



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



**Mental health, patient empowerment
and self-management of care and treatment**

Call to Action

16 May 2018, 11.00 – 13.00
European Parliament – Room A5F 385

MEETING REPORT

Meeting chair **John Bowis** opened the meeting and gave the floor to **host MEP Tomas Zdechovsky**, who welcomed participants and underlined his interest in all issues related to mental health. He reminded participants on the March workshop which he hosted, which formed the basis of the Call to Action that would be discussed today; as empowerment is at the heart of improving the conditions and quality of life for patients across the board, this Call will be an important advocacy and awareness raising tool inside as well as outside the European Parliament. It will help make mental ill-health more visible.

In his introduction to the meeting, **John Bowis** stated that the concept of 'empowerment' sounds strong coming from a politician. Politicians can have power, but only with the consent of the people that are affected by laws and are participating in that power. Self-management is a more descriptive and more practical form of words. It is not an absolute concept as it refers to enabling people to self-manage their treatment and care to the extent of their ability and their wish.

Fortunately, mental health is rising up the policy agenda, as - for example - demonstrated by the recent UK initiative on children and young people in mental health.

However, the allocated budget is not in line with this political attention: only 13% down to a miserable 4% of health budgets is spent on mental health. As mental health is one of the fastest growing areas in healthcare this needs to be corrected. In addition, current paternalistic attitudes need to be corrected. This was undoubtedly well-meaning when it started but it has now bedeviled the system, with paternalism taking control. Paternalism leads to stigma, and stigma (by others or self-imposed) adds to the burden of people trying to cope with and manage their mental health. This attitude suggests that individuals can't be involved with or in charge of their healthcare and decisions that concern them. We want to show that people can be enabled to do just that, with the range of services and treatment in support, e.g. psychotherapy, medication, distance monitoring...The opportunities offered by new technologies should be fully used to enable people to take control.

All of us who have physical health needs may have mental health problems as well and vice versa. A holistic individual approach needs to be put in place. The March expert workshop designed the makings of a Call to Action; this has now been put into words that can be used beyond this meeting. Participants were invited to reflect on the text as it stands and come forward with comments so that it can be finalised put to action.

‘The allocated budget is not in line with this political attention given to mental health: only 13% down to a miserable 4% of health budgets is spent on mental health’



"Patients should be considered a resource; empowering patients will ensure the best possible 'use' of that resource and put patients at the heart of care provision."

Patrick Colemont

Vice President, Ups & Downs

Before passing the floor to **Patrick Colemont**, **John Bowis** welcomed the other MEPs present, i.e. **Nessa Childers**, **Ana Zaboraska**, **José Ignacio Faria** and **Julie Ward**. He apologised for **Francesc Gambus MEP**, who was unexpectedly detained.

The first speaker, Patrick Colemont (Vice President, Ups & Downs) briefly introduced his Ups & Downs as a self-help organisation for people suffering from bipolar disorder and chronic depression' run by patients or experts by experience. Patrick Colemont himself was professionally inactive for five years because of mental ill-health.

He underlined the burden of mental health with some 27 % of the European adult population experience mental ill health every year. However, the proportion of national health budget devoted to mental health ranges between 4% to 13% across the EU and is not in line with this burden.

Mental ill health can affect persons at any age in a variety of forms, and go hand in hand with stigma, costs and consequences that impact individuals, families and carers, health and social systems, society and the economy.

Life expectancy can be reduced by mental disorders; there is a higher risk of comorbidities. Poor physical health increases the risk of mental ill health and children experiencing a serious or chronic illness are also twice as likely to develop emotional disorders. It follows that there is an obvious need to address mental ill health in the most effective way

On the positive side it can be noted that good mental health is increasingly recognised as important for economic growth and social development. However, on the negative side, there is still a lack of adequate mental health services and support available across the EU.

Patrick Colemont used the EPF definition to describe patient empowerment as 'a process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important'. It is opposed to 'disempowerment': this refers to taking away power from an individual. Unfortunately, disempowerment is widespread, within health care, education, the workplace and society at large.

Anti-discrimination legislation is in place in some countries; however, the stigma (individual and societal) attached to mental ill-health issue (as opposed to having a physical health issue) - is pervasive and can be viewed as one of the main barriers to patient empowerment.

Self-management of care and treatment is an important element of patient empowerment, as it refers to the active engagement of patients in dealing with his/her health problem. Contrary to popular belief, most people with mental ill health, most of the time, do have the competence to self-manage their treatment and care. So, it follows that empowered patients should be regarded as a precious resource.

