



European Parliament Interest Group on Mental Health, Well-being and Brain Disorders

*Organised by GAMIAN-Europe (secretariat) and
the Expert Platform on depression – Focus on Depression*

Depression and Care Services

24 January 13.00 – 15.00

Chairs: Nessa Childers MEP
Antonyia Parvanova MEP

Antonyia Parvanova MEP opened the meeting, welcomed participants and reminded them of the objectives of the Interest Group, i.e. to advocate the development of sound EU policies which contribute to prevention of mental health problems and ensure good services, care and empowerment for those affected by mental health problems. Mrs Parvanova underlined the prevalence of depression (3– 5% in the general population, 10 – 15% among people contacting general health services and 15 – 25% in people with chronic illnesses) as well as the fact that this prevalence is on the increase. This makes depression one of the most important issues in the field of mental health. Unfortunately, while the impact of depression on the individual, his family and carers, society and the economy as a whole is huge, cuts to health services in many countries are having a profound impact on the availability of and access to care services. The quality of care is suffering as well; policy makers need to take account of depression in their decisions impacting on health services.

The first speaker (by means of a video message) was **Kjell Magnus Bondevik (former Prime Minister of Norway)** who talked about his personal experience with depression. He described his lack of energy and his sleeping, leading to the situation where he could not undertake any activity at all; When it became clear that he would not be in a position to attend one of the most serious political debates in his country, he and his staff decided to put out a press release stating that he was suffering from depression to avoid speculation and to make a contribution towards fighting stigma. The press release became breaking news and led to a huge public response, with many Norwegians thanking Mr Bondevik for being open about his illness. When asked whether there were any lessons that could be learnt from his experience, Mr Bondevik replied that is important to realize that mental health problems are much more common than is normally assumed: some 450 million people are affected across the globe, according to WHO statistics. This is why it is important to 'normalise' mental health; it is not more mysterious than physical health. Furthermore, the fact that Mr Bondevik went back to work after four weeks functioned as a positive example and a message of hope: it made people realize that mental health problems can be overcome.

Mr Bondevik closed his statement with three recommendations to policy makers. The first relates to the need to address stigma as this is the main problem in the area of mental health. The second addresses the need for more and better education of health professionals. The last recommendation underlines the need for smaller centres for mental health care as opposed to large, isolated institutions. (link to the interview: <http://www.depressionplatform.eu/voices-from-the-frontlines>)

The second speaker was **Prof. Norman Sartorius (Co chair of the Expert Platform on Mental Health - Focus on Depression)**. He first introduced the objectives of the Expert Platform, i.e. to support the implementation of the European Pact on Mental Health and Well-being as well as develop recommendations concerning depression in areas not covered by the Pact. These include the early diagnosis and appropriate treatment of depression and the economic impact of depression. Increasing public awareness and striving for changing the societal and health professionals' perception and thinking in relation to severity of depression are part of the Platform's activities to reach these goals. The Expert Platform is composed of 10 leading stakeholder organisations (professionals and patients), complemented by a number of high level experts. It has recently carried out a survey with the aim to describe existing care services in the field of depression.

The survey was conducted between July 2009 and February 2011. It covers the availability of health services, infrastructures, other structures available, self-help, information and quality of care. The data were subsequently complemented by contributions made by 21 Ministries of Health, and checked against the WHO 2008 review of services in Europe. Amongst the key findings is the fact that although a wide array of services for people living with depression are in place in the EU Member States, access to these services is by no means equitable. Likewise, information about services is difficult to obtain and interpret because there is little agreement on the definition of the terms used for their description. Lastly, there is insufficient agreement among experts about the best treatment or service organisation.

The Expert Platform on Mental Health – Focus on Depression has developed a set of recommendations based on review of evidence and the findings of the survey. These include improvement of the diagnosis and care of depression and better involvement of people living with depression as well as their families and carers in the planning and evaluation of services for depressive disorders. Furthermore, representatives of different disciplines should come together in order to reach consensus about the adequate management of depression. The European Commission, in cooperation with the Member States, should collect information about mental healthcare services available in each country in a dedicated database. National policy-makers, on the other hand, should fund initiatives that will raise awareness of depression and its consequences as well as of the means to deal with it and improve existing information systems concerning depression – including its economic consequences. There is also a clear need for a centralised information resource to serve as a reference base for interventions as well as further, targeted research. Lastly, the Platform recommends that, in order to expand coverage of mental healthcare services, decision makers should consider:

- The reimbursement of innovative treatment interventions responding to unmet needs, including psychotherapy, pharmacotherapy and psycho-education shown to be effective,
- The education of health care professionals in raising awareness of the importance of early diagnosis and adequate treatment for people with depression,
- The use of new technologies to improve access to health care services and coordination among healthcare professionals,
The creation of a European Depression Services Map of available health care services, and the inclusion of identified services and best practices in the EU-Compass for Action on Mental Health and Well-being,
- The creation of a European Dictionary on Depression to highlight the different terminology used in different Member States.

