



ENTER Mental Health

Developing institutional and academic strategies across Europe for User Empowerment in Mental Health

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ENTER Mental Health

AQRP Conference

Montréal, Canada

10 November 2014





“Patient” : a concept of doubtful origins

6 meanings for the word ‘patient’
(according to Larousse Dictionary, 1873)

- ▶ He who suffers
- ▶ He who tolerates
- ▶ He who perseveres with tranquility
- ▶ He who has been condemned to death and is about to be executed
- ▶ He whom the inquisitor puts to the question
- ▶ He who is in the hands of surgeons.



The notion of 'patient'

- ▶ Aristotle: the theory of causality
 - Agent → Patient
 - Active → Passive



In contemporary mental health care, a person living with a mental health problem is not just a patient



USERS ARE active healthcare agents

- ▶ Recognise that we are all actors in the healthcare system
- ▶ Accept that defining healthcare needs is a matter of political negotiation and not just of medical science
- ▶ Accept **user participation** in defining and negotiating the healthcare system
- ▶ Imagine new systems together, dream together



User participation in health system decision-making in France

- ▶ User organisations consulted at all **national** levels of decision-making
 - ▶ National Federation of User Organisations in Health System: CISS
- ▶ Users on **regional** health bodies
 - ▶ Collège des Usagers, Conférence régionale de santé et d'autonomie
- ▶ Users on Local Mental Health Councils at **municipal** Level
 - ▶ Users, Carers, Mayor, Mental Healthcare providers, Police, Housing...



User participation inside hospitals in France

- ▶ 1 hospital committee specifically addresses relationships with users
 - ▶ Analyses and handles complaints
 - ▶ Analyses user satisfaction surveys
 - ▶ Initiates actions to improve user satisfaction
- ▶ Users on each major hospital commission: nutrition, pain, avoiding hospital infections, ...
- ▶ Auditing/quality evaluation
- ▶ User information centres
 - ▶ *Maison des usagers*
 - ▶ *Centres d'information sur la santé...*



The patient: an active health care agent

- ▶ Takes care of him/herself (= is not infantilised)
- ▶ Seeks information in order to make intelligent health choices
 - ▶ Consults healthcare professionals
 - ▶ Looks on the Internet
 - ▶ Creates/consults user organisations
- ▶ Seeks training in order to acquire health skills
 - ▶ Health education at school
 - ▶ If health problem → specific therapeutic training
 - ▶ Life Long Health Learning



Recognising users' knowledge and skills

- Users' experience
 - Their experience of handling mental illness
 - Their experience of handling treatment
 - Their experience of handling the health and social care system
- Peer workers
 - Models of recovery: yes, you can recover from psychosis!
 - Telling your story: this is how it happened for me, this is how it happened for different people I have known
- User researchers: what to research, how to research it
- User trainers: training other users, training health and social care professionals



Empowering users

- Rethinking mental health services
 - rethinking health services as places where you go to learn how to handle and live with your illness and not just to be “treated”.
 - rethinking the care relationship as a dialogue in which both parties are there to learn something
- Users’ knowledge
 - Validate therapeutic training acquisition
 - Create accredited user pathways
 - *Ms X has successfully completed this evaluated and accredited therapeutic training program. She is now qualified. Here is her diploma.*





ENTER MENTAL HEALTH

Networking for new ideas using a European network of mental health service providers and universities

In 2014, ENTER has 17 members in 14 European countries (... is Scotland still in the UK ?)

1. Bosnia Herzegovina, Tuzla
2. Denmark, Aarhus
3. Denmark, Zealand
4. Finland, Tampere
5. France, Paris
6. Germany, Essen
7. Greece, Athens
8. Ireland, Dublin
9. Italy, Rovigo
10. Lithuania, Vilnius
11. Norway, Bodø
12. Poland, Warsaw, IPIN
13. Poland, Warsaw, APS
14. Slovenia, Ljubljana
15. Spain, Barcelona
16. UK, Dundee
17. UK, London



History: ENTER AGMs

- 2000 London
- 2001 Paris
- 2002 Warsaw
- 2003 Stockholm
- 2004 Bodø
- 2005 Tampere
- 2006 Perth
- 2007 Vilnius
- 2008 Paros
- 2009 Ljubljana
- 2010 Aarhus
- 2011 Rovigo
- 2012 Sarajevo
- 2013 Warsaw
- 2014 Barcelona
- 2015 Dublin



History: ENTER projects

To date, five major ENTER projects have been funded by the European Commission

- ▶ OSCAR (2001-2004)
- ▶ ISADORA (2002-2005)
- ▶ EMILIA (2005-2010)
- ▶ PROMISE (2009-2012)
- ▶ CAMILLE (2012-2015)

Many other projects have used the ENTER network to find partners.
Example:

- ▶ ORION, ORION-PRO, Self-help groups against depression



ENTER : sharing ideas, sharing ways of doing things

- Through trans-European research projects : EMILIA, ISADORA, OSCAR, CAMILLE, PROMISE...
- Developing training resources
 - Validated through the research process
 - Next step : online training, MOOCs, ...
- Experimenting new approaches : examples with regard to user empowerment
 - Peer support workers at several sites
 - User trainers at many sites
 - User researchers
 - Users with decisional roles
 - User organisations as partners



ENTER in 2014: an overview

- Research
 - CAMILLE project
 - Self-help groups against depression
 - New projects being developed : GOLD project (mental health and ageing in LGBT populations)
- Training: creating an EU platform on training in mental health
- Dissemination
 - Newsletter 1 (Feb 2014)
 - Newsletter 2 (June 2014)
 - Newsletter 3 (November 2014)
- Taking into account the economic crisis: increased competition for EU funding; new project ideas.
- Networking with other networks: AQRP, ISPS...



