



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

Thursday 22 September, 13.00 – 15.00

Mental health and Brain Disorders

Co-Chairs: Nessa Childers MEP
 Marian Harkin MEP
 Jean Lambert MEP
 Antonyia Parvanova MEP

The first part of the meeting was chaired by **Jean Lambert MEP** and **Marian Harkin MEP**.

Jean Lambert welcomed participants and reminded them of the goals 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.* Jean underlined that this meeting was a special occasion, not only because the topic represents the very essence of the Interest Group, but also because it served as a kick off to the annual Convention of GAMIAN-Europe. The fact that the meeting was being supported by the European Brain Council also made it special. Jean emphasized the importance of mental health to society, for instance in the field of employment, and stated that one of the important contributions of the Interest Group was that it could make a serious contribution to understanding mental health and raise awareness of its links with a variety of social issues, such as social inclusion and stigma.



Marian Harkin also welcomed participants and also underlined the importance of the topic. According to Marian, the purpose of the Interest Group to advocate the development of sound EU policies and activities; putting in place high quality and appropriate care services and effectuating empowerment of those affected by mental illness are the main goals in this area. The work carried out under the Mental Health Pact and the current European Innovation Partnership on Active and Healthy Ageing offer clear opportunities to develop sound policies and EU level initiatives in this area. Marian underlined the need for action to combat poverty and social exclusion and to address the social determinants of mental illness. The general move from institutional to home care is a positive development.

The first speaker, **Anton Grech** (University of Malta) focused on the evolution of the science of the brain vs. the evolution of the science of mental health. Why is there a split between the brain and the mind, or, in other words between neurology and psychiatry/clinical psychology. Why not focus on neuropsychiatry?



If a comparison with a computer is made, the brain can be described as the hardware and the mind as the software. When we talk about the brain and the mind, do we talk about the same thing? In order to “see” the brain, technology such as MRI and EEG can be used. To “see” the mind, communication - mostly by means of words – is needed. If we are saying that there is an overlap between the two, can we see the mind by means of the technology we use to see the brain? Some studies do address this (e.g. in the field of schizophrenia where attempts are being made to visualize hallucinations by means of MRI). In the field of depression, functional MRI can measure the outcome of depression and the effect of different antidepressants. This can be helpful in predicting the response to antidepressants.

One thing is clear: if we only focus on the brain we are not going to have the full answers we are looking for. On the other hand, the same holds true for a focus on the mind only. Another important factor is the environment. The mind and brain do not exist in isolation. The physical environment, substance use and physical events all have an impact. So, in order to better understand mental suffering, a system integrating the brain, the mind and the environment is needed. The synergy between different sciences and specialties is also indispensable. In terms of the mind, psychologists (clinical, neuropsychologists) and psychiatrists are needed. In terms of the brain, neurologists, radiologists, technicians, geneticists are required. And last but not least, to help determine the impact of the environment, sociologists are needed. Other sciences can be involved as necessary. However, the crucial question on who would take the lead to accomplish this remains. More research is needed, consisting of large projects involving thousands of subjects, both with as well as without the condition, using clear markers of ‘brain’, assessing environmental

influences (known and looking for potential ones) as well as the interaction between genes and environment.

With regard to clinical work, multidisciplinary as well as transdisciplinary teams are needed, which should also operate outside the medical environment. These should be community based and offer individualized multidisciplinary care packages. They would also need to explore novel interactions between different treatment modalities.

In terms of policy, governments need to recognize the new face of mental care and should stop considering community-based psychiatry as a cost cutting exercise. Policy departments need to be more horizontal; and lastly, policies should be developed that attract more scientists and health care professionals and service providers to the area. The EU can also play a role by developing clear guidelines for member states, work towards more harmonization in the approach to mental health, support research and support a collaborative cross-EU therapeutic network



Anton Grech stressed the importance of the large influence of culture. The different cultural backgrounds cannot be ignored. In conclusion, Anton stated that the brain/mind dichotomy has to end as this ultimately does not benefit patients.