The third speaker, **Prof. Cyril Höschl (European Brain Council)**, addressed the cost of depression in Europe from the perspective of the European Brain Council (EBC). The EBC's mission is to promote brain research in Europe and to improve the quality of life of those affected by brain disease. EBC's membership consists of 7 professional and patient organisations, complemented by industry representatives, observers and 7 associate members and observers. Membership is continuing to

grow. EBS is supporting the development of National Brain Councils (multidisciplinary action groups which share the same mission is the EBC) and is active in a number of areas and projects. One of EBC's most recent publications is a study entitled 'Cost of disorders of the brain in Europe 2010'. The attention for this publication has been overwhelming: more than a 1000 media covered the story in more than 30 countries and over 12,000 people visited the original release from Business Wire. The report covers 19 major groups of brain disorders including over 100 specific mental and neurologic disorders. The study shows that a total of €798 billion (or in other words, €1550 per capita) is being spent on brain disorders: 60% of these are direct costs (37% direct healthcare costs and 23% direct non-medical costs) and 40% are indirect costs associated with patients' production loss. Brain disorders affect over 160 million people, which is more than 36% of the total EU population. In addition, there is no evidence of any improvement since the previous pan-European study, which was conducted in 2005; and it is likely that the burden will increase further because of the ageing European population.

Professor Höschl also provided specific information on the cost of depression in Europe. Depression is the single most burdensome brain disorder. The European prevalence of major depression (age 18+) is 6,9% and the European prevalence of bipolar disorder (age 18-65) is 0,9%. The overall cost of mood disorders is €113.4 billion. The EBC therefore has formulated a number of recommendations, addressing the need to increase support of brain related research, a clear focus on prevention and best practice models in relation to the organisation of healthcare systems, stronger encouragement for industry and investors to engage in brain research, include disorders of the brain in curricula and training in all health professions and improved access to treatment

The final speaker was **Jürgen Scheftlein (European Commission, DG SANCO)** who gave an overview of the EU level activities in the area of mental health. The main initiative in this field is the European Pact for Mental Health and Well-being. This is an intersectoral statement on mental health action in Europe which aims to support and inform Member States and other stakeholders, promote best practice and encourage actions, to help address common challenges and tackle health inequalities. This was implemented by means of a series of thematic conferences on the Pact's 5 priority areas held between 2009 and 2012, i.e. older people, young people mental health in the workplace, stigma and discrimination and prevention of depression and suicide. These aimed to link social, economic and health considerations stimulate the exchange of good practice and to feed into policy development. The conference on prevention of suicide and depression theme took place in December 2009 and led to a series of conclusions on actions that need to be taken, such as strengthen leadership and political commitment, build capacity in the primary care sector, focus on promotion and prevention (throughout the course of life), build partnership with other sectors, better empower users and citizens and strengthen the evidence base.

The Pact has led to the Commission proposing a 'Joint Action (i.e. member States and Commission working together) on mental health and well-being, with the aim to establish a common action framework which will address depression and suicide, moving towards community-based mental health services, the workplace, schools and health in all policies. This Action will probably be launched at the end of 2012 and until now, some 20 Member States have declared their interest, which is a strong indication of the importance attached to this topic. Jürgen Scheftlein also underlined the fact that other departments of the Commission are active in the area of mental health, such as DG Employment and Social Affairs (Occupational Health and Safety), Eurostat (the European Health Interview Survey (EHIS), DG Research (comprehensive approach to research into mental health and the ROAMER-project to develop Roadmap for mental health research. finally, Jürgen Scheftlein also referred to the June 2011 Council conclusions on the Mental Health Pact, which highlight the activities, results and future actions (LINK).

Following the speakers, a statement was made by **Dolores Gauci (President of GAMIAN-Europe and co chair of the Expert Platform on Mental Health – Focus on Depression)**. Mrs Gauci briefly introduced her organisation as a patient-driven pan-European organisation, representing the

interests of persons affected by mental illness and advocating for their rights. GAMIAN-Europe considers depression and its implications as highly important and has been actively collaborating with organisations in order to enhance the understanding of this illness. The organisation also carries out its own studies as it is GAMIAN-Europe's core business to increase and disseminate an understanding from the patient perspective. For instance, a study of stigma from the patient's perspective was finalised last year and the link between depression and stigma was one of the focuses of the study.

Dolores Gauci highlighted the cost of depression is to society, as shown by the EBC report. It is clear that there is disparity in spending on treatment and services in Europe, and that these disparities are increasing. However, the cost to the patient and their family and carers is often not researched. Another issue is that most depression related studies focus on adults only; children and adolescents are not included. The facts on depression are staggering: studies have shown that 1 in every 4 persons will develop depression at some point in their life. One in every 9 persons will develop depression in the next 12 months. Half of these will not seek treatment as they do not realise that they are ill. Only half of those receiving treatment will receive appropriate treatment. Some effective treatments methods are not used enough – psycho education and self help are two examples. And finally, half of those receiving treatment will only have a 1 time contact with a professional. While the awareness amongst the general public, policy makers and others about depression is on the increase, this is far from satisfactory both from a promotion and prevention aspect as well as from the treatment and care aspect.

