

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

Effectively addressing schizophrenia in policy, diagnosis and treatment

Tuesday 5th November

Nessa Childers MEP welcomed participants and reminded them of the aims 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.*

Nessa also underlined the specific aims of this meeting i.e.

- to raise awareness of the need to address schizophrenia in a comprehensive manner;
- to highlight the benefits of appropriate and timely diagnosis and treatment for those affected by the condition and their families.

Professor Silvana Galderisi (University of Naples) started the meeting by briefly outlining some facts on schizophrenia. She described schizophrenia as mental illness characterized by disturbances of thought processes, disrupted perceptions and diminished or exaggerated emotional responses. Across the world, ≥ 26 million people are affected by the condition, which can affect an individual's mood and behaviour and psychosocial functioning. The condition has huge psychosocial consequences, also for the patients' families.

Part 1: GAMIAN-Europe survey on adherence to treatment

The first speaker, **Paul Arteel** (GAMIAN-Europe) presented the background, methodology and outcome of a 2012 GAMIAN-Europe survey on the patients' views on adherence to treatment in schizophrenia.¹ The survey included 403 patients from 18 countries and aimed to learn more real life experience, assess patients' experiences in different countries and investigate reasons for partial or non-adherence. It was compiled by a steering committee of patient representatives and academics. As adherence to treatment is more than adherence to medication, questions were designed to assess patients' experience with the four cornerstones of treatment, i.e. medication, psychotherapy and counselling, psycho-education and self-help initiatives. Understanding poor adherence from a patient perspective may help to identify ways to address adherence more effectively.

Some of the survey's general findings can be summarised as follows:

- 47% of respondents had been hospitalized five times or more;
- Most respondents believe it is important to take treatment as prescribed;
- Fewer than 4% of patients receive the 'best package of care' as considered by GAMIAN-Europe;
- 92% of respondents reported receiving antipsychotic medication;
- 40% of respondents received medication along with psychosocial therapy;
- 48% of respondents received antipsychotic medication alone
- Many patients did not consider themselves well informed about treatment options.

Regarding **stopping or not attending psychotherapy**, dislike of the treatment was the most often reported reason (29.4%). Lack of confidence in the treatment and financial reasons were a close second (22,9% and 22,5% respectively). The treatment not having an effect was a reason for 14,9 % to drop out.

¹ Supported by an unrestricted grant from Janssen Pharmaceuticals

In relation to **not currently taking medication or having stopped altogether**, side effects were the most common reason (31,3%). Lack of confidence in the effect, dislike of treatment and financial reasons were also given (18,1%, 12,5% and 7,6% respectively). It needs to be noted though that over 40% of respondents quoted unspecified reasons for stopping or not taking medicines currently.

Among the reasons for **not attending psycho education**, patients indicated that stigma and not wanting to be informed were the main reasons (32% and 30,3%). Financial reasons and not finding the information useful were other reasons (22,9% and 18,2%). Embarrassment to disclose one's mental illness is obviously a very powerful aspect.

As regards reasons for **not attending self-help**, lack of awareness of existing self-help groups was the main reason (23,7%). Lack of confidence in the effect or lack of effectiveness was also often reported (19,1 % and 17 %). Stigma (16,2%), lack of local groups (15,8 %) and financial reasons (6,6 %) were also referred to.

Interestingly, the survey found that patient organisations have a positive (and often underestimated) role to play as members of patient associations tend to have more positive attitudes towards treatment. Clearly, these organisations can help engage patients in treatment and encourage adherence. Members of patient organisations surveyed had a better understanding of the available treatment choices, were more positive towards treatment and were more likely to receive optimal care.

Paul concluded his presentation with the following observations:

- Adherence to treatment covers more aspects than anti-psychotic medication alone. However, few respondents received medication in combination with other therapies;
- Many patients were not well informed about treatment options;
- Families play an important role in the lives of patients with schizophrenia; patient care and treatment adherence are shared responsibilities;
- Many patients face financial barriers to accessing all forms of treatment.