Mental ill-health needs to be better addressed as a matter of urgency and at a variety of different levels. Involving patients with the treatment and care decisions that affect them will ensure patient-centredness as well as treatment relevance and effectiveness. This in turn will contribute to sustainable health systems and budgets, will help increase the self-confidence and facilitate the integration of people affected by mental ill-health in the community. Patients should be considered a resource; empowering patients will ensure the best possible 'use' of that resource and put patients at the heart of care provision.

Finally, Patrick Colemont made a plea for careful use of language and the need to find more positive words and concepts; for instance, let's speak of 'self-management institutes' instead of psychiatric hospitals.





"The slogan 'nothing about us without us' is more than a slogan; it should be a guideline."

Katarina Nomidou
Secretary General of
GAMIAN-Europe

John Bowis then gave the floor to **Katerina Nomidou (Board member, GAMIAN-Europe and President, POPOPSI, Greek Federation of Mental Health Associations for Families and Service Users)**, who shared her personal experience of disempowerment, related to the schizophrenia affecting her brother. Stigma does not only impact the person affected by mental ill-health; it also applies to family members. The disempowerment and shame experienced earlier in life has motivated Katarina Nomidou's career choice and current activities.

Katarina Nomidou defined patient empowerment as 'the removal of formal and informal barriers and the transformation of power between government, the community and individuals' (WHO definition) and underlined the structural nature of stigma, occurring at all societal levels. It will be difficult to effectively address stigma if governments do not acknowledge the stigmatising nature of some of the laws they pass. For instance, in some countries' patients are not allowed to vote. However, it is not just governments; services need to become much more human rights and person-centred. In order to really address stigma and disempowerment effectively a multi-dimensional and multi-level effort has to be made. This is also at the heart of the Call to Action, as proposed by GAMIAN-Europe: it addresses the various players with specific recommendations for action, i.e. policymakers, health professionals, payers, social services, patients and carers' organisations, schools and universities. The UN Convention on the Rights of Persons with Disabilities should also be seen as a tool to effectuate change. For change and progress to happen relations between the various stakeholders need to change. A transfer of power will need to take place, especially between patients and health care professionals. A human rights approach will be indispensable. Schools and universities should include mental health in their curricula and training courses. Families need to be addressed and supported. Change can be made if patients are involved in a meaningful way with the decisions that concern them. The slogan 'nothing about us without us' is more than a slogan; it should be a guideline.

Katarina Nomidou also underlined the importance of the upcoming European elections as an important focus point for advocacy and change.

PANEL RESPONSE

John Bowis then gave the floor to the first panelist, **Silvana Galderisi (President, European Psychiatric Association)**, who briefly introduced her organisation and outlined why patient empowerment matter to health professionals. Empowerment can contribute to the active engagement of the person with a health problem which is associated with more favourable outcomes, increased collaboration in diagnostic and treatment plans a lower number of errors and reduction of stigma.

In mental health care, empowerment can lead to reduced substance abuse, improved quality of life and increased autonomy. It also empowers health care professionals and can help reduce cost and burden of care. However, Silvana Galderisi underlined that empowerment is not all or nothing; rather, it is a process. Persons affected by mental ill-health differ in their preference for the degree of empowerment along a continuum ranging from absolute dependency (doctors know and decides all) to absolute independence (the doctor is a consultant).

From the health professionals and policymakers point of view, main barriers to patient empowerment relate to stigma/prejudice, lack of resources, lack of information, poor communication skills, poor empathy and poor implementation of patient-centred health systems. For those affected by mental ill-health, self-stigma and poor self-confidence, lack of information, poor communication skills and difficulties in interacting with the health system are the main challenges.

The EPA takes an inclusive approach and actively collaborates with organisations of patients and carers. In addition, the EPA regards good communication skills as essential to enable professional carers to discuss with users risks and benefits of treatment options, clarify their values and preferences, examine together skills and self-efficacy, effectively present information and recommendation, discuss care pathways and share decisions. Therefore, the EPA summer school provides trainees and early career psychiatrists with a basic training on communication skills and, to further promote this approach, the EPA Education Committee has implemented an online training course, open to all those willing to improve communication skills.

"Lobbying for more resources from health insurances and systems like the NHS is crucial, as is the inclusion of training and research institutions, as well as employers/social partners."