Dolores Gauci made a strong plea for a holistic outlook that results in practical tools that can be put to use to the benefit of patients. Developing resilience should be part of any action to promote mental health. Early signs of depression should be noticed and stigma should be actively addressed. Services truly promoting recovery need to be put in place. Patients would like to see the development of tools that will assist them in taking control of their lives and to self-manage their condition. People who experience depression need Information about their illness – preferably information that is provided by patients themselves. There should be better and comprehensive information on treatment: medication, psychotherapy, psycho-education and self help. There is no integrative approach to address depression across Europe. Professionals, policy makers, bureaucrats discuss depression across Europe in their own silos. While a crucial actor in this scenario, the citizen - as the patient or the carer – is not very often involved in these discussions. There is a message of hope though: one third of people experiencing depression recovers totally – another third would only need some support. This information is especially important not only from a human perspective as it promotes hope but also from an inclusion perspective - especially when it comes to the workplace.

Mrs. Gauci ended her commentary with two questions. The first, put to Jürgen Scheftlein, related to the acknowledgement that people who experience mental health problems and families and carers should be involved in all that affects them. However, this acknowledgement is often not reflected in practice and Dolores would like to ask the Commission what can be done to ensure that the concept of patient empowerment and involvement is implemented. The second, put to the Co- Chairs of the Interest Group, called for a Parliamentary Question asking the European Commission whether an EU-coordinated study with the aim to develop solutions to address the disparities in availability and quality of and access to care services in the field of mental health and help build consensus on the best care services.

Discussion

In the discussion following the presentations several issues were raised:

The need to empower and involve patients:

In his response to Dolores Gauci's question Jürgen Scheftlein responded that patient involvement is indeed a commonly agreed concept, which is also underlined in the WHO mental health strategy. The Commission is currently actively involving patients in a project that aims to develop empowerment indicators. Patients and their organisations have also been involved in all conferences and it is

intended that there is a place for patients in the upcoming Joint Action as well; the discussion on what format this involvement would take is still ongoing. A meeting to review the Pact, its implementation and next steps will be held with key stakeholders in the short term. In addition, other parts of the Commission are involved with funding mental health organisations (for instance, Mental Health Europe is being funded by the PROGRESS programme).

The lack of consensus on diagnose and choice of treatment

Currently, there is a lack of consensus on diagnosis as well as on appropriate treatment. Ways to best involve doctors to ensure a proper diagnosis and appropriate care need to be found. It was suggested that this might require a change in the ways knowledge is being currently conveyed. Psychiatry is a vast area; therefore it might be more effective to train professionals by means of smaller training modules which address the most prevalent conditions and which are being taught by practice-oriented people (e.g. GP's, patients or relatives) rather than by psychiatrists.

Realistic and practical solutions are needed:

The day to day reality is that people with mental health problems are 'time consuming' patients. Some health care systems do not really allow for that: if GP's are paid by patients rather than by means of a fixed income, they will simply not have the time. Doctors need to be given incentives to spend more time with these patients. It would also be useful to educate doctors to become GP's with a special interest in psychiatry.

The need to bring the different perspectives together

Patients, health professionals, and carers would need to build consensus and agree on what good quality care for depression entails. A holistic and integrative care package is needed and stakeholders need to collaborate to develop this.

European Year of the Brain:

While some 170 organisations are supporting the idea of designating 2014 as the European Year of the Brain, the Commission has not yet taken a decision to this effect. Apparently there are competing themes and it is not clear what will happen at this stage.

At the end of the meeting, **Nessa Childers MEP** made some observations and comments from her own perspective, both as a clinician and as a politician. She underlined the devastating effects of the current cuts in health care spending in her own country and the need to keep on communicating and advocating on the importance of mental health services. Social cohesion is key in this respect and politicians will need to bear this in mind.

Ireland will hold the EU Presidency in 2013 and Nessa Childers offered her help in ensuring that this Presidency puts depression and mental health on its priority agenda. In her role as MEP, she can table questions to Irish government.

Nessa Childers also underlined the fact that the recent UN Conference on non-communicable disease did not address mental health, which is a serious omission. It is worth remembering that neurological diseases cause disability. She welcomed the fact that the proposed Health for Growth Programme included mental health in its strand on chronic disease and stated that mental illness deserve at least as much attention of the other diseases addressed under this heading. Nessa Childers reminded participants that it is not only mental illness that gets stigmatised; psychiatry and psychology are stigmatised disciplines as well.

Closing the meeting, Mrs Childers thanked the secretariat (GAMIAN-Europe) and the Expert Platform of Mental Health – Focus on Depression for organising the event. She expressed her delight at the fact the Interest Group is going from strength to strength and announced that the next meeting (to be held on 24 April will address mental health and well being in children and teenagers).