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EP Interest Group on Rheumatic and Musculoskeletal Diseases
Meeting IG-11-18/06/2013
New European disability law: Does it help people with chronic diseases?
MINUTES

EDITE ESTRELA (MEP from Portugal, Chair of the Interest Group)

“Welcome and Introduction”

Ms Estrela thanked the speakers and other participants for attending the meeting. She stressed the importance of the Interest Group (IG) for providing MEPs with relevant information on the individual, social and economic consequences of rheumatic and musculoskeletal diseases (RMDs). She also pointed out that the activities of the IG help to promote the debate between MEPs, other EU institutions and stakeholders on how the EU institutions can better contribute to address issues, such as the implementation of persons with disabilities into society. She remarked that the European Disability Strategy 2010-2020 is providing comprehensive framework for the creation of a barrier-free Europe.

JOHAN TEN GEUZENDAM (Head of Unit Rights of Persons with Disabilities, DG Justice – EC)

“EU disability policies: current developments and forthcoming actions”

Mr Ten Geuzendam gave the insight from the European Commission’s work on disability policies. He mentioned that the legal structure is building up on the United Nations Convention on the Rights of Persons with Disabilities. Hence the European Disability Strategy 2010-2020 and the forthcoming European Accessibility Act are in line with the Convention. Main purpose of the strategy is to harmonize the national disability policies and make them conform with the Convention. It was mentioned that the European Accessibility Act will be finalized by the end of September and it will include all mainstream products and services. As the negotiations are still on-going, no further details were revealed. Further, Mr Geuzendam indicated that not only the persons with disabilities, but also the Member States and the industry will benefit from the provisions of the Act.

ÁDÁM KÓSA (MEP from Hungary, Chair of the EP Intergroup on Disability)

“Can the EU do more for people with disabilities?”

Mr Kósa introduced the activities of the EP Intergroup on Disabilities and welcomed further cooperation with the Interest Group on RMDs. In his opinion, it is not clear whether chronic diseases





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should be classified as a disease or as a disability. Since deaf people are using their hands as a communication tool, being not able to properly move them can be regarded as a disabling condition. Therefore, he sees commonalities between the works of both groups. Further, a link between the ageing population and disabilities has been established. By 2050 one-third of the population will be over 60, therefore research on ageing and disabilities should be prioritized. All in all, Mr Kósa believes that the European Accessibility Act will not exclusively address the persons with disabilities but will be beneficiary for the whole society.

RUDI KENNES (Flemish Agency for People with Disabilities)

“Long term developments in EU disability policies: The Belgian perspective”

Mr Kennes introduced the Flemish perspective on the implementation of the disability legislation, pointing out that a concept paper on a new policy for persons with disabilities had been recently approved by the Flemish government. The new legislation should distinguish between two kinds of entitlements, depending on the need for either regular or specialized assistance services. He further made a connection between chronic diseases, such as RMDs and disabilities, elaborating on the presentation of Mr Kósa in regards to the definition of disability. According to Flemish Agency for People with Disabilities, the total functioning of the person in society should be also considered when classifying for the disability benefits.

DR. ROBERTO BERTOLLINI (Chief Scientist and WHO Representative to the EU)

“The WHO perspectives on disabilities”

Dr Bertollini talked about the *“Resolution on Disability”* which was adopted at the World Health Assembly in May 2013. The resolution calls for better health care for people with disabilities by endorsing the recommendations of the 2011 World report on Disability. The resolution encourages Member States to ensure that all mainstream health services are inclusive of people with disabilities; provide more support to informal caregivers; and ensure that people with disabilities have access to rehabilitation services that they need in order to develop, maintain or improve their functional abilities. A consultation process on the Action Plan that should be adopted by May 2014 has been recently launched. According to WHO, it is desirable that the EU Member States exchange best practices and develop guidelines.





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BRENDA O'BRIEN (EU-OSHA, Manager of the Brussels Liaison Office)

"Disability and work: The perspective of the European Agency for Safety and Health at Work"

Ms. O'Brien informed about the importance of proper health and safety measures at the workplace as they protect people with disabilities as much as the rest of the working population. She also flagged the need to further improve the working conditions for elderly workers, as they often leave the labour market before reaching the retirement age due to health issues.