Silvana Galderisi

President, European Psychiatric Association



With respect to the Call to Action, Silvana Galderisi stated that it is timely, effective and balanced. Different (shorter) versions could be developed targeting specific audiences. The current lack of financial and human resources could possibly be emphasised more. Recommendations for social services probably require a more detailed articulation, taking into account the involvement of other sectors. Lobbying for more resources from health insurances and systems like the NHS is crucial, as is the inclusion of training and research institutions, as well as employers/social partners. Silvana Galderisi stated that EPA will certainly endorse the call, support its promotion and, through National Psychiatric Associations, favour lobbying activities at national level.



The second panelist, **Margaret Walker (Executive Director, EUFAMI)** briefly introduced the European Federation of Associations of Families of People with mental illness (EUFAMI), as the representative body for family and carer associations throughout Europe, promoting the interests, rights and wellbeing of people with mental illness and their families and carers. It was founded in 1992 and represents some 25 million carers. She thanked GAMIAN-Europe for its initiative and work on empowerment and self-management of care – these topics are an obvious part of the work of EUFAMI.

A recent survey, commissioned by EUFAMI, has shown that some 80 % of carers are women, and the average age is 60. An average number of 22 hours of caring is spent per week. In 36 % of the cases, the family carer is the only care provider. This means that there is no respite and care provided can be throughout life – especially when the person cared for is affected by a serious mental health condition.

The impact of caring cannot be underestimated and can be felt in many areas of life. For instance, those carers that are not able to combine paid employment with their care responsibilities lose out on social security rights and pensions. Clearly, resources need to be allocated to ensure support for carers to prevent the care burden from being too overwhelming – emotionally as well as physically. The growing number of young carers also needs to be taken into consideration.

EUFAMI believes that caring should not be an obligating but rather, an informed choice, and the fact that the Call explicitly mentions this is very welcome. This choice needs to be supported.

Like previous speakers, Margaret Walker emphasised the stigma attached to mental ill-health and the need to address this as part of any initiative in the field of empowerment. This means that education in a wider sense is needed. Stigma can lead to isolation – of patients and carers alike.

Carers need to be involved in the entire patient journey, from diagnosis to care and treatment. Major care gaps still exist when a person affected by mental ill-health is transferred from hospital to the community and this needs to be addressed as a matter of urgency. Moreover, the huge differences in access to care across the EU need to be addressed. Family care is sometimes viewed as the safety net if all else fails – but this can only work when carers obtain the support they need to continue to care.



"Resources need to be allocated to ensure support for carers to prevent the care burden from being too overwhelming – emotionally as well as physically."

Margaret Walker

Executive Director, EUFAMI



"The Call needs to be in line with the UN Convention on Rights for People with Disabilities."

Maria Nyman

Secretary General, Mental Health Europe

The third speaker was **Maria Nyman (Secretary General, Mental Health Europe)**, who first reminded the audience about MHE's mission, i.e. to advocate for positive mental health and well-being and for the rights of people living with mental ill-health and to raise awareness to end mental health stigma.

The organisation works from a human rights perspective and takes a social model of mental health as its guiding principle. Empowerment concerns us all. Stigma needs to be tackled across society; awareness of the need for empowerment and human rights needs to be raised across the board. Better awareness and more information will also help address self-stigma. Empowerment relates to equality; it also relates to the ownership the recovery process. Formal Barriers to empowerment are still widespread, such as guardianship regimes. The UN Convention on the Rights of People with Disabilities can help address these issues and is a tool that should be used; it explicitly states that patients have the right to be part of the decisions relating to his or her treatment. The Call needs to be in line with the UN Convention on Rights for People with Disabilities for MHE to be able to endorse it.

Maria Nyman also underlined the importance of the use of language. The word 'patient' is disempowering in her view; it can add to self-stigma. It is important not to self-identify with mental ill-health; this is just a part of who a person is. She recommended the MHE website in this respect as suggestions for better use of language can be found there. Stigma can be tackled through the use of language.



The final speaker was **Wilma Boevink (Expert by experience and social scientist, Trimbos Instituut).**

As expert by experience and social scientist, Wilma Boevink (Trumbo's Instituut, NL) talked about her personal experience, underlining the enormous potential of persons dealing with mental ill health, in particular those with ongoing serious psychiatric complaints.

Recovery, empowerment and peer support are very important and hopeful concepts in the lives of persons being patients in psychiatry.

Wilma Boevink warmly welcomed GAMIAN-Europe's initiative on empowerment and self-management of care and the Call to Action and suggested to add pharmaceutical companies as one of the stakeholders to call upon as these play a powerful and crucial role in the debate on how mental ill-health should be framed. In this respect, Wilma Boevink suggested skipping the term "personalised medicine" altogether and replace it by "personalised interventions" as medicine is not the one and only tool for treatment, care and recovery.

