framework in international co-operation, in practical terms this is rarely delivered. Nevertheless, the following case studies highlight several examples of good practices at different levels:

**Case study 1: Sexual and reproductive health programme in Jamaica, focusing particularly on the sexual and reproductive rights of men and women with disabilities. Joint programme developed by UNFPA, the EU and the Government of Jamaica.**

**Mainstreaming disability and the gender perspective in general service provision**

**Why is this a good practice?**

The programme was developed from 2003 to 2008 to promote universal access to sexual and reproductive rights. It was delivered by the UNFPA with assistance from several NGOs and agencies from the Government of Jamaica. The aim of the project was to raise awareness and provide tools for a behavioural shift with regard to the sexual and reproductive rights of those groups in situations of greater vulnerability, such as people with disabilities. Budget: 2 130 million US Dollars.

**Achievements and tools generated**

The project enhances institutional capacity to deliver high quality sexual and reproductive health services. Thanks to this project there were improvements in service accessibility and quality through partnerships with public health systems and civil society organisations. The vulnerability of girls and women in relation to unwanted pregnancies, sexually-transmitted diseases and HIV/Aids was reduced. A tool was developed to verify progress in pregnancies and research was carried out on sexual and reproductive health needs.

<sup>34</sup> Development Assistance Committee (DAC) Peer Review 2011 Spain, page 28.

<sup>35</sup> Idem, page 12.

### **Replicability, visibility and sustainability**

The project was extended in 2007 and people with disabilities were included as a target group for the entire sexual and reproductive health programme. During the final stage of the programme efforts focused on providing counselling, training and other initiatives to increase the number of practitioners and institutions offering information on sexual and reproductive health. The project was flagged up as an example for future international efforts to promote the rights of persons with disabilities. An expert network involving practitioners engaged in the project has been set up, as has a web site to facilitate discussion and provide guidance to other countries.

### **Main lessons learnt**

Strong technical support with expertise in sexual and reproductive health issues for men and women with disabilities is required. A mechanism must be in place to enable NGOs and the government to work together to address structural issues for those groups in situations of greatest vulnerability — such as people with disabilities— to be able to access these services.

Source: UNFPA / WHO -

[http://www.unfpa.org/webdav/site/global/shared/documents/publications/2009/unfpa\\_povertycard\\_jam\\_en.pdf](http://www.unfpa.org/webdav/site/global/shared/documents/publications/2009/unfpa_povertycard_jam_en.pdf)

### **Case study 2: Danish International Development Agency (DANIDA)**

#### **Projects to mainstream gender and disability in programmes targeting people with disabilities and general programmes**

#### **Why is this a good practice?**

The Danish International Development Agency (DANIDA) seeks to promote the inclusion of girls and women with disabilities in development efforts in Uganda by mainstreaming gender in the disability field and through government-backed programmes.

#### **Achievements and tools generated**

Women with disabilities have been empowered through the setting up of women's committees in organisations of persons with disabilities, such as the National Union of Disabled Persons of Uganda (NUDIPU) and seven other major organisations in the country. Women's seminars have been held and there has been co-operation with microfinance institutions to provide financial guarantees so that women with disabilities can receive loans. Empowerment programmes targeting women with disabilities have been delivered to assist them in taking on representative positions in their organisations of persons with disabilities and women's organisations. An umbrella organisation for women has been set up to push for women's inclusion in development programmes. The organisation also offers guidance to other women on their sexual and reproductive rights and carries out awareness-raising campaigns targeting public authorities and the general public. In addition, 160 men with and without disabilities have received awareness training and now promote the sexual and reproductive rights of girls and women with disabilities in two districts in the country.

Furthermore, legislation furthering the inclusion of disability has been adopted, such as the Local Government Act and the Parliamentary Elections Act (for instance, of the five seats reserved in parliament for persons with disabilities, one is set aside for a woman). DANIDA is also supporting the Agricultural Development Programme through the National Agricultural Advice Service. The programme, which aims to train farmers in new techniques, includes women with disabilities in its community-based farmers groups.

**Replicability, visibility and sustainability**

With appropriate accommodations to suit local circumstances, this experience could be replicated in any part of the world.

**Main lessons learnt**

All stakeholders must engage in the project, and it is necessary to work permanently on visibilisation and awareness-raising.

Source: Experiences of Gender Mainstreaming in development work in Uganda (DANIDA)

**Case study 3: Movement for Peace, Disarmament and Freedom - actions in disability projects with gender mainstreaming**

**Budget: 3 750 000 Euros.**

**Why is this a good practice?**

Movement for Peace, Disarmament and Freedom is developing a project with the main aims of improving the living conditions, enhancing inclusion in the community and promoting the human rights of persons with disabilities in Lebanon, Jordan and the occupied Palestinian territories. The lead funding agency is AECID<sup>36</sup>. The project includes the following local partners: Health Work Committee (HWC) and Palestinian Medical Relief Society (PMRS), both in the occupied Palestinian territories; Lebanon Physical Handicap Union (LPHU) in Lebanon, and Community Development Committee (CDC) in Jordan.

