



Joint Meeting of the European Parliament Interest Group on Carers and the Interest Group on Mental Health, Well-being and Brain Disorders

Brussels, 12 January 2016

Report

Marian Harkin MEP opened the meeting, welcoming the cooperation between the two Interest Groups as they have many issues in common; a joint voice is a stronger voice.

A recent EUFAMI survey, entitled 'Caring4Carers', commissioned to the University of Leuven University was the main focus of the meeting, and key note speaker **Prof. Chantal van Audenhove (LUCAS, the Centre for Care Research and Consultancy, University of Leuven)** presented its main findings.

The study investigated the experiences of family carers for persons with severe mental illness. Background to this work is the fact that the shift of mental health care provision towards the community increases the demands on family carers; it is therefore important to have a better idea of their experiences and needs in this respect.

Data were gathered between June and December 2015 2014 in 22 countries, with 1111 persons completing an anonymous questionnaire. The sampling frame consisted of carers linked with a family carer organisation (there were no other specific inclusion or exclusion criteria).

Some of the main outcomes:

- The typical carer for a person with a severe mental illness is female (80%) and around 60 years of age; 76% takes care of a son or daughter, 10% for a partner or spouse and 7 % for a brother or sister. On average, 22 hours are spent on care provision per week. The job of caring is often solitary and with little respite: 36% are the only carer, nearly half never take a break. Of those that do take breaks, only 6 to 8% relies on paid respite care.
- Caring for people with severe mental illness involves feelings of stigma and burden (one third of the respondents indicates they are at breaking point); however, these experiences can go together with positive feelings as well as more than half of the respondents indicated having discovered inner strengths, met helpful people, learnt more about themselves and became closer to their families.
- However, worry and stress mean that one third of carers lack sleep and feel depressed; and 1 in 5 is unable to see anything positive in their life. Moreover, caring can have a detrimental impact on the carers' own health; moreover, many carers face emotional AND social AND physical AND relationship AND financial burden. This cumulative and long-standing burdening experiences across life domains can weigh upon the balance and quality of family life.
- The survey also looked at the level of satisfaction of family carers with the support they received from patient/carers organisations (highest satisfaction), doctors, nurses, the workplace, social workers, pharmaceutical companies and insurance companies (lowest satisfaction).
- One of the most important sources of dissatisfaction is the felt lack of involvement in taking important decisions in treatment and care planning: only one third are satisfied and only 4 out of ten, feel that medical and care staff take them seriously.
- More information is critical: almost half of the respondents indicate that they are not satisfied with information on the longer term development of the illness of the person cared for. And lastly, there is a huge unmet need in terms of support: only 7 % of carers state they need no additional support. Eight out of ten carers would like more information (88%), emotional support (83 %), respite care (78%) and financial support (62%); ideally, this support would come from organisations such as EUFAMI and family organisations.

- Nine out of ten would want opportunities to meet and share experiences with professional carers (93%) and other carers (90%).

Based on all of the above, the Caring4Carers study concludes that there is clear evidence of inadequate recognition of family carers in mental health care despite high, cumulative and long-standing demands made on them. A paradigm shift that views family carers as a resource and a partner in the care requirements of persons with severe mental illness is required as a matter of urgency. Furthermore, the study recommends a number of issues for policy and practice, such as the need to raise awareness, the need for education on mental illness, for offering respite, for empowerment of carers and for better research and monitoring. It would be useful to build on this survey, setting targets for specific indicators, and measure again. The results need to be fed back into the policy development process.

The next speaker, **Spyros Zorbas (KINAPSI, Greece)** talked about his experiences as the carer of his sister, who is affected by schizophrenia. When his sister's illness became more challenging, exchanging views with people with more experience than he or his parents gave hope that recovery is possible. Following best practices and a sense of commitment would enable a better life, both for his sister as well as for himself and his parents. Mr. Zorbas gained a deeper understanding of mental health issues from books, the Internet, health professionals and family and patient associations. In reality, the burden of care-giving is too heavy to be carried by a single person, no matter their financial or social status. Searching for answers and sharing the process with other people is what associations and self-help groups are about and sharing good practices and offering/ receiving support from people who face the same problems is invaluable. However, good ideas and knowledge as such do not suffice; a human network is crucial to offer understanding and guidance.

Spyros Zorbas underlined the difficulty of knowing what is best when a relative is faced with mental illness. Stigma is an important element as well. For those who provide care, their personal priorities make way for the requirements of the person cared for. Caring for a person with a severe mental illness is a stressful experience; it is like living in an emergency situation all the time.

However, there is a bright side; Mr. Zorbas told the audience of discovering his inner strength and increased tolerance. His sister now goes to a Public Day Care Center twice per week: she is happy when she returns, she has a social life. However, not every professional, carer or family member knows about the support that is available; in many cases stigma prevents people from looking for best practices and helpful solutions.