Paul's presentation was followed by some observations from two respondents. The first, **Marc Hermans (Child & Adolescent Psychiatrist)**, warmly welcomed the survey, as this addresses the four cornerstones of therapy and takes a holistic approach. He also welcomed the fact that the survey made a distinction between adherence and compliance. The fact that it was a multilingual questionnaire, anonymously completed with most likely chronically ill persons as participants gave this questionnaire a lower access threshold. Marc noted that, as all survey participants are part of a patient network – which has a positive influence on adherence – with 63 % agreeing with the diagnosis and 74 % considering their illness as a treatable problem, the actual reality could be far worse.

He underlined that the survey clearly shows that psychotherapy and counseling are undervalued. This could possibly be explained by the current lack of regulations concerning psychotherapy; legal and official recognition of psychotherapy, with appropriate reimbursement rules, might help change this. Marc also commented on the fact that use of alternative medicine (e.g. homeopathy, herbal therapy, acupuncture) was not included in the survey. He underlined the importance of family, friends, carers and patient associations in fostering adherence.

Marc gave some suggestion to address non-adherence were also made. He strongly recommended trans-disciplinary actions as the best way to work towards recovery – involving researchers, clinicians, patients, carers, policy makers, media and the general public. Long-acting medication, fighting stigma and more research are also highly necessary.

Marc stressed the disruptive effect of hospitalization and the need for medication specifically developed for their use in children and adolescents.

The second respondent, **Rebecca Mueller (GAMIAN-Europe)** provided a personal insight into the effects of mental illness on those affected. Living with a mental illness affects the whole of a person's life and all the societal roles that are part of that. In Rebecca's case, the impact of the long time before a diagnose

could finally be made and the effect of hospitalisation on her life were quite severe. Rebecca underlined that, even if hospitalisation is the best solution at a given time, it is very disruptive. Treatment is obviously needed but it severely impacts on the lives of those affected. Once the diagnose has been made, once the label is there, stigma also starts to play a role. While stigma relates to all forms of mental illness, it seems to particularly apply to patients affected by schizophrenia. In the field of psychiatry, recovery seems to be a new concept. Looking at the possibilities of the person rather than just seeing the problems should become the trend rather than the exception. As regards, the survey, Rebecca was saddened to note that only 3 % of the survey participants receive the ideal 4-cornerstone treatment (medication, psychotherapy, psycho-education and self-help). It remains a huge challenge to inform patients of what treatment options exists and make them ask for these. In any case, it is hard enough for patients to ensure access to the best treatment available and manage their own illness. Patients need support; and it is useful to note the positive potential of self-help groups. Questions remain as to how to best address those that do not know the diagnose of their condition or do not know there is something wrong with them.

Part 2: Report ‘Schizophrenia: Time to Commit to Policy Change’

The second speaker, **Professor Silvana Galderisi (University of Naples)**, presented a recent report entitled ‘Schizophrenia: Time to Commit to Policy Change’². The goals of this report were to highlight the burden of schizophrenia and set out the current needs to policy makers and all relevant stakeholders who influence care quality. In addition, it aimed to

- Recommend areas for intervention;
- Support the commitment of stakeholders to creating a better future;
- Foster a positive outlook;
- Promote ‘recovery’.

The report was authored by international experts, including psychiatrists, researchers, policy advisers, nurses, patients, carers and advocacy groups and endorsed by nine professional associations and patient groups, including the European Brain Council, EUFAMI, GAMIAN-Europe and the Royal College of Psychiatrists (UK).

The report clearly fulfils a need as there are rising public expectations about increasing life expectancy and continuing high quality of life. Moreover, bringing new treatments to the world in areas of unmet medical need is no longer just about doing research.

Current challenges relate to the fact that medication is just one part of changing the lives of people with schizophrenia. Many patients still experience social isolation, unemployment, homelessness or imprisonment, poor quality of life, premature death and suicide and prejudice and discrimination. In fact, society as a whole faces these issues, not just people with schizophrenia and their carers.

The report lists a number of concrete policy recommendations under 6 headings:

- Provide an evidence-based, integrated care package for people with schizophrenia that addresses their mental and physical health needs. This should be underpinned with an integrated approach by their healthcare professionals and supported by the national healthcare system and by educational and research facilities;
- Provide support for people with schizophrenia to enter and to remain in their community, and develop mechanisms to help guide them through the often complex benefit and employment systems to enhance recovery;

² Funded by educational grant from F. Hoffmann-La Roche; writing support provided by Oxford PharmaGenesis Ltd.