The project involves a full assessment leading to recommendations on how to mainstream the gender perspective. The goal is to perform the tasks necessary to remove obstacles preventing men and women with disabilities from enjoying their rights on an equal footing with the rest of the population. The project is delivered from a human rights-based approach and includes measures to improve equal opportunities in the areas of relations, family life, motherhood, sexuality and protection from violence and abuse. In addition, it also includes steps to ensure participation in political and public life, education, training, employment and social and cultural life.

To roll out the project Movement for Peace, Disarmament and Freedom partnered with Stars of Hope (SoH), a local organisation of women with disabilities, to draw up recommendations on

<sup>36</sup> The project has also received funding from ECHO, Junta de Andalucía, Burjasott Town council, ICOMM, ONCE, Diputación de Sevilla and other local funders.

disability and gender in action, to guarantee that the specific circumstances of both women and men were taken into account in the project, and to ensure the project had a positive impact on their lives. Staff receive training in gender, methods are introduced to facilitate participation and equal access to resources by men and women, and outcomes are monitored using data which are disaggregated by sex and other gender-sensitive indicators.

#### **Achievements and tools generated**

Indicators to assess gender impact (empowerment and equality) are used in each project outcome. Helpful general recommendations for the inclusion of gender in other projects are available. A two-pronged process is used: people with disabilities are mainstreamed in all development services and activities with a gender perspective, and support is given to targeted actions for the empowerment of persons with disabilities. Furthermore, the rest of the community and other actors, such as institutions and local associations, are involved in addition to project partners.

#### **Replicability, visibility and sustainability**

The project can be replicated in any context. The project methodology for mainstreaming the gender perspective is very effective, and above all the specific indicators and the participatory nature of the project, which is a key element.

#### **Main lessons learnt**

To mainstream the gender perspective some concrete measures are needed, such as gathering data disaggregated by sex, developing tools to measure impact, employing gender budgeting and targeted budgeting to deliver measures for women's empowerment, monitoring processes and project assessment. It is essential to work with local organisations because they know the real situation on the ground, and to have the community participate in the project.

Source: MPDL Gender & Disability Study. Draft of Final Report. Submitted by Stars of Hope Society. August 30, 2010

#### **Case study 4: Spanish Confederation of Persons with Physical and Organic Disabilities (COCEMFE) - projects with gender mainstreaming for persons with disabilities**

##### **Why is this a good practice?**

The aim is to break down existing stereotypes in order to bring about improved gender interaction among all stakeholders. Since 2001, when the Ibero-American Network of Organisations of Persons with Physical Disabilities (RED in Spanish) was set up, COCEMFE has focused all its co-operation activities through RED and its member organisations, its partners in international development co-operation. RED is an organisation made up of 30 organisations working in physical disability issues from 14 Latin American countries and Spain. Its main purpose is to advocate for and represent the common interests of people with physical disabilities, and its goal is to further the capacity of its member organisations. One of the cross-cutting themes in RED's strategic plan is the gender perspective.

Projects focusing on people with disabilities have been delivered involving local seminars on gender and disability. These were attended by leaders and have led to greater capacity in the movement of women with disabilities and a realization of the need for them to come together and form associations.

Other projects have been developed to foster access to the labour market, such as a project in El Salvador which led job seekers through the entire process and offered them guidance, training and assistance for job placement. Gender is fully mainstreamed in the project. Figures for the first phase of the project indicated clearly that participation rates disaggregated by sex for the different activities were much lower for women than for men. As a result, in the second stage of the project it was vital to strengthen the gender aspect to facilitate access to the labour market for women with disabilities.

#### **Achievements and tools generated**

A gender and disability manual has been published. The guide, which includes innovative premises and a fresh conception of the scope of the gender dimension, addresses social and family violence against women with disabilities. Girls and women have been encouraged to take part in the workshops with a view to raising their self-esteem and enhancing their social development and participation skills.

#### **Replicability, visibility and sustainability**

There is an ongoing need to create capacity and assist local organisations to build up organisational structures.

#### **Main lessons learnt**

It has been a constant struggle to overcome the social, family and personal barriers preventing women with disabilities from engaging equally in any activities outwith the domestic setting, and above all in social integration and employment.

Source: information provided by COCEMFE.

