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Women with Disability across Europe: Issues on Updated and Available Data

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Abstract

The collection of comparable estimates of Women with Disability (WwD) is essential for successful policy-making, and can be directly addressed to the reduction of the barriers that WwD have to face so to achieve full participation in all aspects of their lives. In order to minimize and prevent barriers for WwD, a common policy and a research framework is needed within the European countries. Therefore, the aim of this paper is to underline the issues related to availability, type, and comparability of European data about WwD, and to suggest how to overcome some of the open needs. In particular, the International Classification of Functioning, Disability and Health (ICF) issued by the World Health Organization could be the core conceptual model for collecting data and measuring disability, acting as the basis for relevant social policies, since information at all levels on the functioning of WwD is essential for policy purposes.

Keywords: Women; Disability; Comparable data; Europe; International Classification of Functioning, Disability and Health (ICF)

International and European Mandates to Collect Data on Women and Girls with Disability

In June 2012, the Council of Europe recommended European Union Member States to ensure and develop consistent statistics and data for people with disability, in particular women and girls [1]. The Council underlined the need to produce information on people with disability in accordance with the United Nations Convention for the Rights of People with Disability (UNCRPD) and with the biopsychosocial framework of the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) [2,3]. The biopsychosocial model of health and disability defined in ICF describes disability as a multi-dimensional phenomenon: as the interaction between the features of the individual's health status and the features of his or her physical, social and attitudinal environment. It makes ICF a framework for documenting the interaction between a person's health condition and the contextual factors surrounding him/her and uses an internationally comparable language; so that difficulties in functioning and disability can be conceptualized and operationalized [4].

The codification, collection and analysis of consistent information about health and disability is important in order to construct and implement policies which promote the rights of persons with disabilities, as it has been recognised at an international level by the Article 31 (about Statistics and data collection of the UNCRPD). According to this Article: "States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" and shall assume the responsibility for the dissemination of these statistics [2].

Usually, disability population surveys include a small number of items related to functioning (e.g. activities for daily living – ADL) and inquire about a limited number of impairments (i.e. physical or mental disabilities), which makes it difficult to identify persons with disability, for example, associated with mental or substance abuse disorders (for a detailed and comparative analysis of European surveys on the situation of people with disabilities see [5]). In addition, disability surveys include questions that are not easily or directly connected to population health surveys, so it is difficult to link health status to impairment and to identify the role of environmental factors in participation across different activities. Therefore, it is extremely difficult to identify the

impact of demographic data (e.g., age, gender) or social changes (e.g. legislation, policy, lifestyle, gender role) on disability [6].

The importance of disaggregating data is also highlighted by the abovementioned Article 31 stating that "the information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights". In accordance with the same source, State Parties are called to promote and safeguard anti-discrimination of women with disability (WwD) by ensuring: their equal and full enjoyment of their fundamental freedoms and human rights (Article 6), and their access to social protection and poverty reduction programmes (Article 28). EU ratified UNCRPD in 2010 as well as the Governments of the 27 member countries did, in different periods, from 2007 to 2012 [2].

The collection of comparable estimates of WwD is essential for successful policy-making, and can directly address the barriers that WwD confront in order to achieve full participation in all aspects of their lives [7]. Regarding demographic data, these are particularly important considering that the European population is an increasingly ageing population with a higher number of individuals with chronic diseases, the so-called compression of morbidity. Thus it can be assumed that the number of people with disabilities will raise in the years to come. Gender perspective at all ages is crucial to understand the health of a population as well as for policy development [8].

In order to minimize and prevent barriers for WwD, a common policy and research framework is needed within European countries (both EU and non-EU members), therefore, the aim of this paper is

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to underline issues related to availability, type, and comparability of European data about WwD, and to suggest how to overcome some of the open needs raised in conjunction with the usefulness of the ICF framework to respond to UNCRPD mandate to have data on women and girls with disabilities. For this purpose, data from existing official reports are explored as well as their definitions of disability, highlighting the necessity for comparable data on WwD across Europe and the contribution of the ICF to potentially solve this important issue.