The need for communication with like-minded individuals of a similar age people, who also care for a relative with a mental illness helped unite a group of people in 2007 in Athens. This was transformed into KINAPSI in 2008 (www.kinapsi.gr). Its mission is to provide support /help to siblings of those with mental illness, to promote networking and information exchange for siblings and for those with mental illness, to promote better conditions in public and private care facilities, to promote de-institutionalization and occupational rehabilitation for those affected, to organise events promoting mental health, and ultimately to provide care for people with mental illness and their siblings through a network of affiliated professionals and therapeutic institutions.

The current financial situation in Greece makes care provision in the community more challenging and with more difficulties: there is not enough support for people with mental health problems nor for carers. As a result, the number of involuntary treatments has increased during the last years. KINAPSI works to convince leaders at EU and national level that investing in prevention, in day care centers supporting carers and services in the community is the best way to avoid the high costs of hospitalisation – and much better for the quality of life of patients as well.

Lastly, Spyros Zorbas informed the meeting of an upcoming KINAPSI event, 'Mental Health First Aid', taking place in Athens on 11 October under the auspices of World Federation for Mental Health, bringing together associations of the mental health sector from across Europe to share their experiences of current practices.

The next speaker, **John Dunne (Eurocarers)** reminded the audience of the limited EU remit in relation to care provision and mental health. However, in recent years, an agenda has been emerging: the 2011

European Pact on Mental health and Well-being was the first initiative, addressing mental health in older and younger people, mental health in the workplace, depression and suicide and stigma. While useful, the initiative did not really address the role of the family. However, the 2013 Joint Action on Mental Health and Well-being, building on the work of the Pact, did include a work stream on community care. The 2012 Social Investment Package - focusing on the ageing agenda and sustainable economies - and the 2013 Social Protection Committee report on long term care were further useful steps on the way to an EU focus on long term care provision; and the current efforts by the Commission to develop a roadmap to address the challenges of work/life balance is a welcome development as well.

From the EUFAMI report it is clear that the vast majority of carers is overwhelmed by the burden of care. John Dunne underlined the most striking findings, e.g. the cumulative, multidimensional cost of caring and the worry many carers express about the future. Health and social security systems do presume on carers; and in general, it can be said that, where there are carers, they are exploited.

Of course, as also underlined by Prof. Van Audenhove, there are positive sides to providing care. But even if the carers themselves derive positive feelings from the care they provide, they may be providing care which is not of the quality required by the person cared for; in addition, they may be failing themselves by taking on too much.

The wide variety of long term care systems across the EU makes it a challenge for the development of a European approach. Public policy, chiefly concerned with health/social care and income support/social protection policies, varies. The legal context varies as well: in some countries, families are legally responsible for care provision (Estonia, Portugal). There are different levels of patient rights protocols and privacy and data protection regulations; levels of mental health capacity/resources and formal recognition of informal/family carers in the treatment process vary as well. The role of the state is also different.

John Dunne went on to state that social exclusion can be both cause as well as consequence of mental illness; the burden of care can lead to mental illness of carers. Carers are often diagnosed with stress, anxiety and depression in which case a co-dependency between the carer and the person cared can develop. The consequences can be fatal.

One thing is clear: providing care is becoming increasingly complex and the duration of time spent as a carer is on the rise as well. The EUFAMI study has pointed out the growing importance of peer support. However, the number of peer support groups is diminishing across the EU and these groups are becoming harder to sustain. These groups heavily rely on volunteers and the question is if and how the required peer support can be organised across the EU on a voluntary basis.

A recent study by EUROFOUND research on the future of informal care has found that there are a number of issues that impact on carers: there are worries about the future and about the present. There is a commitment to take on the care, with a limited and no guaranteed exit. Financial worries are rampant, and so are worries about the growing dependency of the person cared for. If the choice to become a carer is a conscious one it can help cope with the situation better.

The current trend towards shifting the burden of care to the community puts families in the front line; in many cases there is no possibility of a conscious choice. There are emotional and physical risks for those families. Clearly, carers need support; and it has to be said that that support on offer in many countries is sadly lacking. Carers carry a burden – John Dunne stated that they are the ‘Atlases’ of the EU – and without them, society will collapse. A system that cannot appreciate and support carers is not care friendly and therefore not sustainable.

Jürgen Schefflein (European Commission, DG Santé) focused on the role of the EU in the area of care provision for those affected by mental health problems, which is not easy and not always clear. The EU-level can help raise awareness and share experience in areas where its remit is limited, and can act as a catalyst for action within the Member States. There are some policy instruments that provide concrete support, such as the European Social Fund, and there are research funds as well.

The EUFAMI survey and the other presentations clearly underlined the importance of the role of carers and the need to recognize their invaluable contribution. The burden of caring is impressive; so are the problems related to this burden. For Jürgen Schefflein, the positive elements highlighted were an eye-opener, such as the determination with which carers play their role, and how providing care can be positive for carers as well as their cared-for relatives. Carers seem to be realistic about their needs and

expectations. Nevertheless, it should be possible to respond to these expectations as they are very concrete; and there are practical structural aspects involved as well.