- Provide concrete support, information and educational programmes to families and carers on how to enhance care for an individual living with schizophrenia in a manner that entails minimal disruption to their own personal lives;
- Consult with healthcare professionals and other stakeholders directly involved in the management of schizophrenia, in order to regularly revise, update and improve policy on the management of schizophrenia;
- Provide support, which is proportionate to the impact of the disease, for research and development of new treatments that improve the overall outlook for people with schizophrenia, including those that target negative symptoms and cognitive impairment;
- Establish adequately funded, on-going and regular awareness-raising campaigns to: increase the understanding of schizophrenia and emphasize the importance of positive societal attitudes towards mental illnesses.

The messages in the report will be communicated to as wide an audience as possible for maximum impact in order to create awareness and drive policy change.

In conclusion, Silvana underlined that better lives for people living with schizophrenia are a realistic goal. In order to reach this goal, the following are needed

- an integrated team approach
- collaboration with people with schizophrenia, their families and other sources of support
- adequate funding
- engagement by every stakeholder: policy makers at every level, clinicians and public agencies

The first of three respondents was **Jelmer Abrahams (Anoiksis)**; having been diagnosed with schizophrenia and schizo-affective disorder himself, he provided his outlook on what patients can do to maintain a good quality of life. As regards the report presented by Silvana, he underlined the positive notions it contained, most notably the focus on recovery and the motivation to be a healthy person. From his experience, personal motivation is very important, along with the acceptance of the condition and family support.

In The Netherlands, it is proposed to replace the term 'schizophrenia' by 'psychosis susceptibility syndrome' as it is believed that this new term will help de-stigmatise the condition. As far as dealing with the condition is concerned, medication can play a major role: if the right medication can be found it increases health and the positive sides of life. Psychosocial aspects are also very important; it is sometimes beneficial to 'leave' your mind and relax; sport is a good way of doing so. Furthermore, a healthy lifestyle is important: healthy food, lots of exercise, no alcohol, tobacco or cannabis. Jelmer himself benefits from neurolinguistic programming and yoga. Having the right information and psycho-education is also very important. Jelmer would advise all those with a mental illness to do what they can themselves to manage and address it.

Treating mentally ill people like healthy persons will have a very positive effect. Confidence building and being positive and realistic will help. It is also highly relevant to look beyond the illusions that people are experiencing and try to find out what is behind them.

In conclusion, Jelmer advocated the need for more recovery workers as their personal experience can benefit and support others. A focus on a person's strengths and qualities will be far more beneficial than merely addressing their illness.

The second respondent, **Mary Baker (European Brain Council)**, welcomed the report's strong message about the possibility of recovery and having a positive quality of life. The actual term schizophrenia means 'split mind'; in the classical languages of Greek and Latin. However, the Korean term when translated into English means 'disjointed thinking' – and this could apply to any one of us. The report underlines the high economic burden of schizophrenia; this is to a large extent caused by the lack of

connection between the various health services. Mind and body are being treated like two separate entities, with services in different places. The report links mind and body and this is very welcome. The voice of patients is crucial in raising awareness and effectuating change. Case histories enable empathy with the patient experience; this is what is often lacking.

Mary went on to underline the importance of the pharmaceutical industry as part of the health system. They should not be kept at a distance as their medicines can be life-changing for patients and their families.

A study published in 2011 by the European Brain Council has found that the cost of brain disorders amounts to 800 billion euro per year -more than is spent on cancer, cardiovascular disease and diabetes together. Brain disorders are not more important than anything else but the brain manages all human organs and the understanding of medication; in the case of diabetes, for instance, once a diabetic is depressed, hospital appointments are missed, medication is neglected and the secondary symptoms resulting in amputation and blindness occur. The economic cost of treating mental illness is high but not as high as it would be if left untreated. It is imperative to conduct research on the cost of not treating mental illness to provide a powerful argument for advocacy and action. The upcoming Year of the Brain will in all probability address the cost of non-treatment.