Women with Disability: Prevalence from European and International Studies

Women are about 3 billion out of the 6.9 billion of the total world population, while European women stand at 256 million out of 502.5 million of people in Europe [9,10]. Also, 10% of women in the world – approximately 300 million – are defined as WwD as they present physical, mental, intellectual and/or sensory impairments, while in conformity with the most recent data, the percentage of WwD in Europe is 3.8% of total population (approximately 16.2 million) and about 21.5 million of men with disabilities (5.01% of total population) [11,12]. These data come from a recent study supported by the European Community Programme for Employment and Social Solidarity that collated data on Europeans with disabilities from 33 different countries thus producing a detailed report on WwD. This report highlights national available data, source, year of collection and prevalence. Furthermore, the proportion of WwD aged 16-64 is 15.6%: 3.1% of women between 16-24, 8.4% between 25-54, and 18.8% between 55-64. These percentages are slightly lower than those of men with disabilities, who represent 16.2% of the total population: 3.6% in the age group 16-24, 8.3% in group 25-54, and 22% in 55-64 range. The report stresses also the lack of a common data source and a time frame at European level for the collection of data on disability, underlined by the lack of a common definition of disability across Europe. About this, a recent USAID report on thirteen Europe and Eurasia regions (Albania, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Georgia, Kosovo, Republic of Macedonia, Moldova, Montenegro, Russia, Serbia, Ukraine) summaries a gender analysis of issues faced by people with disabilities [13]. Again, it emerged that the incidence of WwD is not always available from every country analysed, and data are not comparable because of the lack of a single definition for disability or due to the difference of definitions used in data collection.

Generally, available data on European WwD vary considerably among countries, though they were collected through pan-European surveys and were based on self-reports rather than on objective measurements such as definitions and classifications used by Member

States. This may have occurred because the concept and the definition of disability used by different countries in different surveys vary (Table 1) (for more details on measures used for measuring disability in Europe see and [14,15]). Consequently, Europe needs a common definition for disability to break such measurement barriers.

There are also other more recent European data on disability such as those provided by the European Health Interview Survey (EHIS) and those by the European Survey on Health and Social Integration (ESHIS) study which was implemented in 2012 [8]. These two studies are part of an EU project launched in the last decade whose purpose was to obtain comparable data from the 27 Member States on health and disability through surveys [16]. Both the abovementioned studies considered the biopsychosocial model of the WHO ICF classification [3].

To get an overall view on the statistics of the topic under discussion, it is also useful to mention worldwide available data that also present prevalence of the European WwD. Data on WwD have been presented, as well, in the World Report on Disability 2011 [7]. This report, which was produced jointly by WHO and the World Bank, has focused on the prevalence of estimates of disability based on two data sources: the WHO World Health Survey (WHS) of 2002-2004 that involved 59 countries¹ – representing 64% of the world population – and the WHO Global Burden of Disease (GBD) study of 2004 [17,18].

In order to divide the sample into: “with disability” and “without disability” population groups, in the WHO WHS, threshold values (cut-off points) were created by WHO in the World Report. A cut-off point of 40 on scale of 0–100 was set to include estimates of disability, those experiencing great difficulties in their everyday lives; while a threshold of 50 was set to assess the rate of persons experiencing greater difficulties [8]. As reported by this study, in 59 countries across the world the average disability prevalence in adults who experienced major functioning difficulties in their everyday lives was 15.6% (about 650 million people of the estimated 4.2 billion adults aged 18 and older in 2004). The female population with a threshold of 40 was 19.2% (moderate disability) and 2.7% with a threshold of 50 (severe disability), while male population was 12.0% and 1.4%, respectively. In the GBD study, the estimated prevalence of moderate and severe disability was 15.3% of the world population (about 978 million people of the estimated 6.4 billion in 2004). In accordance with this data, world disability prevalence for women with “moderate”

¹ Of the participating countries, 27 were European: Austria, Belgium, Bosnia and Herzegovina, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Ireland, Italy, Latvia, Luxembourg, Netherlands, Norway, Portugal, Russia, Slovakia, Slovenia, Spain, Sweden, Ukraine, and United Kingdom.