In relation to mental health, the Commission has implemented the European Pact on Mental health and Well-being, which led to a set of Council conclusions in 2012. These were developed together with the authority of the Member States and helped shape the current Joint Action on Mental health and Well-being, which will come to a close next week. The recommendations stemming from this Joint Action will be presented at a conference on 21 and 22 January. These recommendations now need to be implemented. The EU Compass on mental health will be helpful in measuring results and tangible reports on what is happening will be produced over the next three years, along with specific events.

Jürgen Schefflein underlined that the Juncker Commission aims to be more concrete and focused than has been the case in the past: economic growth and financial sustainability are main priorities. This does not weaken the case of health and social policy in EU policy development– it actually strengthens these areas as a healthy population is key for economic growth. Therefore, improving health promotion, illness prevention, health literacy and self-care will be important. The knowledge about mental health needs to be increased, and awareness needs to be raised.

As co-morbidities are frequent, mental health cannot be left to mental health specialists alone. Better community care is needed for people affected by severe mental health issues. In-patient care should be avoided as much as possible, while ensuring support to families. Social inclusion and social infrastructures can support independent living for many. E-Health can make a huge contribution in this respect. In conclusion, Jürgen Schefflein emphasized the importance of involving patients and carers in defining and implementing care as a key principle for improving mental health systems.

Discussion

Financial crisis: budget cuts related to the economic crisis have had a major impact on health systems and care resources.

Refugees: the available resources to address the physical and mental health of the large numbers of refugees currently coming into Europe are becoming a real issue. GAMIAN-Europe is currently organising a regional seminar on this topic (taking place in March) and will also issue a Declaration, which can be discussed in one of the next meeting of the Interest Group on Mental Health.

EU Package on work/life balance: a joint undertaking between DG EMPL and DG JUST is currently underway in relation to developing a package of measures to improve work/life balance. One of the questions in this respect is how to improve the balance between work and caring duties and allow working people with care responsibilities to combine both. A consultation is currently being held on this topic. This is part of the Commission work programme for 2016. A broader debate on the legal basis for this initiative will need to take place as well.

A more demanding carers' advocacy approach: caring aspects are often seen as 'soft'. However, despite efforts of trade unions for decent working conditions, it seems to still be acceptable for women in particular to work much more, combining paid work and caring tasks. These working hours would not be tolerated in the paid workplace. Carers often have minimal skills, but are expected to carry out increasingly complex care tasks. They are left to sort out the care in the home without support from professionals. We need to be more demanding and more specific about what needs to be done to improve the situation.

Cooperation between carers and patients: patients and carers have to work together as they have many things in common, such as addressing stigma related to mental health, the need to/importance of work and many others.

The need for comparative studies to support better policy decisions: a study was done two years ago to describe the Member States mental health services profiles. This functioned as a starting point of the work of the Joint Action, where groups of Member States representatives worked together, looking at

existing literature and good practices and coming forward with concrete policy recommendations. We now have to make sure that the Member States act on these recommendations. Having Member States play a lead role in the Joint Action's Work Packages is one way of committing them. Some of the recommendations overlap with the WHO actions plans which has tangible targets (e.g. reduction of suicide rates).

Need for a legal base to act at EU level: the ongoing Commission work on combining work with caring duties is very welcome, but as long as there is no clear legal base for EU action, any proposal in this area may be blocked by the Council. Subsidiarity is the key word. The Council needs to be pushed into action; Council recommendations (also in the mental health field) are rarely being put into practice. Mention was made in this respect to the EU action on Alzheimer. This is not a 'competence' area either, but because of pressure from NGOs and a powerful Member State (France) we now have a set of Council conclusions mandating the Commission to take action. So, step by step, competences can be created and we could learn from this specific process to exert political pressure.

Making the care for EU action: In the case of the Package on work/life balance, this initiative follows the withdrawal of the maternity leave Directive. The new Package is broader and includes carers and will entail different types of instruments. We need to bear in mind the political realities; there will be an impact assessment which will take subsidiarity into account as the Council will need to agree and adopt the Package. A Directive would have been more forceful, but the new Package could still lead to positive action. Arguments in favour relate to the need to take into account the impact of the cross border health care Directive. There is also a link with Europe 2020, as demographic developments are rapidly leading to shortages of professional carers. All of this justifies this topic not being left to the Member States: there is a concrete European angle.

The need for a carers' strategy: the strategy as formulated by the Interest Group on Carers and Eurocarers needs to be put on the agenda. This identifies and recognises the role of the carer and calls for certain rights for carers (e.g. right to health care, respite, (peer) support). Questions remain as to whether we would require measures for specific groups of carers as the needs of the various groups (by age, by condition) vary enormously.

Close

On behalf of Eurocarers and GAMIAN-Europe, **John Dunne** expressed his thanks to Heinz K. Becker MEP for hosting the meeting and offering the lunch.

Bert Johnson (EUFAMI) welcomed the meeting and underlined the crucial need for family carers to be seen as a full partner in care provision. The care demand is increasing, and care is transferred from hospitals to the community care. This paradigm shift calls for a policy response. The EUFAMI survey should be seen as the start of a process; the report contains valuable information that can be used for advocacy purposes in our countries and associations.