For these reasons, a replacement for the recently expired European Community Strategy for Health and Safety at Work is desirable. Before putting a new strategy in place, the European Commission has decided to launch a public consultation. Further Ms. O'Brien remarked that one of EU-OSHA's principal tools for raising awareness of issues related to occupational safety and health are the Healthy Workplaces Campaigns. The focus of the Agency's campaign for 2012-2013 is on reducing the number of work-related accidents and occupational illnesses. This Campaign is also addressing RMDs, as they are one of the major reasons for leaving work.

NEIL BETTERIDGE (EULAR Vice President, representing People with Arthritis/Rheumatism in Europe)

"How can the EU and Member States improve the living conditions of people with disabling chronic conditions? The perspective of people with RMDs"

Mr Betteridge made the connection between disabilities and chronic conditions, referring to the contribution of Mr. Kósa. He remarked that the majority of disabled people suffer from chronic diseases; further 4 out of the 10 most disabling conditions are caused due to RMDs. It is of concern for the EU and its Member States, to involve people with disabilities into society, in particular into the labour market and education. Hence, creating flexible and accessible environment in every aspect is crucial. Mr Betteridge pointed out that through the EUMUSC.NET project and the forthcoming Conference which will take place on the 17 October 2013, EULAR is calling on the EU and the Member States to strengthen disability legislation.

Primary and secondary prevention, awareness raising as well as research are the most effective measures to reduce the prevalence of RMDs and thus the significant number of disabilities. Finally, promotion of positive attitudes towards people with disabilities (particularly RMDs) and their needs should be actively taken into account when defining disability policies.

EDITE ESTRELA (MEP from Portugal, Chair of the Interest Group)

"Discussion with Participants and Closing Remarks"

Mr. Ten Geuzendam from the European Commission opened the discussion with a first remark stating that the European Disability Strategy aims at getting rid of divergences between the Member





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states by providing a common framework. Particularly all persons should be able to access the goods and services, among others also the healthcare services that are available on the single market. As he was not able to give a precise answer on the content of the European Accessibility Act, he indicated that the Act will be based on the "*design for all approach*" and will include all mainstream services. Further, the disability policies should be based on the "*human rights approach*". Stephanie Johnston from the European Union of Deaf confirmed that the rights of people with disabilities should be tackled from both the medical as well as the social perspective. Mr Massay-Kosubek from the European Public Health Alliance had the same opinion; moreover he sees commonalities between the work on disability legislation and chronic disease. Mr Betteridge from EULAR agreed with this and added that a change of approach towards persons with disabilities is desirable, especially in establishments providing healthcare services.

Mr Estrela thanked everyone for the participation in the meeting and the discussion. She concluded that there is a strong link between disability and chronic diseases, given that RMDs are one of the most disabling conditions. As agreed by all participants, the social agenda has to be taken into consideration when implementing disability legislation. In this sense, it is necessary to further promote synergies between those mainly working in the medical and social perspective.

About rheumatic and musculoskeletal diseases:

Chronic rheumatic and musculoskeletal diseases affect almost one-quarter of all Europeans (more than 120 million). These people have impaired quality of life, various degrees of disability and often premature death. Rheumatic diseases elicit the highest costs to health care and social systems. In Europe alone, due to health care costs, work-disability, sick leave and premature retirement, rheumatic diseases impose an economic burden of more than € 240 billion per year on state budgets. The impact of these diseases is expected to grow immensely due to demographic and lifestyle changes.

About EULAR:

The European League against Rheumatism (EULAR) is the European umbrella organisation in the area of rheumatic and musculoskeletal diseases. EULAR represents scientific societies, health professionals associations and organisations of people with arthritis/rheumatism throughout Europe. The aims of EULAR are to reduce the burden of rheumatic diseases on the individual and society and to improve the treatment, prevention and rehabilitation of musculoskeletal diseases. More information at www.EULAR.org.

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