As a social scientist Wilma Boevink noted how users of mental health care services are taking the lead in giving content to the concepts of recovery, empowerment and expertise based on experience. User involvement refocuses the relevance of care on the daily life of a person, i.e. on having meaningful relations, on being able to participate. Traditional psychiatry has an exclusive focus on what goes wrong, disregarding personal strengths; User involvement revalorises what matters for users of mental health care.

At Trimbos-institute it is felt that a User Research Center is the primary instrument to accumulate the evidence that will help develop and implement recovery-oriented care into mainstream psychiatry. The added value of experiential expertise and user research is beyond any doubt. However, the development of experiential knowledge is challenging and demands new ways of conducting research. With the current deliberations on FP9, the European Commission, Parliament and Council have a unique opportunity to make a huge difference for people with mental ill-health; mental health can be made a key part in this new R&D Framework Programme, taking the results of the ROAMER project into account.

We should skip the term "personalised medicine" altogether and replace it by "personalised interventions" as medicine is not the one and only tool for treatment, care and recovery.

Wilma Boevink

Expert by experience and social scientist, Trimbos Instituut



DISCUSSION



Jose Ignacio Faria, MEP

Jose Ignacio Faria MEP underlined the importance of today's discussion, particularly the focus on stigma. Mental ill-health -as opposed to physical illness- is not really visible. He also underlined the importance of informal careers in caring for persons affected by ill-health, as they have no support and often no access to information and services. Often, carers have no or diminished access to pension rights, as a result of decreasing or leaving paid employment as a result of caring responsibilities. Fortunately, those affected by mental ill-health as well as their carers are finding a voice and actively advocating for change.

Julie Ward MEP underlined the need for a common response from those involved with mental health, advocating a persons-centred approach. Mental ill-health is not just something that happens to other people; it affects all of us and our families. We have to get that message across somehow if stigma is to be addressed effectively.



Julie Ward, MEP

She reminded the audience of a recent EUFAMI project, where works of art (produced by people affected by mental health issues from all over the world) were exposed, expressing the human side of mental ill-health. Art and culture need to be included as a tool to 'normalise' mental ill-health. We have to be more creative in listening to and hearing the voice of patients. The use of the arts can give performers new confidence and expression and helps others to understand better.

Andreas Maercker (European Association for Clinical Psychology and Psychological Treatment) briefly introduced his recently established association, and welcomed the Call to Action, mostly because it underlines the need to support patients in the treatment and management decision making processes. He also emphasized the importance is building more capacity for psycho-education and the need to create different settings for peer support as the knowledge of patients cannot be underestimated.

Strengthening health literacy is crucial but it is not always easy to assess the quality of information provided. The evaluation of information and its quality needs to be strengthened.

Two orientations are possible when addressing mental ill-health: a 'resource' orientation (where empowerment plays a critical role) or a 'deficit' orientation (which is related to stigma). The first is the preferred one as this relates to helping people 'help' themselves. The new association reflects these changes in thinking and will strive to ensure that mental health becomes a more important and visible issue in society. The threshold to go and see a psychologist is now lower than ever before; therapy is an important means to recovery. Psychopharmacology is not the only possibility.



Andreas Maercker

European Association for Clinical Psychology and Psychological Treatment

Nessa Childers MEP emphasised the importance of the use of language and the need to ensure that language is not disempowering. It might be useful to devote a meeting just to the use of language, in training as well as in communication.

Other points raised:

- **Pride** is the opposite of stigma; psychiatrists should be proud of their role and contribution.
- Policymakers need to be made more aware of what patients need.
- Patients need to be meaningfully involved in research and development projects if we want to develop better treatment solutions and more empowerment.
- Mental health should be made a priority in the next European elections. However, we should not wait for these as there are dedicated policymakers in place now too.
- The rules and concept of patient confidentiality should not be used as a reason to exclude and not inform parents and carers; these can be an accelerator of recovery. While of course necessary, these confidentiality laws have to include a sense of proportionality and should not be abused.

In **conclusion**, John Bowis invited participants to send in comments on the Call to Action (**hard deadline: 22 May COB**). The Call can make a contribution to the quality of life of those affected by mental ill health and their carers and can have great value as an advocacy tool.

He thanked all participants for their contributions so far and urged them to endorse the Call once finalised.



Nessa Childers, MEP





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