



## Interest Group on Carers

and

## Interest Group on Mental health, Well-being and Brain Disorders

Wednesday 10 July,

**The Joint Action on Mental health: Community Care**

### ***Meeting report***

**Marian Harkin MEP** and **Nessa Childers MEP** opened the meeting, reminding participants of the aims of both Interest Groups, i.e. to discuss and debate European policy development for their impact and to initiating policy action that can lead to or influence EU policy initiatives. Ms Harkin underlined the importance of this Joint Meeting, as this will amplify the voice of both Interest Groups within the Parliament as well as provide greater visibility for the two areas of activity. The joint meeting was organised to provide background information on the Joint Action on Mental Health - its aims and expected outputs - more specifically in relation to the planned actions on community care; it also had the objective to raise awareness of the importance for policymakers to take account of mental health and well being, for patients as well as carers.

The first speaker, **Jürgen Schefflein (European Commission, DG SANCO)** provided the context and background of the Joint Action on Mental Health. The Commission views mental health not just as a disorder, but also takes the potential of health promotion and illness prevention into account. The WHO's Global Burden of Disease update for 2010 has recently reported a shift from communicable to non-communicable diseases and that mental disorders are one of the categories which would lead to increasing challenges for health systems.

Social factors play a huge role in mental health. Social exclusion, for instance, can be a cause as well as a consequence of mental illness.

The 2010 EBC study has revealed that, issues related to mental health cost the economy 800 million Euros each year. The current crisis is impacting on mental health as well: financial difficulties through job loss, job insecurity and stress all take their toll. Investment in mental health is urgently required – and the Social Investment Package, one of the Commission's latest initiatives, urges Member States to invest more in social resources – but resources are scarce.

One of the specific EU level initiatives in the field of mental health is the European Pact on Mental Health and Well-being; this sought to raise awareness of the challenges of mental health in 5 main areas, i.e. stigma, depression and suicide, mental health at work and mental health in older and younger age groups. The Pact aimed to grow understanding of mental health issues at national level and to stimulate taking account of these issues in all relevant policy areas. The Pact was implemented in cooperation with different actors; apart from a number of different Commission DG's a large number of external stakeholders was involved. A milestone in the implementation of the Pact was a set of Council conclusions on mental health, adopted in June 2011. There is an ongoing commitment to focus on mental health issues, as demonstrated

by the current Lithuanian Presidency. The current key initiative to implement the Pact in work with Member States is the Joint Action on Mental Health and Well-being under the EU-Health Programme.

The Pact did not have a strong focus on carers; however, one of the Pact's conferences (mental health in old age) organized a workshop on carers; the vital role of carers in reforming community care health systems was emphasized on this occasion. Moreover, the Commission has built a good cooperation with EUFAMI, and Commissioner Borg participated in its annual conference of this year in Dublin. The Commission is also involved with mental health research and one of the projects, ROAMER, looks into well-being issues, including the well-being of carers. Mr Scheftlein referred to a 2012 study by L. Bradshaw and others<sup>[1]</sup>, which points out that the mental health of carers is poor in one third of the cases. Interestingly, there was no difference between carers caring for their family member at home or for those in care homes. This means that health professionals need to be alerted to sources of carers strain. The study also revealed that, in many cases, carers feel undervalued and under-recognised. A study from Australia (R.A. Cummins et al, The Wellbeing of Australians – Caregiving at Home, 2005) showed that carers have the lowest well-being levels of any group under study. Depression in particular is very high. Female carers have lower well-being rates than males; in many cases they feel the strain of trying to combine care responsibilities with employment. An article by K Jones (2009) had expressed that carers often feel undervalued.

It is clear that further EU level mental health action will need to include carers as they play a vital role in community care.

The next speaker was **Professor José Miguel Caldas de Almeida** (University of Lisbon and Coordinator of the Joint Action on Mental health). Professor Almeida highlighted two main reasons for the development of the Joint Action: the high prevalence of mental disorders in Europe (and the burden that it brings for individuals and Society) and the huge treatment gaps across the EU.