The last respondent, **Juergen Scheftlein (European Commission, DG SANCO)** underlined the Commission's continued interest in the field of mental health and the increasing cooperation with other Directorates General, such as DG CONNECT, which is looking at eHealth and telecare solutions. Juergen welcomed the report, which will help bring schizophrenia back to attention of stakeholders. It highlights the fundamental dimensions surrounding schizophrenia, such as the quality of life and care, social inclusion and access to work. In this context he referred to the HELPS-project³ under the EU-Health Programme between 2008 and 2011, led by the University of Ulm in relation to developing a protocol for promoting the physical health of residents in psychiatric and social care Institutions; its deliverables may be useful across Europe.

The current Joint Action Mental health and Well-being, which is led by Portugal, includes a strand on depression and suicide, with a focus on community care, which promotes social inclusion. However, the possibilities for action by the Commission are limited. There is still a need to raise awareness, as became clear from the refusal of the UN to include mental health in its Declaration on non-communicable diseases in addition to the four major physical disorders, despite the EU's concrete proposal to do so. Similar discussions are taking place in relation to action on chronic disease; in building up own work on chronic disease, the Commission will use a more integrated approach. Furthermore, there needs to be more of a balance between out-patient and in-patient care.

As far as the report's references to social inclusion and access to work are concerned, Juergen advised the audience to take this up with the Commission's Directorate General Employment, Social Affairs & Inclusion. The OECD has also discovered the better inclusion of people with mental disorders in employment as an important issue.

Juergen concluded by stating that it is useful to put pressure on policy makers. However, a broader effort is needed; pressure also needs to be put on other main stakeholders such as health professionals as well if the current mindset is to be changed.

Discussion

Bring in the wider employment and social affairs community

There is indeed a need to look at other parts of the Commission and Parliament to raise awareness and push for action, such as DG Employment and the Parliament's employment and social affairs committee. This will make sure that important themes such as diversity and inclusion are being addressed. Employers organisations and trade unions should also be engaged in this debate.

³ <http://www.uni-ulm.de/helps-net/>

The role of industry

The pharmaceutical industry has an interest and is working in this field: the Innovative Medicines Initiative (IMI) is actually addressing schizophrenia. However, industry realises that one single company cannot take on all the work required. Cooperation and partnership are essential.

The Roamer project:

ROAMER is a three-year project funded by the European Commission, under the Seventh Framework Programme, to create a coordinated road map for the promotion and integration of mental health and well-being research across Europe, based on a common methodology and conceptual framework that covers the full spectrum of biological, psychological, epidemiological, public health, social and economic aspects of mental health and well-being.

Schizophrenia and gender:

Males are more often diagnosed with schizophrenia as in females specific hormones seem to function as a protective mechanism. In child psychiatry, girls and boys are treated the same until puberty; after that a different approach is required.

Uncertainty amongst psychiatrists

Psychiatrists themselves don't always know what actions are most suitable and what to prescribe. For instance, there are many uncertainties about prescription of medicines to pregnant women affected by schizophrenia.

Labels and use of language:

'Schizophrenia' as a term has strong negative connotations. Labels and language matter; the potential name change in The Netherlands will hopefully lead to more curiosity and open-mindedness about the condition. However, it is not easy to change these labels. The WHO for instance seems very reluctant to do so (despite positive experiences with the name change from 'manic-depressive' to 'bipolar') as this terminology is so widely used. Politicians can support the acceptability of changed labels by starting to use new descriptive concepts in their public statements. Change may be gradual but using the new words in daily language will eventually lead to their uptake. It was also remarked that certain labels are not always equally meaningful, i.e. schizo-affective disorder. Others underlined that it is not a problem of the labels as such, but rather the problem of the negative perspectives attached to them.

The crucial role of carers:

Carers play a crucial role in terms of adherence to treatment, as documented by many studies. However, carers do not always know how to cope, even if they know the patient best. The health professional field grossly underestimates the potential of patients and carers; carers often feel unrecognized and unappreciated.

Adherence to psychotherapy:

Questions were raised as to whether this relates to dislike of psychotherapy, the therapy or the therapist? Psychotherapy is a question of desire; so compliance or adherence does not really apply in this area.

Nessa Childers MEP and **Jean Lambert MEP** thanked participants for their contributions and closed the meeting.