The second speaker, **Tinne Vandensande (King Baudouin Foundation)** informed the meeting of a unique pilot project entitled Meeting of Minds. This was the first European, public deliberation, involving a panel of 126 citizens from 9 European countries on the question “How are we going to use the new-found knowledge on the brain?” Rationale behind the project was that brain sciences are rapidly gaining societal importance; it was felt that the brain is too important to leave the discussion to brain scientists only. The project ran from 2004 to 2006 and was supported by the European Commission’s DG



Research, with the King Baudouin Foundation being responsible for the project coordination and co-funding. The process consisted of five steps: first, to learn about brain research; second, to assess the issues from the participating citizen’s perspective; and third, to assess the scientific, technological, social, ethical and policy aspects; fourth, to discuss questions and ideas with researchers, stakeholders

and policy-makers and finally, to develop and present recommendations to decision-makers and opinion leaders.

A series of meetings (both involving the full number of participants as well as national-level meetings) took place, following an issue analysis by experts.

The outcome of the project consisted of 9 national assessment reports as well as a European report with 37 recommendations, grouped under 7 EU policy dimensions, such as ethics, research policy, governance of science, health and pharma policies, education and training policies and communication policy.

Some examples of recommendations:

- Establish mandatory informed consent procedures for brain imaging techniques
- Increase the EU funding of basic and fundamental research
- Encourage pharmaceutical companies to undertake research on rare brain disorders
- Establish EU guidelines for MS medical assistance to ensure dignity of life for mentally ill
- Provide information brochures on the brain for prospective parents
- Encourage the education and training system to take full advantage of the knowledge available from brain research to improve the learning process at all stages

The “Meeting of Minds’ was formally evaluated and according to the conclusions, it has demonstrated that citizen participation is not only possible, but also desirable to draw on citizens’ intellectual and creative capital in shaping a common future of which we can all feel part”.

While the project was finished 4 years ago, its outcomes are still quoted and discussed by ethical bodies, scientific associations and scientific literature.



Antonyia Parvanova MEP and **Nessa Childers MEP** took over the chair and both made short introductory statements. **Antonyia Parvanova** underlined the importance of combining the two topics of mental health and the brain as these two should be seen as two parts of a whole. This unfortunately does not seem to be policy makers’ common approach. **Nessa Childers** also stressed that the brain vs. mind dichotomy does not help patients. We can perceive our minds but not our brains; is the mind some kind of ghost in the machine? More clarity on both concepts is desirable. ‘Mental illness’ comprises many different meanings. In many cases we do not know what lies at the root of a certain kind of mental illness but we

prescribe treatment nevertheless. Paying attention to what happens to individuals in their first years of life when body and mind develop at a fast pace is crucial as the foundations for later mental and physical development is laid at this stage. What are the genetics that can trigger a mental illness to develop? What switches on those genes, what activates the malfunctioning of the brain, and in turn affects the mind?

The first speaker in this session, **Philippe Cupers** (DG Research) provided information on how mental health and the brain feature in current EU research efforts. The main source of EU funding for research comes out of the current 7th Framework Programme of Research and Development. This consists of various strands, and one of the areas is called 'collaborative research'. This area contains a specific strand on health research, and covers a wide variety of topics and themes such as cancer. Research on the functioning of the brain is part of this. Neurodegenerative diseases such as Alzheimers disease are also included in the research activities. The aim of research in this field is to develop a better understanding which in turn can lead to better diagnosis and treatment.

FP7 normally funds large projects, with large numbers of participants and with the involvement of various stakeholders. Industries and SME's are also part of the activities. Since its inception in 2007 FP7 has funded some 100 projects focusing on brain research. Some 450 million euro has been invested in this. The range of types of research is broad, varying from a focus on the mechanisms of brain disorders to addressing the impact of genes and the impact of the environment. Topics under research are schizophrenia, autism, stress depression, bipolar, suicide prevention, mental health and ageing. The ultimate aim would of course be to improve mental health and wellbeing.

FP7 will come to an end in 2013 and new activities are already being discussed. A new framework programme entitled 'Horizon2020' will be launched in 2014, and while the content of this initiative is not yet known, it is highly likely that research on the brain and mental health will again be part of this future programme.

The next speaker, **Juergen Scheftlein (DG SANCO)** informed the meeting of the activities under the European Mental Health Pact and next steps in relation to EU activity in this vital area.



