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

Date:	Wednesday 19 November 12.30 - 15.30
Venue:	European Parliament – Room P5B001
Topic:	Mental health and societal integration – work and community

Report

Nessa Childers MEP opened this first meeting of the Interest Group in the new European Parliament, reminding the audience that the Group was launched 5 years ago and has been one of the most active in the previous Parliament. The panel of co-chairs now consists of MEPs Cristian Silviu Busoi, Nessa Childers, Jean Lambert and Marian Harkin. The aims of the Interest Group have remained the same, 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.* The Group aims to create a wider support base in the European Parliament and will continue to address current policy files and topics; it will continue to table PQs and amendments to Commission reports to ensure a strong mental health dimension in all policies that have a bearing on health and well-being. Today's meeting serves to formally re-launch the Interest Group on Mental health, Well-being and Brain Disorders and to introduce and discuss the recently published Mental Health Index and GAMIAN-Europe survey on mental health in employment.

The first speaker, **Dr Paul Kielstra (Economist Intelligence Unit)** introduced a recent survey on mental health and integration and the provision for supporting people with mental illness, the Mental Health Index (MHI). It is clear that mental illness is less understood and more subject to prejudice than other health conditions. Moreover, few impose the same burden on those affected as well as society as a whole.
While there is widespread consensus of the benefits of integrating those affected into society, few countries have actually realized this ideal. The MHI therefore serves to provide facts on integration in order to inform policy development. At the core of this research is an 18 indicators benchmarking index ranking 30 countries—the EU28 plus Switzerland and Norway—based on their commitment to integrating those with mental illness. The 18 indicators are grouped into four categories:

- Environment for those with mental illness in leading a full life
- Access for people with mental illness to medical help and services
- Opportunities, specifically job-related, available to those with mental illness
- Governance of the system, including human rights issues and efforts to combat stigma

For 12 selected countries, the EIU conducted a detailed analysis of index results showing each country's strengths and weaknesses related to mental health integration.
The main findings are as follows:

- **Mental illness exacts a substantial human and economic toll on Europe, and has a substantial treatment gap**. An estimated 38% of residents of the EU, or around 165m people, are affected by a mental illness at some point in any given year; however, oonly about 25% of those affected in Europe get any treatment at all. A mere 10% receive "notionally adequate" care.
- **Germany's strong healthcare system and generous social provision put it at the top of**

the index. The UK and Scandinavian states are not far behind. The lowest-scoring countries in the index are from Europe's south-east, where there is a long history of neglecting mental illness. It has to be said though that the leading countries are not the only sources of best practice in integrating those with mental illness.

- **Employment is the field of greatest concern for those with mental illness**, but also the area with the most inconsistent policies across Europe. Inability to find gainful employment is the biggest frustration for those with mental illness, interviewees say. People with mental health problems face considerable employment disadvantages across Europe.
- **Real investment separates those addressing the issue from those setting only aspirational policies.** The investment figure is a proxy for seriousness in establishing good policy and practice. Unfortunately, there are many examples of policies that are largely aspirational. Consistency across categories pays off: Those with the highest overall scores tend to do well across all four index categories.
- **Europe is only in the early stages of the journey from institution- to community-based care**. Even deinstitutionalisation is very much a work in progress. Availability of therapy and medication is inadequate. Medical services for the mentally ill are poorly integrated, and integrated medical, social and employment services are rare. Government-wide policy in these areas is the exception.
- **Lack of data makes greater understanding of this field difficult.** It also hinders the process of improving structures for integrating those with mental illness into society and employment. The focus on policies/inputs into integration, rather than on outcomes of policies, is largely due to absence of data on outcomes.

In conclusion, Paul Kielstra listed five areas where action is needed:

- ✓ Obtaining better data in all areas of medical and service provision and outcomes;
- ✓ Backing up mental health policies with appropriate funding;
- ✓ Finishing the now decades-old task of deinstitutionalisation;
- ✓ Focusing on the hard task of providing integrated, community-based services;
- ✓ Including integrated employment services provision.

The second speaker, **Paul Arteel (GAMIAN-Europe)** informed the audience of the findings of GAMIAN-Europe surveys in relation to mental health in the workplace, with a focus on the needs of patients and the challenges for Employers. As it is crucial for GAMIAN-Europe to hear from patients about their day-to-day experience, surveys are being carried out on different topics on a regular basis. A snapshot of employment related findings from those various surveys:

Stigma (2006 and 2010): In 2006 54% of respondents think that most employers will hire a former mental health patient if he/she is qualified for the job; in 2010 his figure has decreased to 47%. In 2006 68% of respondents think most employers will pass over the application of a former mental patient in favour of another applicant, in 2010 this figure has increased to 77%.
Physical and mental health (2011): only 5% of respondent felt that colleagues would encourage them to look after their heath (as opposed to (81% for relatives).
Adherence to treatment (2012): some 30 % of respondents reported fear of disclosing their mental condition as a reason for non-adherence to treatment.
Mental Health and Workplace (2013): 50% of respondents had to stay home from work between 10 and 99 days due to mental health problems. 18% were absent up to 9 days and another 18% never were absent from their jobs. For 64% of respondents not being able to work is a more or less permanent situation. Only 24% of respondents are happy with this situation and have accepted that they will probably never be able to work again. On the other hand, 39% of respondents are unhappy with this situation and would like to get back to work.