#### **Case study 5: ONCE Foundation for Solidarity with Blind People in Latin America (FOAL), Latin American Blind Union and the Spanish Agency for International Development Co-operation**

##### **Targeted project for people with disabilities including the gender perspective**

##### **Latin American Blind Union (ULAC) Women's Network**

##### **Why is this a good practice?**

The aim of the project is to mobilise the necessary technical and economic resources to involve women with disabilities and their organisations in development agendas and programmes. Through co-ordination efforts and making good use of available resources, the ULAC Gender Equality

Secretariat set up a virtual network called 'ULAC Women's Network'. The network is a platform for the voices of different enterprising women who are fighting in their respective countries to strengthen the feminist movement. The goal of the project is also to promote women within their national organisations, and the total budget is 27 600 Euros.

#### **Achievements and tools generated**

As a group process, the virtual network acknowledges and strengthens individual, social and political capacities among women with visual impairment.

A study has been carried out on structural conditions which subjugate, exclude and discriminate against these women and allow inequalities, inequity and control, domination or violence on the grounds of gender. The network seeks to put forward solutions to these problems and identify strategies to tackle them.

#### **Replicability, visibility and sustainability**

Other national networks of women with visual impairment have been set up as a result of the international network. Thirty leading women with visual impairment attended an in-person course called 'The impact of blind and low vision women in public policies in Latin America' in Santa Cruz de la Sierra (AECID- Bolivia). Accessible course material was produced and the experience was repeated in Colombia, Ecuador, Costa Rica, Argentina and Mexico.

#### **Main lessons learnt**

There is a need to implement existing national legislation and the Convention on the Rights of Persons with Disabilities, while at the same time considering the demands of women with disabilities. Women should be aware of and use concepts and methodologies in the different legal systems.

Source: Information provided by FOAL and ULAC.

#### **Case study 6: 'Women and Development', international co-operation programme run by the Women's Institute.**

**Programme to promote engagement by women in all areas of development and further their full participation in all aspects of public and private life.**

**Name of the project: '*Institution building in the Circle of Women with Disabilities, and enhancing participation and social inclusion through engagement in public affairs in Dominican society*'**

#### **Why is this a good practice?**

This was a ground-breaking project submitted to the Women's Institute by the Circle of Women with Disabilities (CIMUDIS) in the Dominican Republic. The project ran from 2004 to 2007 and was

monitored and supported by the Spanish Confederation of Persons with Physical and Organic Disabilities (COCEMFE). Budget: 66 615 Euros.

The programme was part of a wider programme developed by CIMUDIS to empower women with disabilities through capacity building in the disability movement while fostering decentralised activities. Women with disabilities took part in drawing up, preparing and executing the project.

The project was aligned with many of the priorities set out by the Women's Institute in its call for proposals: the initiative came from women's organisations; it promoted networking by NGOs; its goal was to build capacity for participation in development among the target group; it contributed to strengthening capacity in civil society and to creating more robust organisations; it involved protecting and promoting women's rights; and it raised awareness in society.

#### **Achievements and tools generated**

CIMUDIS as an organisation became a far stronger institution thanks to the project. CIMUDIS membership had risen by 30% by the end of the project, it had been granted use of government premises and government financial support was increased. Its capacity to enter into partnerships was enhanced and the organisation raised its profile in society, at community level and with the government.

#### **Replicability, visibility and sustainability**

Backing from government agencies. Creation of scenarios for meetings and discussions throughout the project, which led to collective decisions to effect change. Multiplier effect. Factors were identified which enabled the beneficiary population to take ownership of the project: women with disabilities became interested in organising themselves and being part of an association was perceived as a positive element for recognition and mutual support. Participants were highly motivated and there was widespread demand to be part of it. Support was forthcoming from other organisations, not just from the disability sector.

#### **Main lessons learnt**

It is important to overcome certain tensions caused by a conflict between activism and the strategic viewpoint at organisational level —a strategic plan is required. A certain attitude among other institutions that they were assisting when giving support. There is a need to monitor and accompany newly-created groups.

Source: Information provided by the Women's Institute.

### **Case study 7: ONCE Foundation for Solidarity with Blind People in Latin America (FOAL)**

#### **Project targeting persons with disabilities and promoting participation by women with disabilities**

**AGORA Project:** Occupational Management Offices in the Latin American Region

#### **Why is this a good practice?**

The project aims to introduce people with visual impairment into the productive fabric in Latin American countries, seeking out niche employment opportunities which can be filled by people with visual impairment. To achieve this goal, units are created to assess, train and provide job placement services to promote access to the labour market. The project was executed thanks to funding from AECID, ONCE and local partners. Between 2007 and 2011 the project budget was 4.9 million Euros.