The Joint Action will build on the work of the European Pact for Mental Health and Well-being. It also gives sequence to the June 2011 Hungarian Council conclusions. The main objective is to contribute to the promotion of mental health and well-being, the prevention of mental disorders and the improvement of care and social inclusion of people with mental disorders in Europe. In order to reach these objectives, a process for structured collaborative work is being established, involving the Member States, EU institutions, relevant stakeholders and international organizations; this should eventually lead to the development of an endorsed framework for action. Four main themes will be addressed, i.e. promotion of mental health at the workplaces and schools, promoting action against depression and suicide, developing community mental health care promoting the integration of mental health in all policies. The Joint Action is expected to lead to several outcomes:

- Comprehensive knowledge on the situation in Member States in the Joint Action's theme areas
- Inventory of existing evidence, best practices and available resources;
- Strengthening of national and European networks;
- Recommendations for action;
- Building capacity of national mental health leaders and other stakeholders in policy development;
- Framework for action by Member States and EU agencies, and commitment for follow-up action;
- Establishment of a structured stakeholder cooperation

Work package 5 of the Joint Action relates to managing the evolution towards community-based and socially inclusive mental health care. Its objective is to develop a common framework for action to establish community-based and socially-inclusive approaches to mental health, identifying barriers, facilitating factors and good practices in the process of transition from institutional to community care. It will also aim to formulating collaborative actions that could be taken at Member States and at EU-level to overcome the main challenges identified in this process.

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<sup>[1]</sup> <http://www.ncbi.nlm.nih.gov/pubmed/22887452>

Work will consist of:

- Developing a common template and methodology to analyse the situation in countries regarding development of community-based and socially inclusive approaches in mental health;
- Developing a report on the situation in the participating countries, with a description of best practices and identification of barriers and success factors;
- Developing a report on existing knowledge on the implementation of community-based and socially-inclusive approaches to mental health in Europe (cost-effective interventions, strategies leading to change, tools to improve quality of care);
- Identifying data bases of different audiences involved in mental health policy and services development both at national and European level, and producing of materials for dissemination addressed to different stakeholders;
- Developing and assessing collaborative actions supporting the development of community-based care and promotion of human rights and social inclusion of people with mental health problems (e.g. capacity building of mental health leaders, strengthening of participation of users).

The Joint Action was launched 2 months ago. It is looking at areas where more info needs to be collected, more specifically at the factors that cause interventions to succeed or fail. Families and carers are essential in this process as they carry a huge burden and lack support. Professor Caldas de Almeida concluded by underlining that community care improves access to treatment and is the best way to create synergies. It helps promote social inclusion. It looks at housing, day centres, vocational training and employment. Obtaining the commitment of policy makers: that is what the Joint Action is all about.

After Professor Caldas de Almeida's presentation, **Marian Harkin MEP** gave the floor to a panel of stakeholders. The first speaker was **Frank Goodwin (President Eurocarers)**, who underlined the need for a lifecycle approach in relation to community care provision and the need to build citizen empowerment and engagement. The Joint Action seems to do just that; it also facilitates discussion and debate on mental health and how to preserve it. Looking closely at the factors that help or hinder mental health is imperative. Mr Goodwin stressed that some 80% of care across the EU is being provided by informal carers. Caring equals long hours and hard work. It can lead to loneliness and isolation. The caring workload is increasing in terms of hours per day in terms of overall duration due to longevity and increased complexity of multiple conditions requiring high level care. Most carers are in employment and provide essential care to someone with a long term illness or disability. About 25 % of carers are engaged full time in providing homecare support to relatives and friends with long term illnesses and disabilities. There is a need for greater involvement and commitment in relation to those with long term care needs and their carers.

Carers are often diagnosed with stress, anxiety and depression. They very often neglect their own (mental) health due to pressures of caring: research has pointed out that 30% of carers state that their health is affected negatively by their caring role.

The walls of silence surrounding mental illness should be broken down. The impact of current austerity measures should be carefully monitored, also for their impact on carers. Eurocarers is happy to join the Joint Action and make sure that carers issues will be taken into account.

The next panellist was **Pedro Montellano (President GAMIAN- Europe)** who provided the vision of patients on community care. GAMIAN-Europe, a patient-driven pan-European organisation, represents the interests of persons affected by mental illness. The organisation underlines that development of new treatment is more than development of new medication and that inclusive thinking (involving the patients) is required. The patients' vision on treatment and care is holistic and based on experienced burden. Combating physical, neurological and biological symptoms is important and psychotherapy, psycho-education and self-help groups are essential. Community care can guarantee this holistic approach as this type care can offer better treatment through personalized medication, better access to psychotherapy (50% of patients with schizophrenia receive only medication, only 33% receive psychotherapy, better information (psycho-

education) (only 16%) and access to self-help groups (only 20%). Community mental health care can also offer more respect of patients rights, better access to care (both in geographical as well as in financial terms). Lastly, community mental health within institutional care can help break down the walls and open the institution to the society, with citizens coming into the institution and patients going into society. There is a need for collaboration between institutional care and community care: short stays in hospital can be essential in the recovery process. GAMIAN-Europe is actively participating in the Joint Action's Work Package on Community Care.