There are barriers to get back to work as well: for 47% of respondents their symptoms make it impossible. 16% of respondents are convinced that their former employer does not want to have them back.19% of respondents are afraid to have a relapse if they return to their former job.

Interestingly, 33% of respondents do not inform their employer about their mental illness, for fear of a lack of understanding, discrimination and even job loss. Some 25% had no choice as the name of a psychiatric clinic was mentioned in their medical records. Only 18% decided themselves to tell their employer about their mental health problems. Over 50% of the respondents believe that better training of the HR department and a good support from a medical professional would have helped them to keep their work. 77% think that a change in attitude of the management is needed and 84% would find a change in attitude of their colleagues helpful.
Paul Arteel concluded that combating stigma and increasing understanding of mental health issues with decision makers, employers, managers and the general public is crucial. There is also a need for effective treatments to ensure sufficient symptom reduction so that people can work again and keep their jobs as in many cases, being at work contributes to life quality. Special efforts need to be made to support people with mental health problems to find and keep a job.

Panel response

The first speaker was **Pedro Montellano (GAMIAN-Europe)**, emphasized the importance of a number of the findings such as the burden and treatment gap, with only about 25% of those affected in Europe getting any treatment at all. He also underlined the problematic area of mental illness as current policies are varied and inconsistent and stigma continues to play a huge part. He informed the audience that GAMIAN-Europe has recently joined the European 'stress at work' campaign as an official partner and has also listed his organisation's issues in a letter welcoming the new social affairs Commissioner , calling for concrete action. For instance, the European Strategy for health and safety at work should explicitly address mental health and well-being as a key factor in the workplace. Another important issue relates to Europe only being in the early stages of the journey from institution to community-based care. Silo thinking remains the norm: mental health is not seen as an integral part of physical health and vice versa. GAMIAN-Europe is part of Work Package 5 of the EU Joint Action on Mental Health on Community care, and the outcome of the MHI will be useful as an advocacy tool. Pedro Montellano also highlighted the need for better data. GAMIAN-Europe and the Interest Group have worked hard to ensure that Horizon2020 includes references to mental health, and intend to devote one of the upcoming Interest Group meetings to research.
Lastly, he stated GAMIAN-Europe's intention to advocate the need for a comprehensive EU action plan on mental health. While the Mental Health Pact and Joint Action have been and are very useful initiatives, a stronger push to really raise awareness of the importance of mental health and issues relating to mental illness is urgently required.

The second panelist **Dr Slawomir Murawiec (Dialogue Therapy Centre, Warsaw)**, talked about the surprise that Poland's high MHI ranking caused amongst fellow psychiatrists. Paradoxically, the Polish policy regulations in the field of mental health integration and services provision are very good; the problem is that there is no money to implement them. This is why the finding that investment is a proxy for policy and practice is so important. The gap between funding and policy needs to be addressed. This is particularly important in the field of prescription medication, as many controls and restrictions exist, especially where innovative medication is concerned. The level of funds for social welfare benefits is also highly worrying. Low level of income plays a huge role in mental illness and prospects for patients. Poverty is a barrier to fully participate in social life, and social resources are a factor in sound mental health. Stigma does not only affect patients; it also affects psychiatrist and others working in the mental health arena. Politicians often do not want to be associated with psychiatrists and do not want to support activities in the field of mental health. Efforts are being made in Poland to raise awareness of mental health and combat stigma and seeing a psychiatrist now seems considerably more socially acceptable and easier.

Slawomir Murawiec concluded by underlining that, if perfect regulations have been agreed but are not being implemented, policy makers are seriously lagging behind.