Equality was a priority throughout the project and, when it was realised that women with visual impairment were victims of greater discrimination and faced personal, family and social obstacles, positive action steps were taken to boost inclusion in the labour market. Targeted monitoring of the pathway for each woman was carried out by visiting their families and their workplaces and supporting them to avoid drop-outs. Mothers with disabilities were given special support to ensure they were able to reconcile work and family life, such as economic support for them to provide childcare while they attended training, work experience schemes and interviews.

#### **Achievements and tools generated**

Since 2007 the number of women taking part in training has increased and a higher percentage has become self-employed. Of the 576 people who found a job in 2011, 35% were women. A standard project has been developed based on ONCE and ONCE Foundation experiences in the field of access to the labour market in Spain; this can be extrapolated to Latin American with the necessary modifications to take account of local circumstances. FOAL provides each participant with a standard interview technique manual, a personalised employment plan and an on-line tool for inputting information. Experiences from the various AGORA projects can be shared at meetings and on-line.

#### **Replicability, visibility and sustainability**

Five AGORA projects began in 2006 and 13 are currently ongoing. To give the experience visibility and sustainability, a meeting is held to present outcomes every two years at AECID. Press coverage has increased since the beginning of the project, and it regularly features on local radio stations and in the written press. AGORA is present in employment fairs. Jobs in call centres and as tasters for new food products have been exported to different countries.

#### **Main lessons learnt**

Positive actions related to gender, which started out as a requirement, have helped to train our local partners, who now take on this role themselves. Micro-business projects are led exclusively by women and are highly successful because of the firm buy-in by participants. For instance in Uruguay a group of women who took part in training successfully applied for a grant to set up their own call centre to attend to customers from a bank.

Source: Information provided by FOAL.

### **Case study 8: Vicente Ferrer Foundation**

#### **Projects targeting persons with disabilities and promoting participation by women with disabilities**

#### **Mainstreaming gender in projects in literacy, social research on sign language, sport, sexual and reproductive education and social awareness in Anantapur, India**

#### **Why is this a good practice?**

Increased participation by girls and women in workshops, raising their self-esteem and developing skills to function and participate actively in society. Women with disabilities (deaf and deafblind women) have been involved in all projects carried out, participating voluntarily and running, co-ordinating and managing the projects.

#### **Achievements and tools generated**

The twelve deaf women who took part in literacy workshops improved their communication skills and raised their self-esteem. Sports activities including girls fostered more harmonious and equal co-existence and respect for values. Women with disabilities learnt about their own bodies and how to avoid sexually-transmitted diseases in the sexual and reproductive health workshops, resulting in a higher reduction in the prevalence of these diseases among the women with disabilities involved.

This was all achieved with the direct participation of women with disabilities in managing and developing the projects, producing a dual effect. The girls and women with disabilities who took part are more motivated as they consider the volunteers to be role models. There is now a greater awareness among the foundation's own staff regarding the capacities of women with disabilities. Finally, education for development took place in Spain and the women volunteers themselves presented their work at several events.

#### **Replicability, visibility and sustainability**

The aim is to ensure the projects have some type of continuity. Volunteer involvement has led to greater voluntary participation by other people with disabilities in the foundation's projects. A volunteer co-ordination department has been set up under the leadership of a deafblind woman.

#### **Main lessons learnt**

Having women with disabilities directly involved in project execution empowers other women with disabilities and makes other participants more aware of their capabilities.

Source: Activities report 2007-2010, Sign Language Unit, Vicente Ferrer Foundation.

**SUMMARY OF OTHER PROGRAMMES IN GENDER AND DISABILITY FUNDED THROUGH OFFICIAL DEVELOPMENT AID FROM SPAIN**

**Ministry of Foreign Affairs and Co-operation/Spanish Agency for International Development Co-operation, Department for Co-operation in Asia and Central Europe**

**Including disability in a general programme for women**

**Name:** Access to justice programme.

**Purpose:** Contribute to improvements in access to effective legal protection and to quality social services by women and girls with disabilities, and especially those who are victims of gender-based violence.

**Location:** Cambodia.

**Funding:** 1 000 000 Euros.

**Lead partner:** Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ).

**Expected outcomes:**

- 1 Strengthen formal and institutional legal systems.
- 2 Deliver legal counselling and social services through a finance fund.
- 3 Awareness raising and furthering behavioural shifts.

**Indicators:**

- 1) Standards and guides/procedures for service provision taking into consideration the specific needs of women and children with disabilities. Their needs are incorporated into the training curricula in relevant institutions, more specifically in the Royal Training College for Judges and Prosecutors and in the National Police Academy.
- 2) All Judicial Police officers who are appointed at national level are able to carry out their function efficiently (their mandate and duties are clearly defined, procedural guidelines are in place and in force, training programmes are ongoing and sufficient resources are provided).
- 3) Percentage increase in the number of women victims and survivors of violence who are counselled by a qualified lawyer.
- 4) Percentage increase in the number of qualified staff members delivering social services in the sphere of protection against gender-based violence.