**Kevin Jones (Secretary General, EUFAMI)** welcomed the Joint Action on Mental Health, especially the Work Package on Community Care. EUFAMI is committed to play a proactive part in all its relevant tasks as it supports the concept and principles of Community Care and maintains that modern mental health system should deliver a range of activities to promote positive mental health in the community. However, EUFAMI also notes the paradox of community based services: when care is provided in the community the burden of care shifts to the family. Traditional forms of institutionalised care had the effect of taking the individual away from the family and to a large extent, taking away responsibility for care as well. Community care places extra demands on families who now act as the frontline. This is why EUFAMI underlines that, in order to turn community care from a curse into a blessing for the family and society, there must be formal and informal support for service users and carers. The stigma which often goes hand in hand with mental illness (and is a heavy burden for families) needs to be addressed as it reduces access to services and hinders integration into society. Families should have the right to choose whether or not to accept a caring role. The development of comprehensive community based services is seen as both essential and desirable if recovery is to be a realistic possibility. However, it is imperative that mental health care services provide the services outlined above to family members more effectively so that they can carry out frontline care, which is essential as a consequence of community care. The sharing of information on the well-being of the person affected by mental ill health is essential.

## **Discussion**

**Nessa Childers MEP**, opening the discussion, stated that it needs to be borne in mind that community care should not be driven by the need for austerity; community care needs investment.

In the discussion the following issues were raised:

***Definition of social inclusion for carers and patients:*** in response to questions relating to the definition of social inclusion, Jürgen Schefflein replied that the Joint Action has only recently started its work. In a more general mental health context social inclusion is defined as having the possibility to live in the community and outside of institutions; it also relates to being able to participate in society and employment, despite the challenges that this can bring, both for mental health patients as well as carers. Professor Caldas de Almeida replied that we need to look at different kinds of inclusion and address the discrimination of mental health patients across the board (e.g. at work, as citizens). People have the right to be engaged and involved rather than be treated in a paternalistic way.

***Community care as an essential element in recovery:*** participants remarked that the concern of shifting the care burden to families is justified. On the other hand, going back into the community and being a part of it is a vital element for the recovery for mental health patients. It is less stigmatizing than being in intramural care; it helps keep social roles and can avoid the need to rebuild one's life. Patients need to be in charge of their own recovery; and much expertise on recovery and being part of 'normal' life resides within patients; they are experts by experience and this vital pool of knowledge should be put to a better use.

***From social exclusion to social inclusion:*** it can be a challenge to change the concept of social exclusion into that of social inclusion. This is a different mindset and involves different segments of society.

**From medical to social model:** when it comes to community care, the social model should be prominent. However, it needs to be determined who will be responsible for the organisation and coordination of this care: local community, NGO's, national level? The local level would seem the closest to the citizens.

**Social exclusion of carers:** carers can be stigmatized as a result of caring for a person with a mental health problem, irrespective of the problem. However, carers should be seen as part of the solution rather than a problem. Recognition of carers is vital in this respect; they should be seen as an equitable partner in provision of care. This is slowly changing, thanks to the stronger voice of the NGOs in this area.

**The impact of mental health:** mental health episodes have a traumatic effect on the individual affected and his/her family. It needs to be borne in mind that it is not a matter of simply moving from one state of mind to the other; the episode is a crisis in itself. Feeling safe and then moving to being 'normal' again takes time and this needs to be communicated.

**Community care a blessing or a curse:** the fact that it can be difficult to get community care delivery right should not be a reason to continue to work on this. On the contrary, it is a reason to persist and make progress. This transition to community care is a complex process, which requires vision, technical capacity and resources.

**The distance between the EU and the local levels:** it was remarked that the distance between the EU level and the local level needs to be bridged. The Commission makes efforts to do this, for instance by supporting local action against suicide. The perception of issues to be addressed varies from whichever level they are looked at so this cooperation is indeed important. Finding resources to do this are problematic; the European Structural Funds can help here, although it is the national level that defines the priorities for action. In any case, issues relating to mental health needs to be communicated in such a way that it is clear to all.

**The impact of austerity:** too little is known of the impact of the austerity measures that will affect mental health and mental health services. This is a priority. For instance, in some countries, half of the young people have no job; the impact of this on their mental health is unknown. Clearly, resources are scarce and we need to be innovative; we need to reflect on how to keep high standards of care within new models and interventions. For instance, access to local level tools to assess the level of our well-being; making people aware of their own mental health could be helpful. We have to make sure we do not develop into an economy rather than a society.

Closing the session, **Jean Lambert MEP** referred to a report voted in the July plenary session of the European Parliament, addressing access to care for vulnerable groups. This includes various references to carers, and carers and their organizations have worked closely with the European Parliament to effectuate this. The value and recognition of carers are key words. The report also refers to a Directive on Carers leave. Moreover, the report pushes national government for impact assessment of cutbacks and their implications on those that are most affected.

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