

## **ABOUT THE FORUM ON STUDIES OF SOCIETY**

The first edition of the **Forum on Studies of Society (FSS) International Conference on Social Sciences and Humanities** was organized by the University of Craiova, Faculty of Social Sciences, Specializations: Sociology and Social Work, Romania, in co-operation with National College of Social Workers-Branch Dolj, Faculty of Sociology and Social Work, Department of Social Work, University of Bucharest, Romania, Faculty of Philosophy and Faculty of Economics, St. Cyril and St. Methodius University, Bulgaria and Faculty of Science and Literature and Faculty of Economics and Administrative Sciences, Süleyman Demirel University, Turkey and The Off-Campus Faculty of Law & Social Sciences in Stalowa Wola, The John Paul II Catholic University of Lublin, Poland.

The purpose of the Conference was to create a forum for debating topics of great interest to society, thus, trying to expand the network of interested stakeholders and extend the ground for best practice exchanges from different institutions and various domains.

The Conference aimed to bring together already involved key actors as well as engaged participants, representatives of academic, economic and social partners to discuss and exchange their experiences and research results on different aspects of Social and Humanistic Science. Based on the multi-field methodology-encompassing, inter-disciplinary character of the Conference, we strongly encouraged potential participants and stakeholders with background and research interests in the fields of Sociology and Social Work, European Studies, International Relations and Security. There are currently numerous challenges to be tackled in approaching past and present subjects on society.

The rationale for the Conference relied on initiating reflection and launching debates on the following main topics: Sociology and Social Work, European Studies, International Relations and Security Studies, Political Sciences, History and Philosophy.

The conference sessions for paper presentations were as follows:

- Session 1: Sociology: “New social realities”
- Session 2: Social Work: “Social workers towards an undivided humanity”
- Session 3: European studies: “United in diversity”
- Session 4: International Relations and Security Studies: “Towards a new world order”
- Session 5: Political Science: “Europeanization, policy-making and institutional change”
- Session 6: History: “History and Politics through time”
- Session 7: Philosophy: “Contemporary Philosophical Issues”

The Conference sessions welcomed papers approaching theoretical studies and empirical research, good practice examples or lessons learnt in practice.

Aiming to create a space for discussing different approaches related to social sciences and humanities, the conference included over 120 communications from 140 participants representing 8 countries.

The international conference Forum on Studies of Society (FSS) was included and indexed in 7 international databases and services:

- **Elsevier**, Global Events List:

<http://www.globaleventslist.elsevier.com/events/2016/03/forum-on-studies-of-society-fssinternational-conference-on-social-sciences-and-humanities>

- **GoREF**, Indexed Conferences:

<http://goref.ro/conferences-and-proceedings/goref-index-conferences/>

- **Conferences International**:

<http://conferences-in.com/conference/romania/2016/europe/forum-studies-society-fssinternational-conference-social-sciences-humanities/>

- **Conference Index**: <https://index.conferencesites.eu/conference/9068/forum-on-studies-of-society-fss-internationalconference-on-social-sciences-and-humanities>

- **Web of Conference**:

[http://www.webofconferences.org/index.php?option=com\\_conference&task=search&type=conference&lang=en](http://www.webofconferences.org/index.php?option=com_conference&task=search&type=conference&lang=en)

- **Conal. Conference Alerts**:

<http://www.conferencealerts.com/show-event?id=168449>

- **Scientific Indexing Services (SIS), USA**:

<http://www.sindexs.org/Conflist.aspx?ID=525>

Over 50 employees in the fields of sociology and social work also attended the sessions of the Conference, and were involved in the debates occasioned by the Forum on Studies of Society.

We provided the authors with the opportunity to publish the results of their research in scientific journals indexed in international databases and collective volumes. Some papers have been published in the partner journals and another part in the present volume.