The website:

www.entermentalhealth.net

- Communicating about ENTER
 - ENTER project results
 - ENTER member sites: what each has to offer
- Communicating between ENTER members
 - Sharing knowledge and ideas between members
- Proposing E-learning
 - Disseminating training programmes developed during research projects : OSCAR, ISADORA, EMILIA, PROMISE, CAMILLE ...



Et à Paris ?



Feb 16, 2005 13:08

A typical
Parisian
trying
hard
to
look
normal
and avoid
stigma





But some days we feel a bit flat





and
other
days,
we
feel
a
bit
nervy

Feb 16, 2005 13:08





The Paris Plan: the Emilia Centre

Three programmes

1. The Emilia programme

Empowering people with mental health problems

2. The Well-Being Programme

Empowering citizens in mental health

3. The Mental Health Programme

Empowering professionals working in other areas on mental health issues



Empowering people with mental health problems

Training on empowerment, recovery, accessing training and employment

- ▶ Training mental health service users; group training; partnership between mental health services, clubhouse, Œuvre Falret
 - ▶ Training modules developed during the EMILIA project
- ▶ Training mental health and social work professionals to support empowerment
 - ▶ Training modules developed during the 'Un Chez Soi d'Abord' (Housing First)' Project: Marseille, Lille, Toulouse, Paris...



Empowering all citizens in mental health

Online training including assessment (MOOC etc) targeting the general public, people wanting to work on their mental health or living with or close to someone with a mental health problem

- ▶ Depression (targeting populations : young people, women, men, older people, jobless, minority groups, migrants, pregnant women ...)
 - ▶ Depression in times of economic crisis
 - ▶ Modules from *PROMISE*, *SELF HELP GROUPS AGAINST DEPRESSION (2014-2016)*
 - ▶ Suicide prevention
 - ▶ Modules from *EMILIA*, *PROMISE*
- ▶ Drugs and alcohol
 - ▶ Modules from *ISADORA*, *PROMISE*
- ▶ Looking after a friend, a colleague
 - ▶ Senile dementia, Alzheimer (*PAERPA*)
 - ▶ Psychosis : National Carer Organisation (*UNAFAM*)
- ▶ etc.



Empowering professionals working in other areas on mental health issues

- ▶ Empowering professionals who in the course of their work come into contact with people living with mental health problems
 - ▶ Social housing professionals
 - ▶ Organisations recruiting people with mental health problems
 - ▶ Sports clubs integrating people with mental health problems
- ▶ Empowering community actors on mental health promotion and health democracy in the area of mental health; how to target the determinants of mental health; working on mental health in the community, with the community
- ▶ Empowering enterprises on mental health issues



EMILIA outcome: the user's point of view (1/3)

The EMILIA Project, a beautiful story in this mad mad world.

- *I met Emmanuelle Jouet in June 2007. She sat me down and explained the EMILIA Project to me. I remember bringing my CV with me, convinced that someone was going to offer me a job.*
- *I'd really got it wrong. Emmanuelle explained that if I participated in the EMILIA Project, I would have access to different sorts of training programmes but not necessarily to a job straight away.*
- *So be it. I gave my consent to participate in the research project. Had nothing to lose. No job. I was a sick guy with serious suicidal ideas that kept coming back.*
- *The first training session took place in September 2007. I learnt about the EMILIA programme. The team explained to me that, like all the participants, I would be considered as a co-researcher. I was to rethink my care pathway through the psychiatric system as a possible force on which to build. Even the nasty things that had happened might prove useful.*



EMILIA outcome: the user's point of view (2/3)

- *Time went by. EMILIA gave me access to a Job Centre where I was able to talk about my work plans, about the job ideas that I'd worked on during the EMILIA training sessions, and visiting the Cité Des Métiers.*
- *But I was still tired all the time, depressed, no future. I don't feel like working. But I try to hold things together, waiting for the psychological cyclone to pass on by so that I can lift up my head again.*
- *The different training sessions move forward, one after the other: Activate your social network, Recovery, Building research skills, Suicide prevention (where both care professionals and users were trained at the same time). My main difficulty: maintaining social contact with certain of the other users - but there were only a tiny few amongst the 30 odd participants who were difficult for me.*
- *But the EMILIA team are there. Present. Bit by bit I learn to become the main actor of my own life. It's me who decides. The opposite of what happens in mental health services. Bit by bit, I come to understand the different concepts (empowerment...). I take my life in hand.*
- *But, in spite of my Personal and Professional Project, I don't seem to be able to project myself into the future, even though I keep participating actively in EMILIA.*



EMILIA outcome: the user's point of view (3/3)

- *In September 2008, my job hunting hasn't led to anything, I seem to be going nowhere, my life is on hold*
- *Then Emmanuelle suggests that I meet Mr S for a possible job on a research project.*
- *I 'accept' to meet Mr S and, at the end of November 2008, I begin working as a research assistant-administrative worker for the Maison Blanche Research Laboratory. I work two half-days a week.*
- *Working conditions are very good. The lab team does all they can to make me feel integrated. Mr S makes sure there's no pressure, no stress. I do my best. My self-esteem is on the increase, I manage things myself, I'm becoming more and more autonomous with regard to the work that has to be done.*
- *I have become part of things.*



Merci !