

## **Report Brussels preparation meeting Budapest conference on depression and suicide prevention due to be held in December 2009. Anne-Laure Donskoy.**

As you may remember this meeting was first scheduled to take place in April but had to be cancelled due to the swine flu crisis. The new date was June 4<sup>th</sup>.

### **A few general preliminary points:**

- Interestingly enough, I was sent documents at the last minute, on the afternoon of June 2<sup>nd</sup>, i.e. the day before I was due to fly to Brussels. I was not too impressed by this, considering that those documents had been ready by the time of the previous date.
- Many attendees were not present. Mary Van Dievel, for instance, was meant to be there but was not.
- I had no experience or knowledge of the European Mental Health legislation, which I think was a bit of a problem at times.
- I was mostly not prepared for Lundbeck. I had never heard of them. For those who you in the same position, Lundbeck was created in 1954. It is a commercial venture which supports bio-medical research. I had asked Peter the night before I left for more information but did not get any back. It was not that aspect of the Foundation which was represented but it's "Institute", i.e. the so-called education arm of the Foundation. Their representative, a French person living in Denmark, was remarkably aggressive and suave in turn, trying to co-opt me every time she could. She misunderstood me when I said I was working for Bristol Mind. She thought I had said Bristol Myers, the well known drug company. When she realised her mistake, the tone changed and she became quite nasty at times.

### **Notes and comments from the meeting**

- This conference is a partnership with Hungary. It signals a wish to work with EU members and asks: "Is there an interest at member state level in mental health?" Past experience suggests that there is not. So having a conference and implementing actions together is important..
- This will be the second thematic conference to implement the PACT.
- There was a "foresight study" conference in January in Brussels, followed but a roundtable if economic impact on of mental health.
- There was also a conference in the Czech Republic at the end of May on policy and care
- There will be a conference on Youth and Education in Sweden in September.
- The preparation for this meeting had been going on for the past six months. The idea is also to collect information about activities from around Europe and launch the PACT at the Hungary conference. To this effect, the Lundbeck representative told us at length about the work of the Institute which is about education of the patient, mental health issues, and the development of new treatments and to

support the PACT. Other examples included the Dresden initiatives around early interventions (for instance for pregnant women).

After the presentation of the conference, there was a lengthy discussion, with a theme which became recurrent throughout the day: should depression and the prevention of suicide be treated/presented separately at the conference or together? This showed that this was an issue and be discussed as an issue.

### **Conference objectives:**

#### Make the case for action against depression and suicide:

- Health systems and well being dimensions should be put forward. I argued that the conference should fully acknowledge the need for a social critique of psycho-social distress otherwise it would only be merely be repeating what has been said many times before and only focus on treatments. Ignoring the impact of the economic crisis and other social factors would in my mind be a mistake. The panel agreed but I am not sure this will happen on the day.

#### Present and endorse action frameworks:

- Building on and taking forward consensus paper for high level conference. This is referring to one of the documents sent to me the day before and which I attach.
- Background paper: key messages and compass key actions. Draft example: parents and early years, education and learning.
- This “consensus paper” is anything but a consensus paper as it represents the status quo and totally ignores (excludes) the views from the service user and survivor community. I did say so. The reaction was mixed. It was reasonably well received from some corners but not at all well received from Lundbeck and a couple of the psychiatrists.

### **Roadmap to Budapest:**

- Meeting with experts: 19<sup>th</sup> June, Luxemburg
- Mental Health and Youth and Education conference in Sweden, 29-30<sup>th</sup> September
- Scientific conference on suicide prevention in Stockholm, 14/15<sup>th</sup> October, which will be research oriented
- Budapest: the conference: 10-11<sup>th</sup> December

### **Key messages for the conference:**

- Depression is a key health problem
- Depression and suicide can be addressed effectively ("treatable mental disorders")
- Key factors: political issues
- Major responsibility for action lies with member states

### **EU added value for the conference:**

- Raising awareness
- Facilitate the exchange of good practice (through the consensus paper and Mental Health Compass)
- Promote the coordination and cooperation between member states and regions: I raised the issue of cultural differences between different regions and member states: should we strive towards too much (if at all) "normalisation" of mental health?
- Involve non- health agencies
- Involve non-governmental agencies and actors
- Commission research and collect data:

Sources: OSPI, EAAD, EHIS, WMHS. (I'm not sure what they are. I asked at several points that abbreviations and acronyms should be spelt out but they were not. Anyone who knows, please feel free to fill in!)

This is where mostly, but at other times too during the day, I pitched our standpoint with regards to the need for the collection of suicide data. At that point I was deluged by a lot of aggression from Lundbeck and some from a German scientist who works for the University of Wuerzburg, as well as from the Hungarian psychiatrists. The German scientist said that there was already a very good register with the right sort of data and no need for anything else. The usual arguments about non compliance, about patients not taking their medication, polypharmacy as the main reasons for suicides were put forward and nothing I could say at that point seemed to make any difference.