Country	Definition of Disability	Source
Austria	Disabled persons are those who are not able to sustain regular social relationships, acquire and perform gainful employment and achieve a reasonable and adequate income without assistance.	Microcensus, 2002, Statistics Austria http://www.coe.int/t/e/social_cohesion/soc-sp/7th%20edition%20legislation%20e%20in%20color.pdf
Poland	A disabled person is a person whose physical, psychic or mental status permanently or temporarily impedes, limits or makes impossible the fulfilment of his/her social roles (and in particular ability to perform work), provided that his or her disability has been legally confirmed.	The Act on Vocational and Social Rehabilitation and Employment of Disabled Persons of 27 August 1997. http://www.coe.int/t/e/social_cohesion/soc-sp/7th%20edition%20legislation%20e%20in%20color.pdf
United Kingdom	A person to be disabled if he/she has a physical or mental impairment which has a substantial and long-term adverse effect on his/her ability to carry out normal day-to-day activities.	Smith, A. and Twomey, B. (2002) Labour market experience of people with disabilities, Labour Market Trends, vol. 110, no 8 http://www.ons.gov.uk/ons/search/index.html?newquery=smith+Twomey
Italy	A disable person is a person with severe difficulty at least in one of the following dimensions: difficulty in movement, difficulty in daily activities, difficulty in communication skills (sight, hearing or speaking).	ISTAT (Italian National Institute for Statistics) Persons with disability in Italy 2010. http://www3.istat.it/dati/catalogo/20100513_00/arg_09_37_la_disabilita_in_Italia.pdf

Table 1: Example of variety of definitions of disability used in European surveys.

disability was estimated to be 0.7% for girls from 0 to 14 years, 2.6% for women from 15 to 59 years, and 9.8% for women of 60 years and over. Furthermore, the estimated prevalence for "moderate and severe disability" was 5% for girls from 0 to 14 years, 15.7% for women from 15 to 59 years, and 46.3% for women of 60 years and over. Due to the different approaches used during data collection, both the European and the world prevalence of WwD mentioned above are, unfortunately, not comparable.

Implementation of the Icf in Research on Women with Disabilities

The biopsychosocial framework of the ICF, providing a universal common language across sciences and disciplines, has been used in various studies mainly aiming in exploring the association of their subjects to functioning, disability and health, both at theoretical or practical level. The ICF has been used in qualitative research [19] in order to map narratives of women with spinal injury to the ICF framework, showing that elaboration of the personal factors and their inclusion in the ICF classification would contribute to capture information on categories such as biography, stress appraisal, coping strategy and self-understanding. Another qualitative study [20] has used the ICF in order to explore personal and social effects of women with Rheumatoid Arthritis that live under poverty, and from its results the ICF has been proven a useful framework in order to understand and describe these complex experiences. Additionally, another study [21] conducted a cross-country qualitative study with focus groups of patients with hand osteoarthritis (51 of the 56 patients included in the study were women). They used an ICF-based mapping process in the initial steps of the data analysis in order to combine qualitative data from different countries using a common language before proceeding to the final step of their analysis [2].

Moreover, Scherer and DiCowden [23] performed a study on the use of the ICF in research and service provision for WwD: they concluded that ICF has an important practical application for evaluating interventions and they identified the use of the ICF as useful to recognise and emphasise more on Activities and Participation within interventions, suggesting that future research should focus more on the diverse social and psychological concerns of women.

A cross-sectional study [24] investigated those aspects of health which differ between working women with Fibromyalgia (FM) and nonworking women with FM. The sample, (129 women of working age with FM), completed a battery of questionnaires aimed at studying personal and environmental factors, body function, activity and participation factors and elements in overall health status. Thanks to the ICF biopsychosocial approach, this research examined the health of women with FM condition and the possible influence of environmental factors on their health status. A more recent study detected the importance of investigating the social domain, and its influence on the physical sphere, conforming to the ICF biopsychosocial approach [25]. Authors used the ICF in order to investigate possible associations of the different ICF disability domains with mortality and results suggested that improving complex activities or social participation, the risk of dying might decrease. These studies, as well as many recent research trends, show the importance of a holistic approach so as to be able to evaluate all personal and environmental factors when describing disability.

Data about Life Areas of Women with Disabilities

As reported in the scientific literature and in various reports and

European recommendations, WwD are particularly disadvantaged in many areas of life when compared to women without disabilities (inter alia [26, 12]). We believe it is useful to understand which these areas are that WwD disadvantages using the main themes proposed by [7] in the report realized in co-operation with the Drafting Group on Discrimination against Women with Disabilities. These themes/areas, based on previously published European reports and recommendations, are: Education and training; Employment; Social policy; Participation and access to decision-making; Sexuality; Prejudices and social representation; Motherhood, family and domestic life; Violence. These areas have been adopted as relevant to WwD for monitoring purposes by the Committee of Ministers, Council of Europe, which has recently added to those, also: Participation in culture, Sport, Leisure and tourism for WwD, and Raising awareness and changing attitudes towards WwD (e.g. in order to combat stereotypes and prejudices) [1]. Most of the information/data on the identified areas are missing and are not being collected consistently at national or at European level. European data on issues relevant for WwD are available at the moment only on Education, Employment and Violence.

Education and Employment are both matters of vital importance for the independence of WwD, and the two factors are closely interlinked. Most recent information on levels of education of persons with disabilities has been provided in the final report published by the DG Employment, Social Affairs and Equal Opportunities [27]. The study was based on the following sources of data: the European Union and 2002 Labour Force Survey (LSF), and the EU Statistics on Incomes and Living Conditions (EU-SILC) [28]. The report has shown a clear inverse relationship between having a long-standing health problem or disability that limits and restricts the ability to work and the level of education, as well as the level of access to education and employment. The effect of restrictions or limitations seems to be more pronounced for women than for men, with a percentage respectively of 53.7 and 34.4 of low education attainment levels for European women, and of 47.6 and 30.1 for European men (considerably restricted or without restrictions), with large differences among Member States. As regard to European data on employment rates of WwD, the report indicated that while the differences between men and women who were considerably restricted were small, 33.4% for men and 30.4% for women, if we consider the gap between men and women without restrictions, the figure was much higher for men, with 89.9% for men without restrictions, and 69.4% for women without restrictions. This is because men's employment rates are in general higher than women's.

Finally, as regards the issue of violence against women, [7] has argued that violence can have different forms: active, meaning to be expressed in words or actions, or passive, for example when food is not administered to a woman who is unable to feed herself, or when a woman is not allowed to lead a normal life. It can be estimated that of 250 million women in Europe, 40 million have disabilities (16%) and of them about the 50% has suffered some kind of violence, against 30% of women without disabilities [29]. However, according to a European Parliament report [30], about 80% of women with disability are exposed to the risk of psychological and physical violence, while the risk of sexual violence is greater for them than for other women. The European Union Agency for Fundamental Rights [31] has been conducting an EU-wide survey on violence against women that involves a sample of 40,000 women across the 27 EU Member States.

The Need for Comparable Data on Women's Health and Disability: Implications and Recommendations

Based on all above, up-to-date worldwide comparable data about

functioning and disability are not available, including data on WwD [7]. The main reason is the current existence of various definitions for disability referring to the same purpose, and the lack of a consistent, common underlying model of disability. Across Europe there is an evident need for measurement methods in the health and disability sector towards a common understanding of the distribution and types of impairments of individuals and populations, as well as of levels of disability at population levels. European data on disability, in general, and on women and girls with disabilities, in particular, have not been gathered in a consistent way since there are countries which define disability in terms of the level of performance in employment/labour market or other social activities, whilst other countries define disability based only on medical or rehabilitation-based terms. These definitions are inconsistent between countries but also between policy sectors in the same country [14]. Within the employment sector, for example, European policies have been undermined by the lack of comparable data on prevalence of disability and employment of people with disability in Europe [28,32].

To respond to UNCRPD there is the necessity to have a common and shared theoretical framework of disability. Without valid and reliable information, it is impossible to design, implement or evaluate policies and legislation, to combat discrimination and to promote social integration, participation and enhancing opportunities. To remedy this lack, the WHO proposes the use of ICF as a starting point for a common definition of disability [3, 33]. Defining disability as an interaction, as supported by ICF, means that policy makers can act both at the environmental level and the individual level, thus making disability a dynamic experience [10]. Regarding WwD and the need to have gender oriented data (as suggested by UNCRPD), the ICF biopsychosocial model is suitable for collecting data, measuring disability, and acting as the basis for relevant social policies, since information on all levels of the functioning of WwD is essential for policy purposes. Subsequently, more work should be done by Policies in order to coordinate and integrate the concept of disability at all policy levels, plus, to create suitable definitions in accordance with the consistent and complete underlying conception of disability included in the ICF [34].

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