As part of the Mental Health Pact, a series of thematic conferences was organised, focusing on young people older people, workplace issues, depression and stigma. These aimed to link social, economic and health considerations, stimulate the exchange of good practice and to feed into policy development.

These conferences were organised in cooperation with Member States and made use of the input from a variety of different

Directorates General in the Commission (social affairs, education, information society...).

The outcome of the events has helped to underline the need for further action to improve mental health and to redefine and strengthen the role of care providers and care policies.

In addition, the events have supported the case for mainstreaming mental health across all policies.

The work under the Pact has been evaluated and a set of Council Conclusions was adopted in June. These invite the Commission to continue with the work in this area and call for a 'Joint Action'. This would entail Member States to coordinate certain priority areas in their mental health activities in cooperation with the Commission. The interest seems to be on workplace mental health community based care, social inclusion of mental health services, depression and the interface between health actors. It needs to be underlined that the Member States are not the only partners in the Joint Action; other stakeholders will be involved as well. Also, work has started on linking various policy areas, such as workplace mental health and eHealth. The Commission is also planning to publish a paper on best practice in mental health, elaborated by a group of government experts. Deinstitutionalisation seems to be a key theme.

Last but not least, while the upcoming UN summit on chronic disorders will not explicitly address mental health, it will help to increase awareness and visibility as mental health plays such an obvious role in chronic disease.

Economic growth is EU's the main policy priority at this point, but improving mental health will have a positive effect on the economy as well as it is linked with such a number of social and economic factors.

Dolores Gauci (President of GAMIAN-Europe) briefly introduced her organisation and underlined that for GAMIAN-Europe's members, mental illness is a complex experience which results from biopsychosocial factors. It is because of this understanding that patients want to ensure that mental health and the brain are acknowledged as two parts of a whole. This concept promotes the integration of neurology, psychiatry and psychology and does away with the splitting which more often than not is found in health.

For GAMIAN-Europe the importance of both mental health in the wider sense and the brain is reflected in the name of this Interest Group which is supported by GAMIAN-Europe's secretariat. GAMIAN-Europe facilitated the launch and supports the Group together with the four Co-Chairs, who have proved their commitment on many occasions.

If success is to be registered all stakeholders working in mental health and the brain need to work together in looking for synergies and parallels rather than focus on what is different. Whilst specialization is helpful in bringing understanding it must be emphasized that such an understanding is brought together to form a whole and not to increase fragmentation. Patients expect to be treated holistically and as people first. It is with this aim in mind that GAMIAN-Europe is actively represented on the Board of the major European organisations and networks including the European Brain Council and the Expert Platform on Depression and involved with the WHO working party to develop a European mental health strategy.

Dolores stated that the possibility of 2014 being dedicated to the Brain and Mental Health has been mentioned on innumerable occasions. Whilst it is easy to focus on the concrete by carrying out research on the brain, the more complex and less tangible psychosocial and environmental determinants should not be put aside and she called on the Commission to ensure that its initiatives are inclusive. Dolores emphasized GAMIAN-Europe's support for the Year and the efforts of her organization to ensure that it will be based on bio-psychosocial approach. Dolores concluded her presentation by suggesting to the Interest Group to table a Parliamentary Question in relation to the designation of 2014 as the European Year of the Brain and offered the help of GAMIAN-Europe, in its role as secretariat of the Interest Group to prepare such a question.

Mary Baker (President of the European Brain Council) also introduced her organisation and expressed her thanks to DG SANCO for their initiative to launch the European Innovation

Partnership on Active and Healthy Ageing with its overarching aim to prolong healthy life years by 2 years. This fits in very well with the current EBC campaign to designate 2014 as the European Year of the Brain. This Year will aim to help understand the internal mechanisms as well as the other external determinants which impact on the functioning of the brain and to prevent brain and mental illness. In recent years it has become apparent that disorders of the brain and nervous system are among the most serious and prevalent health problems globally. People affected by nervous system disorders are more likely to be subjected to discrimination and stigmatisation than people affected by other disorders. Advances in neuroscience during the past 50 years have left us not knowing how or where to



draw a line between brain and mental problems, or between psychiatric and neurological disorders. From the EBC's angle of vision, there are brain disorders that psychiatrists prefer to treat and other brain disorders that neurologists (and neurosurgeons) prefer to treat.