**Ministry of Foreign Affairs and Co-operation/Spanish Agency for International Development Co-operation, Department for Non-Governmental Development Organisations (NGDOs)**

**Mainstreaming the gender perspective in a project for persons with disabilities**

**Name:** Women Empowerment.

**Purpose:** Strengthen the capacities of women who are part of local organisations of persons with disabilities to enable them to reach sufficient capacity to lead advocacy processes and defend the human, social, economic and political rights of local people with disabilities. The immediate goal of the project is to empower 800 women with disabilities socially, economically and politically. The women are members of local organisations of persons with disabilities in two districts in Bangladesh.

Indirectly, the capacity of other members of the same organisations – around 900 men with disabilities – will also be raised, and efforts will be made to increase participation by other non-organised men and women with disabilities – approximately 2 205 people. The project includes positive action measures for women with disabilities in the organisations.

**Location:** Chittagong and Chapai Nawabgonj, Bangladesh.

**Funding:** 373 745 Euros.

**Lead partner:** NGDO Cives Mundi.

**Expected outcomes:** Strengthen the capacity of women who are members of local organisations of persons with disabilities.

**Indicators:** The capacity of those women who are direct beneficiaries of the project in terms of human rights and social, economic and political participation for persons with disabilities is measured against an initial baseline assessment.

**Ministry of Foreign Affairs and Co-operation/Spanish Agency for International Development Co-operation, Department for Non-Governmental Development Organisations (NGDOs)**

**Mainstreaming disability in a general programme for women**

**Name:** Development for All.

**Purpose:** Social, political and economic empowerment for women with and without disabilities. Increase participants' self-determination by strengthening their social, political and economic capacity. The project involves Muslim communities and Garo and Hajong (two ethnic groups) from the Lengura, Nazirpur and Kharnai Unions. Beneficiaries are women with disabilities in the last two groups (80% of the group of women with disabilities) and, in Lengura Union, women without disabilities also (90% of the women identified).

The goal of the project will be met through actions in four areas:

**Social approach:** the lack of unity, organisation and information among the women involved in the project further excludes them. The project will foster the setting up of grassroots organisations as a starting point (Grassroots Disabled People's Organizations to Development, GDPOD, and Disabled People's Organizations for Development, DPOD).

**Economic approach:** the project aims to facilitate access to saving by beneficiaries through a range of activities, such as training groups to set up their own businesses, guaranteeing access to local markets for their products by carrying out a study in the region, and fostering personalised Income Generating Activities (IGA) for each participant by providing loans.

**Education approach:** activities in this area focus on enrolment in the education system by girls with disabilities. Through management committees in schools, building work to improve accessibility, teacher training in inclusive education, government commitments to make grants available to enable girls with disabilities to continue in education, and other measures, girls will be able to attend school regularly.

**Health approach:** health problems are caused by multiple factors, but mainly by a lack of information and suitable aids for people with disabilities. The project will train women in areas such as family planning and good nutritional practises with a view to giving them some basic notions in health issues.

**Location:** Netrokona, Bangladesh.

**Funding:** 385 411 Euros.

**Lead partner:** NGDO Cives Mundi.

**Expected outcomes:** increase political, economic and social self-determination among women both with and without disabilities in the Muslim communities and among the Garo and Hajong people.

**Indicators:** at the end of the project a DPOD (Disabled Persons Organizations for Development) will have been set up with representatives of the GDPOD (80% women) in the sub-district of Kalmakanda in the Netrokona district. The members will have received the training needed to manage the organisation. By the end of the project, at least 80% of the women will be aware of their rights and a training centre (Netrokona PSID Center) will have been built in Netrokona and will be ready to be used by the GDPOD members. In addition, all GDPOD will have an action plan for the next six months (technically independent) including activities to be developed.

**Ministry for Health, Social Policy and Equality, General Directorate for Co-ordinating Sectoral Disability Policies**

**Mainstreaming gender in a project for persons with disabilities**

**Name:** Course entitled 'Women with disabilities: engagement in political and public life'.

**Purpose:** mainstream gender in disability policies and empower women.

**Location:** Uruguay.

**Funding:** 8 601 Euros.

**Ministry for Health, Social Policy and Equality, General Directorate for Co-ordinating Sectoral Disability Policies**

**Mainstreaming gender in a project for persons with disabilities**

**Name:** course entitled 'The United Nations Convention for persons with disabilities: strategies to include independent living and care for people with high support needs'.