The third speaker was **Kevin Jones (EUFAMI)**, who highlighted the specific situation of families affected by mental illness, as in many cases, families are forgotten. However, families are also affected by mental illness. Social isolation, work related issues, financial burden, lack of support and stigma are amongst the factors from which family members suffer.
In relation to employment, there is a need for education of employers as well as flexibility. EUFAMI recently released the first results of a survey showing that one third of respondents (who are family carers) are in full time employment. It also shows that a sizeable amount of respondents cannot get employment due to their caring role, and that many need in fact to take early retirement.
This is why EUFAMI is calling for *'Flexible employment opportunities to be made available to allow people with mental illness and their families make their full contribution to society*'. There is also a need for greater societal, financial and training support for families. The move from de-institutionalisation to community care has placed an additional layer of burden on families as the reality is that in many countries community care equates to family care.
Stigma also affects families and can be far reaching and more widely felt than for their relatives directly affected by the mental illness. EUFAMI is calling for *'strategies to be put in place to minimise stigma and discrimination against people living with and affected by mental illness'.* And lastly, social isolation is yet another factor which greatly affects family members. Therefore, EUFAMI calls for *'People living with mental illness and their families and caregivers to be given every opportunity to network with people in similar circumstances'.*

EUFAMI has developed a Charter of rights for families and carers addresses the role and needs of families and also calls for actions from Public Authorities and statutory service providers.
Kevin welcomed the Mental Health Index and the GAMIAN-Europe survey, as the information can helps to keep the issues high on the political agenda.
In conclusion, Kevin welcomed the work done as part of the Joint Action on Mental Health. He also called for the further promotion of the EU Compass on Mental Health.

The final speaker was Professor **Peter Huxley** (University of Bangor) who underlined his interest and vast experience in research work with the aim to improve the quality of life of all people with mental health problems.
Peter commented on the four sections of the Index, starting with the fact that polices across Europe in the field of employment are highly variable. Work is important for self-esteem and a sense of purpose, but it can also be a source of stress and related ill-health, leading to days lost to production. It is therefore important that employers are aware of the mental health needs of their employees, and make suitable adjustments to keep them in work. .
The second comment related to inclusion. In the MHII and surveys in the UK it people with the most intractable inclusion difficulties are those affected by common mental disorders, who are often untreated and who are disabled and socially isolated by their symptoms.
A third point addressed the need for supportive environments. Research has shown that people with mental health problems are far more resilient when they move from an institutional to a community setting. However, there are widespread beliefs across Europe that institutional care is the right form of care and in these countries resistance to change is an obstacle to de-institutionalisation.
The last issue related to governance and the fact that many of the countries included in the MHII research have rights-based policies in place that include social inclusion as a goal for those affected by mental health problems and the right not to be discriminated against. However, the MHII showed that only 7 countries are making use of patient recorded outcome measures (PROMS) develop by or in association with service users.
Regarding next steps, Peter Huxley expressed his hope for the MHI research to be repeated over time. Data quality needs to be improved and the Index can make a contribution to understanding knowledge transfer of effective interventions. The most important step is to study how policy and policy changes directly affect quality of life.

Discussion

The following issues were raised:

- There is a **lack of research data** on the issues faced by people affected by mild to moderate mental illness.
- Policy development should include measures to ensure better integration of people affected by mental health problems, and also focus on **mild to moderate mental illness**. While important, the focus should not just be on severe mental disorders such as schizophrenia or bipolar disorder.
- The EU has adopted a **Directive prohibiting discrimination on the grounds of disability**. Mental health could be regarded as a disability. However, discrimination is still very common.
- The **Europe2020 Strategy** includes a set of clear employment targets; however, the impact of mental health of people's ability to work is not considered anywhere.
- **Human rights** can be used as a useful policy hook for policy change. For instance, the move towards deinstitutionalisation was inspired by principles of human rights. However, it needs to be realized that in some countries the human rights approach has meant that people with mental health problems are treated the same as anybody else. This does not always work as in many cases extra support services are still required. Human rights does not merely equal access to services in theory – in practice people with mental health problems need support in accessing (special) services.
- Mental health at work and the needs of those affected does not feature on the agenda of the **trade unions**; there is no pressure from members to do so as those with mental health problems are not organized or vocal.
- Current research data are limited and **representativeness of data** across the EU is lacking. This is a barrier to effective change
- Recent research has shown that 40% of those caring for somebody with dementia are clinical depressed. A special programme (START) has been developed to **support relatives** of dementia patients. It would be useful to know whether there are any other programmes such as this in existence. In many instances NGOs are the drivers and suppliers of this type support programme.
- For those with mental health problems it is not simple to just get back into work. **Employers** have to made more aware of and respond to this.
- The economic crisis has led to widespread **insecurity about employment** and this can have a serious effect on mental health. It is too early to tell but it could be that this new insecurity could lead to new chronic anxieties.
- **Social security systems** should cater for people with mental health issues getting back into work and then failing. In many cases it is difficult to get social support back.

Conclusions

In conclusion, **Nessa Childers** stated that, while mental health is a national responsibility, there are ways the EU level can help, for instance by funding research, and facilitating the exchange of good practice. The new Commission may be willing to put a stronger emphasis on mental health but that remains to be seen. The Interest Group will in any case play its part and keep exerting pressure on the EU institutions.