Neurology and psychiatry must end the 20th century schism that has divided their fields.

There must be closer collaboration in neuroscience research and clinical practice. Partnerships with patients and with societies at large are required, in order to advance prevention and treatment of brain and nervous system disorders and to end the stigma that still prevails with mental illness.

The brain is an incredible organ that should be taken good care off throughout life. There should be a focus on young people in this respect, and young people should be more aware of the negative effects of alcohol, drugs and lifestyle on the brain. Mary stressed that illnesses of the brain or mental illness are not more or less important than cancer or other chronic disease; however, the brain is also important in managing other health conditions; a brain that is not functioning properly will have a negative impact on disease management.

The question is who will lead in putting illness of the brain higher on the agenda. Who can make sure that psychiatry and neurology are in unison rather than working in separation?

Discussion

In the discussion following the presentations, several issues were raised:

Year of the Brain:

As industry seems to be pulling out of research in this field and HTA in this field is underdeveloped, every single part of the process in relation to brain disease is problematic. This area is very important as brain disease has a knock on effect on other (chronic) diseases. A Year of the Brain should make a contribution to developing and exchanging solutions to lessen the (economic, social and personal) burden of brain disease. Patients, families, economies – are all affected. All individuals are vulnerable. More awareness, more information is needed.

The Interest Group would be happy to table a Parliamentary Question to push for 2014 to be designated as the European Year of the Brain. Other actions to advocate the Year would be for the Interest Group to send a letter to Parliament President Jerzy Buzek, who will formally call for the Year at a Presidency conference addressing ageing, stroke and dementia this autumn. His successor, Martin Schulz should also be approached to support the initiative. It would also be useful to address a message to the Polish Presidency.

Bringing neurology and psychiatry/psychology together:

It is agreed that bringing the brain and the mind specialists together is crucial. But who will lead on this and how far should it go? Should we strive for education to focus on both together or to continue with 'separate' education? Currently, educational programmes train in 'silo'. Both specialties are clearly needed, and it will be difficult to change the culture and current thinking. However both specialties should be more open to each other and see where they compensate. Links during the education and training programmes between the two specialties might help facilitate better understanding, which could lead to better cooperation at a later stage; the current fragmentation keep the brain vs. mind dichotomy going.

According to some, however, the culture could and should be changed, and turned into a mental health/brain culture. Clearly, health science and medical science are at a different level, with health science being (considered) more conservative and medical science as more innovative focus; health care should follow medical science development more closely. The WHO estimates that some 35% of total health cost relates to brain disease ; however, only 8 % of medical training time is spent on these disorders. This does not reflect reality.

Mental health in children and adolescents:

There does not seem to be enough attention for mental health in children and adolescents. There is a strong focus on adults and older people but children and adolescents are a vulnerable group as well. It was suggested to dedicate one of the upcoming Interest Group meetings to this topic as this phase of life is crucial for the development in later life. The first conference held under the Mental Health Pact addressed this theme so an Interest Group meeting could build on the outcome of that event.

Stigma:

Stigma continues to be an important area both in relation to brain disease as well as in the area of mental health. The costs of brain diseases are going up, as will become evident from a report that the EBC will launch on October 4. We need to pull together to ensure that something is being done and the Year could be an important contribution.

Self help:

Some participants commented on the fact that the meeting had not addressed the important topic of (funding for) self help. GAMIAN-Europe is very active in promoting the empowerment and self help capacity of people affected by mental problems as this can make a huge contribution to cost reduction.

Role of patients and their associations:

In research activities, the role of patients and their organisations should not be forgotten. Expert patients can contribute and should not be forgotten. Furthermore they should form part of policy development.

Mental health and European Parliament chronic disease Resolution:

Antonyia Parvanova MEP referred to a Resolution adopted in the Parliament's September plenary session on non-communicable diseases. This has a strong focus on cardiovascular disease, cancer, respiratory disease and diabetes, but a special point was made about mental health as well, calling on Health Commissioner Dalli to carry on the work started in this field.

EU Health budget:

Current discussions in the Parliament on the budget have revealed that the budget for the current and future Public Health Programmes may be cut. There is a task for the Interest Group to ensure that this does not happen.

Christine Marking

27 September 2012