**Purpose:** mainstream the gender perspective in disability policies and empower women.

**Location:** Bolivia.

**Funding:** 4 041 Euros.

**Aragon Regional Government**

**Mainstreaming disability in a general programme for women**

**Name:** Continuity in gender-sensitive citizenship-building processes through raising capacity in grassroots social organisations.

**Purpose:** the project aimed to provide continuity to citizenship-building processes in three ways: continue to strengthen the association 'Woman to Woman'; continue to strengthen the FRATER association (Christian Fraternity of Persons with Disabilities); and strengthen administrative capacity in the Community Legal Service.

**Location:** Nicaragua.

**Funding:** 8 675 Euros and 44 623 Euros.

**Lead partner:** Aragon Solidarity Action.

**Expected outcomes:** the 'Woman to Woman' association will have consolidated its structure and internal arrangements and will take part in the women against gender-based violence network; FRATER will have strengthened its organisation through building up grassroots groups in neighbourhoods and rural communities, and will influence public policies effectively and efficiently; the Community Legal Service will work to a higher quality and more efficiently through acquiring a computer-based accounting system.

**Balearic Islands Regional Government**

**Programme for women with disabilities**

**Name:** 'Creating new fair trade crafts alongside women with disabilities'.

**Purpose:** the project involves five volunteers working on creating new handicraft products using fair trade methods, and assessment of how the handicraft workshops are managed.

**Location:** Anantapur, India.

**Funding:** 10 000 Euros.

**Lead partner:** Vicente Ferrer Foundation.

**Expected outcomes:** women with disabilities will learn to produce crafts using quality control methods.

**Valencia Regional Government, General Directorate for Immigration and Development Co-operation**

**Mainstreaming disability in a general programme for women**

**Name:** 'Improving education for women in suburban areas, indigenous women, displaced women, women with disabilities and illiterate women through the construction of module 5, Housing Area, Residence at the Phase III Tagua Centre'.

**Purpose:** the project involved building module 5 (bedrooms) in the housing area at the Phase III Tagua Centre to allow women between the ages of 18 and 21, in situations of extreme poverty and with some type of disability, to be trained. The centre will have adapted bathrooms and ramps for women with disabilities or reduced mobility. The women will be from indigenous and rural areas, and more specifically from provinces such as Chiriquí, Santiago or Coclé, home to the Kunas and Embera ethnic groups, among others. The housing area will enable access to training programmes in catering (the Tagua Centre is the main catering school in the country).

**Location:** Panama.

**Funding:** 255 000 Euros.

**Lead partner:** Iberoamérica Europa Foundation - Centre for Research, Development and International Co-operation (CIPIE).

As we can see, the projects highlighted vary enormously. One important breakthrough in including gender was the shift from a WID (Women in Development) approach to a GID (Gender in Development) approach. Additionally, another step

forward in projects for persons with disabilities was the move from a medical and rehabilitation model to a human-rights based model. Both shifts mean moving on from a welfare outlook and seeking women's empowerment as a core strategy in reducing inequities due to gender and disability. It must be said that among the projects outlined above some adopt a WID approach which helps to foster participation and the visibilisation of women with disabilities, while others are based on the GID model, which also contributes to empowering women with disabilities and promoting gender equality<sup>37</sup>.

## 6. RECOMMENDATIONS

When putting forward recommendations, we need to bear in mind that girls and women are largely invisible at all levels, so efforts are needed to move in three directions:

- Mainstream the gender perspective in development strategies, policies and programmes for persons with disabilities;
- Mainstream disability in development strategies, policies, programmes and projects involving gender;
- Mainstream gender and disability in general projects.

On the one hand, programmes specifically targeting women with disabilities are needed to reduce existing inequalities; however, it is also crucial to mainstream disability in general programmes and in projects for women's advancement. Including women with disabilities in general programmes does not always require additional funding.

It is possible to group together the focus areas for mainstreaming girls and women with disabilities in international co-operation efforts. The following is a summary of the potential action areas for policymakers and civil society:

### A) *General international co-operation, situations of risk and humanitarian aid projects*

- Raise awareness within the international community of the importance of international co-operation in supporting efforts by partner countries to realise the

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<sup>37</sup> For more information on the stages a project must fulfil to be considered a WID project, see Ministry of Foreign Affairs and Co-operation, 2007, page 29.

right of women and girls with disabilities to fully and equally enjoy all their human rights and fundamental freedoms;