I think I may have made a bit of a difference during lunch when I mentioned the BBC's Panorama investigation which, after a long battle, forced Ely Lilly to publish its own research data which demonstrated the link between Seroxat and suicide in young adults. As a result, the UK government no longer prescribes this medication to under 18's. I also mentioned the example of patients on depot injections who simply could not be accused of not taking their medication, in particular those on

wards, who are usually more closely monitored than patients in the community. How did he explain those deaths? He could not!

I insisted my point was not about telling people not to take medication but to understand better those deaths where people were under neuroleptics of all kinds, provide patients with better information, more transparency about the data held by the pharmaceutical industry and more honesty all round about the true efficacy of medication. In order to do this, new kinds of data had to be collected, registered and researched. This implied a different approach to forensic data than the current one.

Anyway, it is very clear from this that if we want this extremely important aspect to be explored at the conference, ENUSP is going to have to fight for it.

### **Issues for the conference:**

I raised the issue that there was also a danger, partly because of the consensus paper, that the conference was going to focus too much on positive self-defined examples and ignore member states realities, cultural differences, political/economic and social factors.

Someone else said that certain regions and countries do really well but for the vast majority, the system does not work

### **Some of the representatives around the tables talked about their work related to the prevention of suicide:**

#### **The EUREGHA project (Flanders):**

In 2008, there was a surge in suicides in Flanders. (Issues in Nordic countries where there issues around the terminology of suicide prevention)

The purpose of the working party are to:

- Bring together regional and local authorities and experts that are promoting initiatives on mental health, more particularly:
- Identify priority activities on depression and suicidal behavior
- Combine, compare and benchmark efforts in the prevention of suicide
- Consider and value diversity in approaches
- Learn from each other and exchange experiences and best practices
- The outcome and the expertise might contribute:
- To provide insight of the actors closest to the target groups to the European level
- Opportunity such as Conference on Mental Health– Depression and Suicide at the end of 2009 supported by the European Commission and organized by Hungary.

- To further benchmarking where necessary and desired
- To further develop and facilitate exchange amongst policy makers and promote peer exchange between the field actors implementing preventive measures
- To develop best practices and projects

### **Lundbeck Foundation:**

Totally supports the European PACT and is in favour of “optimising treatment and management of treatments”, mostly medication but not only.

It intends to launch an “expert platform” at the Budapest conference “to support the implementation of the Mental Health Euro PACT”. This platform will be made up of users, carers, professionals and scientists. It will be “independent”

The main stance from Lundbeck was the education of the patient and compliance. She kept insisting that depression and suicide were treatable mental disorders and patients needed to be properly educated.

### **Hungary:**

New Hungarian mental health programme has been launched. There had never been one before and no special suicide prevention programme either. However, there had been a number of motivated and dedicated individual psychiatrists actively engaged in the field. Since the launch of the programme, the country has experienced the second biggest drop in suicides in Europe after Denmark while the prescription of anti-depressants has increased 10 folds at the same time. There is also a strong tradition in Hungary of social psychiatry, psychoanalysis, as well as self-help groups.

### **Conference sessions**

The meeting then concentrated on the conference sessions, looking to identify gaps etc.

What ENUSP needs to bear in mind is that the whole context for the conference is the European legislative framework. The conference organisers are also looking for a “good and wide European representation of actors”

**Sessions** (all sessions, as in attachment) will follow the following pattern:

- Policy framework: Key note lecture, epidemiology interventions?
- Policy programme (examples only): Scottish Mental Health Policy, Andalusian Mental Health Plan, Dutch Public Health Policy
- Stakeholder initiative

- Citizen/Civil society/User/Patient/Dimension
- Session 1: Policy Framework and Strategic Approach
- Session 2: Addressing the determinants of mental health and risk factors for depression and suicide
- Session 3: Interdisciplinary health professionals' dimension: the aspect of the criminal justice system has been added
- Session 4: Intersectorial dimension
- Session 5: Media / Internet
- Session 6: Health Care: Added to document: Access to services and availability
- Session 7: Knowledge base: this is probably where user-led research needs to be. Lundbeck rep kept insisting only scientific research that falls under the European framework could go there, i.e. "FP7- INNO" for those of you who know what this refers to, (I don't). I think we need to argue that by definition, we fall out of this dimension and have a perfectly legitimate discourse to voice.

#### **User budget for the conference:**

250 participants altogether:

- Speakers' expenses will be covered.
- There will be 80 places for Hungarian service users.

#### **What I believe ENUSP needs to do next:**

- Find "champions" to represent the "User/survivor" standpoint for each session. They will have to be extremely solid and we will have to argue quite strongly for their presence.
- I would suggest for instance David Webb to talk about suicidality and Peter to talk about the link between neuroleptics and suicide, Jan Wallcraft on crisis, I could talk about non suicidal self-harm (a lot of utter non-sense was talked about with regards to self-harm at the meeting, as I feared would happen).
- We probably need to bombard them regularly with emails, in a lobbying kind of way, to ensure a meaningful user/survivor presence at this conference, otherwise Lundbeck and cronies will seize the day (and the opportunity) to manipulate the event at the expense of what we believe in and fight for.