The coordinators

# Disability and Home Care of Persons with Disability (PWDs) in Turkey

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## Abstract

Policies towards the persons with disabilities (PWDs) started in the 1970s and the disability movement opened up approaches and service models on disability for debate. This change also caused a turn in understanding disability as a matter of citizenship and equality beyond just a matter of care and rehabilitation. As a result, a social model evolved in which the PWDs as individuals are considered to have independent lives as citizens with some basic rights. In Turkey, disability became a topic for discussion as impairment at the end of the 1990s, shaped by the medical model. In the 2000s, home care income support programs for the PWDs and their needy families were developed. Especially after the disability law enacted in 2005, family based home care seems to have replaced institutional care. In fact, the Ministry of Family and Social Policy started to provide income support to the families and relatives caring the PWDs at home in 2006. In 2014, one out of every twenty PWDs (a total of 418.645) received home care. However, there is not any comprehensive research on how identity is socially constructed among the people giving home nursing care to the PWDs and the PWDs themselves. The subject matter of this study is to explore the social construction of identity among the PWDs cared at home and their needy family members or relatives providing home care to them. The process of the social construction of identity among the PWDs takes place basically in families and related social environment in which they are cared for. The social environment in which the PWDs live, the relationship between the normal people (the care takers) and the disabled and the determinants of this relationship, opportunities and resources shape the care taking of the PWDs at home.

**Keywords:** *disability; home care; medical model; social model; identity; Turkey.*

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## 1. Introduction

Disability is a multi-dimensional and complex issue. Disability experience as a result of the interaction of health conditions, personal, social and environmental factors varies greatly from one person to another. The percentage of the persons with disabilities (PWDs) in the world population in 1970 was 10% but it went up to 15% in 2010 (WHO 2011: pp. 3-4). More than one billion people in the world live with some form of disability, nearly 200 million of whom experience considerable difficulties in functioning, live with various types of disability, and struggle with different types of

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discrimination. Across the world, people with disabilities have poorer health outcomes, lower education achievements and economic participation and higher rates of poverty than persons without disabilities. This is partly because people with disabilities experience barriers in accessing services that many of us have long taken for granted, such as health, education, employment, transportation as well as information (WHO 2011: p. xi).

Although it is difficult to describe disability, WHO (2011) sees disability as an umbrella term, “covering impairments, activity limitations, and participation restrictions.” An impairment is a problem in body function or structure. Yet, an activity limitation is a difficulty encountered by an individual in executing a task or action and a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is not just a health problem but a complex phenomenon, reflecting the interaction between features of a person’s body and the society in which he or she lives.

Overcoming the difficulties faced by the PWDs requires interventions to remove environmental and social barriers. It means that the PWDs have diverse personal factors with differences in gender, age, socioeconomic status, sexuality, ethnicity, or cultural heritage. Therefore, people with disabilities have some similar health needs as non-disabled people (immunization, cancer screening etc.). Yet, they have further social, economic and health needs due to the fact that they experience increased risks of poverty, social exclusion, and extra health problems. Besides; evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings (WHO 2016).

## **2. Shift from the Medical Model to the Rights Based Social Model**

Until the 1960s the medical sociological approach was widely embraced. The medical perspective emphasized the biological roots of disabilities, and situates the ‘problem’ within the individual. The impaired people were seen as ill and offered medical help. The aim was to rehabilitate the impaired and make them “normal people” like the others. (Oliver 1990; Thomas 2011) The medical approach to disability has fostered artificial divisions within the disabled population. At the end of 1960s, this was accepted as the stigma and caste of second-hand citizenship and the incorrect judgement of social inferiority (Oliver and Zarb 1989; Oliver 1990). So policies towards the PWDs started in the 1970s and disability was not seen simply as a purely medical problem anymore.

The disability movement, started during the late 1970s and early 1980s and spearheaded by disabled activists and academics predominantly based in the United Kingdom and the United States, opened up approaches and service models on disability for debate. In the context of post-Fordist economy, the disabled formed themselves into a new social movement, and waged a struggle for emancipation from social oppression and exclusion. People are viewed as being disabled by society rather than bodies. It is also the same for the people with impairments who do not conform to mainstream expectations of appearance, behaviour and/or economic performance (Finkelstein 1980; Oliver 1990). Thus, the issue of disability has been transformed from a purely medical problem to a political one and social model. This change has caused a turn in the understanding of disability as a matter of citizenship and equality beyond just a matter of care and rehabilitation (Finkelstein 2007).