- Foster in-country statistics-gathering capacity. Gender- and disability-sensitive indicators must be included to measure exclusion and, in addition, gender-sensitive monitoring is needed to set objectives for inclusion and gauge outcomes<sup>38</sup>;
- Ensure organisations representing girls and women with disabilities are actively involved, both in donor countries and in partner countries, in drawing up, executing, monitoring and assessing co-operation policies carried out at local, national, community and international level. This can be done by exchanging and disseminating information, experiences, training programmes and best practises;
- Train all stakeholders in formulating policies for development co-operation, situations of risk and humanitarian aid in equality and disability issues;
- Draw up and disseminate tools for mainstreaming gender equality and disability in development projects and programmes<sup>39</sup>;
- Funding for development programmes aimed at women and girls with disabilities must be set as a priority. Earmark funds for this purpose in general programmes and provide funding for programmes or parts of programmes for women and girls with disabilities;
- Make support conditional upon meeting certain minimum requirements in terms of gender and disability. In order to do this, official funding agencies must assess projects<sup>40</sup> to ensure disability and gender are considered or to urge countries receiving aid to adopt gender-sensitive disability plans to complement their national development plans;

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<sup>38</sup> One of the challenges faced when formulating development policies which are truly inclusive is the lack of data on people with disabilities and, in particular, on women with disabilities. The 2010 agenda for the Millennium Goals highlighted this shortcoming and called for improvements in data gathering on persons with disabilities in countries with lower economic development.

<sup>39</sup> In developing such tools it is helpful to consider the work carried out in disability by the US Development Agency (USAID) and the Finnish Development Agency ([www.stakes.fi/sfa](http://www.stakes.fi/sfa)), as well as the tools employed by the International Disability and Development Consortium (<http://www.make-development-inclusive.org/>). In terms of gender, the practical guide for including equality between men and women in Spanish development projects, published by the Ministry for Foreign Affairs and Co-operation, is recommended.

<sup>40</sup> Checklists need to be drawn up and used and application and assessment documents for programmes and projects must include specific sections on these issues.

- Donor countries, the European Union and international organisations must include the rights of women and girls with disabilities in long-term bilateral co-operation with local, national and regional authorities. In addition, they should provide direct economic support in their multi-lateral development co-operation and humanitarian aid policies through financial contributions to international organisations;
- Organisations and agencies in the United Nations system and regional governmental organisations should provide financial support and other types of assistance to NGOs and organisations representing women with disabilities in partner countries, in order to promote efforts to ensure women and girls with disabilities are able to exercise their rights on an equal basis with others;
- Protocols need to be developed and services delivered to meet the individual needs of women and girls with disabilities in situations of risk and humanitarian emergencies. These need to be made accessible by removing barriers and including steps to take quality services to rural and remote areas so that they reach those in situations of greater risk;
- Promote universal availability, accessibility and inclusiveness for all people, including women with disabilities, in micro financing facilities<sup>41</sup>;
- Visibilise local organisations advocating for human rights and using a gender, disability and development approach in their work. Facilitate discussions and seminars on these issues and support cultural events, conferences and social projects;
- Foster the use of communication platforms to spread messages about positions adopted by policymakers and social agents on issues related to gender, disability and development. Use new technologies and social networks such as Twitter and Facebook;
- Include representatives from civil society in parallel events at international gatherings on development in order to raise the profile of issues related to the rights of women and girls with disabilities.

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<sup>41</sup> One example of good practise in this respect is the work carried out by the Center for Financial Inclusion, which has started a campaign to make sure people with disabilities are ensured full access to microcredits (<http://www.centerforfinancialinclusion.org>). See also the following document: Handicap International (2004): Good Practices for the Economic Inclusion of People with Disabilities in Developing Countries Funding Mechanisms for Self-Employment, available at: [www.handicap-international.org](http://www.handicap-international.org).

B) *United Nations: recommendations*

- The newly-created United Nations Partnership on the Rights of Persons with Disabilities must focus especially on girls and women with disabilities and ensure their representative organisations participate fully in projects funded through the partnership;
- People with disabilities, and especially women and girls with disabilities, must be included in the United Nations General Assembly Resolution on the quadrennial comprehensive review of policies in the United Nations development system. This resolution is a reference document for strategic planning in those UN agencies leading efforts in developing countries;
- The Human Rights Monitoring Mechanism put in place by the United Nations Development Group (UNDG), and the new Multi-Donor Trust Fund set up to promote it, must give prominence to the rights of girls and women with disabilities. Mainstreaming the gender and disability perspective must be a requirement for all initiatives receiving financial support from the fund;
- The rights of women and girls with disabilities must be a priority in the new international framework that will replace the MDG post-2015. The High-level Meeting on Disability and Development scheduled to be held in New York on September 23rd 2013 may be a key forum to achieve this goal;
- Disseminate the UNDG/IASG guidelines on the rights of persons with disabilities and ensure they are respected. It is particularly important to have these CRPD Inter-Agency Support Group guidelines considered when preparing, monitoring and assessing the United Nations Development Assistance Framework (UNDAF), which is agreed periodically by developing countries and the UN system;
- Urge UN Women to mainstream the rights of girls and women with disabilities in their operations. To do this, the agency should draw up and adopt guidelines and set up a unit responsible for implementing and monitoring them;
- The United Nations Statistics Commission should increase its focus on statistics about men and women with disabilities to ensure data are considered in all development actions;
- The review process for the World Bank's safeguard policies, due to conclude in 2013, should adopt measures to include a cross-cutting safeguard on people with disabilities in order to guarantee that women and men with disabilities are considered in all World Bank projects;

- In its recommendations to both donor and recipient countries, the Committee on the Rights of Persons with Disabilities should highlight the rights of women and men with disabilities in relation to international co-operation activities and humanitarian emergency protocols, in keeping with articles 11 and 32 of the CRPD;
- The OECD Development Assistance Committee should heighten its focus on the rights of women and men with disabilities in actions undertaken in pursuance of the decisions reached at the Busan High-level Forum.

*C) Recommendations: Europe*

- Research on the position of persons with disabilities within Member State national development policies are needed to be able to formulate more efficient and effective strategies for inclusion, considering women and girls are more likely to suffer severe poverty;
- The gender perspective must be included in the work to update the Guidance Note on Disability and Development for European Union delegations and services in partner countries;
- Encourage EU and Member States to adhere to the principles enshrined in the 'European Consensus' and mainstream disability in their development co-operation policies, programmes and projects. Targeted projects to foster equal opportunities for women and girls with disabilities must be guaranteed;
- European Neighbourhood Policy partner countries should be encouraged to engage in protecting the rights of women and girls with disabilities through policy dialogue and exchange of experiences.
- Draw attention to the rights of women and girls with disabilities in national declarations and discussions during interactive dialogues at the Organisation for Safety and Cooperation in Europe (OSCE), as well as in OSCE commitments and decisions taken at its Ministerial Council, when appropriate.

*D) Recommendations: Spain*

Although the recommendations in this section refer specifically to Spain, they can be applied in all countries.

- Given the central role it plays in this issue, mainstream disability and gender in the development and humanitarian aid agendas of the Spanish Agency for International Development Co-operation (AECID);

- Include disability and gender in the next Master Plan as both cross-cutting and sectoral issues;
- The disability and gender movements should reflect on planning instruments for Spanish development policies (the disability movement on gender and the gender movement on disability);
- Draw up a strategic action plan on gender-sensitive disability mainstreaming in development policies, including concrete goals, timelines and an assessment methodology using objectively verifiable indicators;
- Publish a guide on gender-sensitive mainstreaming of disability and universal accessibility in development policies. Distribute the guide to all stakeholders involved in formulating, developing, initiating, implementing and monitoring development co-operation policies and humanitarian aid programmes;
- Establish a focal point for disability to promote mainstreaming and deliver technical guidance to all units and offices and other actors in the field of development, in order to ensure that projects do not lead to the creation of new barriers for men and women with disabilities and guarantee that resources are used optimally to generate wellbeing for people with disabilities also;
- Train practitioners in co-operation agencies, DNGOs and partners to enable them to plan actions in such a way that organisations representing men and women with disabilities can participate fully and effectively in planning;
- Include disability and gender as core themes in actions related to education for development and a compulsory part of university curricula and therefore part of the training for future actors in the field;
- Ensure gender-sensitive human rights defenders sit on the Development Co-operation Council. These representatives could be from organisations of persons with disabilities involved in development, independent experts or from human rights associations;
- Set up a working group on policy coherence and disability in the Development Co-operation Council;
- Include the gender and disability components in AECID's sectoral expert networks on health, the environment, gender, climate change, water and education;
- Integrate disability and gender in groups representing civil society in issues related to development co-operation, such as the Spanish Co-ordinating Body

for Development Non-Governmental Organisations, to enable them to shape development policies and to ensure disability is on the agenda.

E) *Recommendations for organisations of persons with disabilities, women's organisations, and other actors involved in civil society and development*

- Build partnerships between organisations of persons with disabilities and organisations active in gender and development so that the latter include girls and women with disabilities in their activities and the former incorporate the gender perspective;
- Introduce drivers for social innovation such as philanthropic initiatives, social businesses and businesses with a social impact to the agenda in political and business spheres and in academia to promote development and the inclusion of disability and gender;
- Foster public budget monitoring from a gender and disability perspective. To achieve this, disability and women's NGOs will need to acquire the necessary skills for the task, and other NGOs with experience in monitoring national budgets from a social perspective may be engaged to help with training;
- Work in recipient countries to train and assist local women's organisations, organisations of persons with disabilities, and other associations representing women with disabilities, in order to build capacity in their organisational structures, enhance their influence and increase their partnership-building capacity.

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