The disability movement has successfully politicised social and physical space by drawing attention to the ways how dominant values and practices in society have impacted the lives of and opportunities for the PWDs. Besides, the challenge to disablism, oppression and exclusion has produced the new politics of disablement which includes, as its intellectual expression, the social model of disability. A rights-based social model has evolved seeing the PWDs as individuals who can live independent lives as citizens with basic rights (Oliver 1990 and 2011; Thomas 2011). The fundamental assumption underpinning the social model approach is that people with impairments are disabled and excluded by a society that is not organised in ways that take account of their needs (Finkelstein 1980; Oliver 1990 1996).

In social model, differentiated impairment and disability are seen as an important issue. *Impairment* is the functional limitation of an individual's capacity, ability and movement caused by physical, mental or sensory impairment. Disability is the loss or limitation of opportunities to take part in the normal life of the community on a fair level with others due to physical and social barriers (Barnes 1991; Tregaskis 2002). Thomas (2011) pointed out that it is not impaired persons that have to be repaired and changed but rather the type of social and spatial organization and social, cultural, mental and physical obstacles that have to be removed. In addition, the social model offers an analysis of the role of culture in creating and maintaining exclusion of the PWDs (Barnes 1991; Hevey 1992; Shakespeare 1994; Burcu 2006). Especially the exclusion of the PWDs and disability are the creations of cultural practice, in that we learn in our family or society and from one another how to categorize and even stigmatize people as the same/different or normal/abnormal. As Barnes (1996: p. 51) stated, we need to see current social responses to impairment as the cultural product of the interaction between the means of production and central societal values. This is also accurate with regard to the use of negative imagery in media and in literature portraying differences as unacceptable, evil, or a punishment from the God (Thomas 1982, Barnes 1991, Hevey 1992).

The social model proposes to take into account impairment as an important issue in the lives of the disabled because this would help to develop a strong argument about social structures and social processes (Shakespeare and Watson 1997: p. 298). Thus, in sociology, disability is considered as a product of sociological construction process rather than impairments in a body. In other words, disability is a process in which a disabled person views oneself from the eyes of normal others and embraces his or her status as disabled and disadvantaged. In sociology, the cultural and mental obstacles are focused upon in addition to hegemonic social institutions, and inclusive and exclusive practices and rituals in order to help to overcome mental, social and cultural barriers (Barnes 1991; Shakespeare and Watson 1997). For instance, social constructionists as Prestley (1991) stressed the role of culture in the formation of attitudes. Thus, disability is considered as socially and structurally constructed rather than as a product of individual interactions between people with and without impairments.

### **3. International Regulations on Disability**

Shift from the medical model to the rights based social model has also had impact on the international efforts to overcome obstacles before the integration of the disabled into society. Especially since 1980's some international organizations, such as the EU and UN, have accepted and used social model, and have taken a leading role in this

shift in understanding of disability, disability rights and the disabled; in the enhancement of medical and other social services for the PWDs; in the fight discrimination against the PWDs and the development of related anti-discrimination programs for the PWDs. In the case of Turkey, Turkey's relationships with international organizations such as the EU and the UN have functioned as an anchor to adapt rights-based approaches in Turkey and, thus, disability has become a matter of social and political rights especially since the mid-1990s (Bezmez 2013: p. 110).

In fact, the history of international regulations on disability could be traced back to Article 25/a of the 1948 Universal Declaration of Human Rights (UDHR), and the 1965 Council of Europe's European Social Charter (signed by Turkey in 1989 with some reservations). Later came the 1976 International Covenant on Civil and Political Rights, ILO's 1983 Convention concerning Vocational Rehabilitation and Employment of Disabled Persons, and the 1986 UN Declaration on the Right to Development have played an important role to improve disability rights. Over 40 countries have accepted to the World Programme of Action Concerning Disabled People (1982), the Convention on the Rights of the Child (1989), and the Standard Rules on the Equalisation of Opportunities for People with Disabilities (1993) in the 1980s and 1990s.

The Convention on the Rights of Persons with Disabilities (UNCRPD), adopted on 13 December 2006 by the United Nations General Assembly and entered into force on May 3, 2008, is the first international human rights treaty specifically related to the rights of people with disabilities. The UNCRPD outlines the civil, cultural, political, social, and economic rights of the persons with disabilities, and includes measures to facilitate providing persons with disabilities full and equal rights within the scope of anti-discrimination principle. It also promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity (WHO 2011: pp. 8-9).

In accordance with the UNCRPD, many states have taken steps to recognize the human rights of persons with disabilities. Turkey was one of the first countries to sign the UNCRPD. Being the first and only international instrument with binding provisions, the UNCRPD was signed by Turkey on 30 March 2007. The Convention was ratified and thus enacted by the cabinet on 27 May 2009. Since the date of ratification, the Convention has been taken as a basis in disability policy of Turkey (MFSS 2013: p. 2).

The European Union also joined the Disability Rights Convention by signing the treaty in March of 2007. However, as of 2015, 11 of the 27 EU members have yet to ratify the convention, including Turkey, Bulgaria, Cyprus and Romania, although all have signed. The UN Convention on the Rights of the Persons with Disabilities has the potential to create a "paradigm shift", (as understood by Thomas Kuhn), in the manner in which disability policy and practice is formulated (Lang 2009: p. 283).

#### **4. Situation and the Rights of the PWDs in Turkey**

Total number of the PWDs in Turkey is around 10 million (12.8 % of the population). 18% of the PWDs have more than one type of impairments. 20% are considerably restricted. 58.6% of the disabled are men while 41.4% are women. 56.8% of the disabled have impairments due to diseases (TÜİK 2011). 35% of the people aged over 75 have disabilities. The PWDs in Turkey are classified accordingly: 29.2% has mental retardation; 25.6% chronicle diseases; 8.8% orthopedic or physical disabilities; 8.4 % visual impairments; 5.9% hearing impairments; 3.9 psychological problems; and 0.2 speaking impairments.

Illiteracy rate was 36.3 % for the PWDs in 2010 as opposed to 12% for general population. 45 % of the disabled have only primary level education, 6 % secondary level, and 7 % high school level. Only 2.4% of them have a university level education. The employment participation rate for the male disabled people was around 33% but only around 20% of them were employed in 2002. This figure radically differs according to gender. It was 32% for the disabled men whereas it was only 6.7% for the disabled women.

Employment rate of the disabled was 25.6% in urban and 17.8% in rural areas in 2002 and no recent data is available. In 2002, over half of the disabled people did not have any social security but that figure has improved over the years. Besides, 75% of 31 thousand disabled people who have applied to İŞKUR (the Public Employment Organization of Turkey) for placement on a job do not have any occupational skills in 2012. The number of the PWDs employed in public institutions increased from 5.777 in 2002 up to 32.021 by June 2013 (MFSS 2013: p. 7).

These numbers show that a great majority of the PWDs in Turkey has not employed and they are cared for by their families. Poverty increases the risk of disability so poor families are provided social aid by government social safety programs. In retrospect, disability has been considered together with poverty and as the responsibility of the family. Disability has been handled on the base of a protective approach combined with a voluntary philanthropy and religious solidarity. In the 19th century, private education institutions were also involved in social aid to people who were disabled, orphan or deserted. After the World War II and Korean War, regulations on pensions for veterans were enacted. In 1976, social benefits given to persons with disabilities who were not able to work or could not find a job in accordance with the law numbered 222, some cash and health assistance was provided for the disabled as well as the lonely and needy elderly who were over the age of 65.

The UN announced the year of 1981 as the International Year of Disabled Persons for “full participation and equality” of the PWDs. The UN brought disability to public attention as a matter of political debate and called for a plan of action at the national, regional and international levels, with an emphasis on equalization of opportunities, rehabilitation and prevention of disabilities. Then, the UN declared the 10-year period from 1983-1992 as the Decade of Disabled Persons to provide a time frame during which Governments and organizations could implement the activities recommended in the World Programme of Action.

Turkey also declared the same period as “the Decade of Disabled Persons” and the problems of the disabled were brought forward and discussed. The Law on Social Services numbered 2828 and enacted in 1983 specified the types of social services to be provided to protect the PWDs. It also established the Bureau for the Disabled People under the Social Services and Child Protection Agency, which had the responsibility to help and protect the disabled people by creating “Care and Rehabilitation Centers”. Under the Ministry and Labor and Social Security, the National Coordination Committee on Protecting the Impaired was established.

Accordingly, disability as impairment has become a topic for discussion at the end of the 1990s and 2000s in Turkey. In the policies on disability adopted by AKP governments in recent years, there seems to be three basic characteristics (Bezmez 2013: p. 100). These characteristics are: