

Institution:

Middlesex University

Unit of Assessment: 22**Title of case study:** Empowering mental health service users**1. Summary of the impact**

Impact resulted from the unit's sustained research in the field, including the leadership of a large EU Framework 6 action project 'EMILIA' – the Empowerment of Mental Illness Service Users: Lifelong Learning, Integration and Action, and the follow up project, PROMISE. The findings identified how to reduce social exclusion among people with serious mental illness through lifelong learning and by improving participation in service delivery, education and training, as well as paid employment. The research recommendations were included in a joint EU/WHO policy statement and subsequently rolled out across European Union Member States. The research impacted on the development of European and national policies regarding mental health service users and, through further knowledge transfer activities and the incorporation of the recommendations by a network of providers in 43 countries, also impacted on the profession and mental health service users directly.

2. Underpinning research

In pioneering research undertaken (1990-1993) jointly between Middlesex University and the Sainsbury Centre for Mental Health, Ryan led the first major Department of Health (DoH) funded evaluation of case management, an approach to coordinating community care specific to the needs of mental health service users with severe, long term mental health difficulties, a vulnerable group with high use of hospital and community services (Sainsbury Centre for Mental Health 1998). As part of the evaluation, Ryan commissioned the UK's first independent service user led research on case management. Ryan and his research group (Griffiths, Hamilton, Machin, Wilks) produced a report which identified the impact of case management on policy and practice, highlighting the significance of a user empowerment approach to case management (Ryan 1999). A key issue to emerge from this work was the lack of empowerment of mental health service users with severe long-term difficulties (Griffiths & Ryan 2008).

In 2005 a team at Middlesex University led by Ryan (as Field Leader and Project Coordinator) and Griffiths, developed and coordinated a major Europe-wide mental health research project, funded under Framework 6, entitled EMILIA. One of the major innovations of EMILIA was that it employed the concept and practices of lifelong learning to facilitate the social inclusion of mental health service users. In doing this, it also attempted to integrate European policy in four areas: lifelong learning, social inclusion, employment and information technology. The project focused on challenging organisational and institutional barriers to the development of service user empowerment and, in particular, the contribution of lifelong learning to this process. The project's aim was to improve user participation and inclusion in the delivery of services or in education and training. The project was funded for five years (2005-2010), to a value of €3.4 million, and involved 18 mental health institutions across Europe. This funding was designed to create a 'critical mass of influence on policy and practice' across Europe (<http://www.emiliaproject.net/>).

The project recruited adults with severe and enduring mental illness (schizophrenia and bipolar disorder), in contact with mental health services for at least three years and who were not in paid employment. They were offered a series of training modules with other service users, and opportunities for employment or significant activities within the demonstration sites as well as connection to potential employers outside the project sites. Extensive quantitative and qualitative evaluation took place at eight demonstration sites (Athens, Barcelona, Bodø, London, Paris, Tuzla, Warsaw, Zealand) at baseline, ten months and twenty months, of their socio-demographic status, take up of the training and of unpaid

and paid employment, own evaluation of the impact of participation in the project in relation to employment, social interaction, training activities, opportunities and obstacles, and goals for the near future, as well as related organisational changes in the demonstration sites.

The EMILIA project identified the need for service user empowerment in the mental health services involved in the project and suggested how the training could be replicated in different European settings (Ancezewska & Ryan 2009). The research provides evidence that service user empowerment is positively correlated with enhanced self esteem, increased social inclusion, enhanced employment levels and reduced use of psychiatric in-patient services (Ryan, Ramon & Greacen (2012). Key findings after 20 months include:

- i. a doubling of paid employment from 7.3 to 14.6 per cent and a similar increase for voluntary employment;
- ii. significant increases in disposable income and quality of life with an increase in the average number of hours per week worked from 0.3 to 3.23;
- iii. an average reduction of days in psychiatric hospital from 14 to 7;
- iv. a self-reported increase in levels of self-confidence, efficacy and hope, and increased skills and knowledge leading to increased employability.

Numerous publications resulted from the project (e.g. Griffiths 2009; Ramon, Ryan, Urek, 2010). (For a list of the project partners see Dermenti 2010). The success of EMILIA led to further EU funding: PROMISE (2009 -2012) (<http://promise-mental-health.com/>). The focus of this project was to develop and evaluate ways in which mental health service users could be empowered to play a full part in the design and development of mental health training across all the main professions involved in delivering mental health services to people experiencing severe and enduring mental health problems: psychiatry, clinical psychology, nursing and social work. The unit's key contribution was the use of Antonovsky's 'sense of coherence' as a measure which was able to detect changes among service users.

3. References to the research (indicative maximum of six references)

The following publications are all of internationally recognised quality or better. They were subject to peer review in high quality journals or expert reports; the research informing these studies was funded by competitive research grants, attracting favourable reviews from authorities in the field.

Ancezewska, M and Ryan, P. (2009) 'Lifelong Learning and Recovery: An Account from the Perspective of the EMILIA Project', *Occasional Papers in Education & Lifelong Learning: An International Journal*, 3(1), 45-56.

Dermentzi, M. (2010), EMILIA Publications. www.epapsy.gr/files/EMILIA_publications.pdf

Griffiths, C., Ryan, P. (2008), 'Recovery and Lifelong Learning: Interrelated Processes', *International Journal of Psychosocial Rehabilitation*, 13(1), 51-56

Griffiths, C. (2009) 'The EMILIA project: The impact of a lifelong learning intervention on the sense of coherence of mental health service users', *The International Journal of Psychosocial Rehabilitation* 14 (1), 35-49.

Ramon, S., Ryan, P., Urek, M. (2010), 'Attempting to mainstream ethnicity in a multi country EU mental health and social inclusion project: lessons for social work', *European Journal of Social Work (Special Issue: 'Race'/Ethnic relations and social work)* 13(2), 163-182.

Ryan, P. (1999), 'The enduring relevance of case management', *British Journal of Social Work*. 29 (1), 97-125.

Ryan P, Ramon, S. & Greacen, T. (2012), *Empowerment, Lifelong Learning, Social Inclusion and Recovery in Mental Health*, Basingstoke, Palgrave.

Sainsbury Centre for Mental Health (1998), *Keys to Engagement: Review of Care for people with Severe mental Illness who are hard to engage with services*.

Grants:

EMILIA: Framework 6 European Union project, funded at €3.4 million over a four and a half year period (2005-2010), co-ordinated by Middlesex University.

<http://www.emiliaproject.net/>.

PROMISE (2009 -2012) EU DG Sanco funded at €670,000 over three years, co-ordinated by

Middlesex University. (<http://promise-mental-health.com/>).

4. Details of the impact

i) *Impact on the development of European and national policies*

In 2009 WHO Europe with the European Commission launched a co-funded partnership project with a brief to promote the empowerment of people with mental health problems and their carers across Europe. Through the prominence of the work of the EMILIA project, Middlesex University (represented by Peter Ryan) was invited to take part as a member of the steering committee for this initiative. The WHO statement described the challenges, and identified the perspectives and the elements that comprise empowerment, and suggested proposed actions to promote empowerment in mental health (1).

Subsequent research by the steering committee was presented at the EU Thematic Conference on Social Inclusion and Combatting Stigma for Mental Health (Lisbon, 8-9 Nov. 2010) (2) and the core recommendations of this group were accepted for 'horizontal action' (3), and later developed into guidelines for the training of health and social care professionals in mental health promotion across the European Union Member States (4).

ii) *Knowledge Transfer: Impact on the profession and mental health service users*

The research on service user empowerment and lifelong learning was disseminated at conferences in 16 European countries: Bosnia, Netherlands, Malta, Denmark, Norway, Sweden, Finland, Germany, Ireland, France, Spain, Slovenia, Lithuania, UK, Greece and Italy. These conferences identified training and service development approaches as positive mechanisms for promoting organisational and institutional change. Our research was specifically used as the evidence base for organisational change across Europe within 8 demonstration sites [See: (7) Flores et. al 2009].

The EMILIA project found that partner universities and health care centres benefited from the knowledge and experience of mental health service users and, based on this finding, systematically restructured their strategic and operational decision-making processes to include the views and opinions of these service users. The universities involved also took on board the findings and subsequently included service users in the planning and delivery of their educational programmes [See: (5): Flores et al (2010); and (6) Greacen & Jouet 2009]. The impact of this research on the profession has been noted in several European countries including Greece (8), Poland (10) and Slovenia (11).

Since the conclusion of the project, the research findings were used to underpin the development of innovative ways to address empowerment among partner service organisations. The findings have been disseminated even further through the 250 registered subscriber organisations on the EMILIA website, based in 43 countries. The impact of this research can now be seen across the profession, across Europe and beyond. For example:

- a) service users are now represented on the regional executive mental health planning council in Bodo, Norway;
- b) in North East Paris, the continuous professional development training course offered by Maison Blanche, is now open to service users;
- c) in Zealand, Denmark, mental health service users are now trained as peer medication mentors.

The role of our research in influencing these changes can be corroborated by WHO Europe's Mental Health Adviser Dr Matt Muijen; Tim Greacen, director of Research at Maison Blanche; and Ian Dawson, Quality Care Coordinator in Bodo, Norway. [Contact details provided].

5. Sources to corroborate the impact (indicative maximum of 10 references)

1. World Health Organisation (2010), User empowerment in mental health – a statement by the WHO Regional Office for Europe. (The contribution of Peter Ryan and the EMILIA project is acknowledged).
http://www.euro.who.int/data/assets/pdf_file/0020/113834/E93430.pdf
2. Background document for the thematic conference “Promoting Social Inclusion and Combating Stigma for better Mental Health and Well-being”, Organised by the European Commission and Portuguese Ministry of Health with the support of the Belgian Presidency of the EU.
http://ec.europa.eu/health/mental_health/docs/ev_20101108_bqdocs_en.pdf
3. PROMISE - Promoting Mental Health, Minimising Mental Illness and Integrating through Education. Developing the PROMISE European Guidelines for training health and social care professionals in mental health promotion
http://promise-mental-health.com/docs/Developing_the_Promise_Guidelines_290812.pdf
4. ‘Promoting Social Inclusion and Combating Stigma for better Mental Health and Well-being’. Summary: Conference Conclusions.
http://ec.europa.eu/health/mental_health/docs/ev_20101108_concl_en.pdf
5. Flores, P., Palomer, E., Domínguez, T., Rosado, S., Izquierdo, R., Ní Laocha y, E., Masferrer, C. (2010), ‘Training of mental health service users, the EMILIA project’, *Spanish Association of Neuropsychiatry AEN*.
6. Greacen, T., Jouet, E. (2009), Psychologie communautaire et recherche : l'exemple du projet EMILIA [Community psychology and research: The example of the EMILIA project], *Pratiques psychologiques* 15(1), 77-88.
7. Flores, P. Leahy, E. Sorro, M., Izquierdo, R., Masferrer, C.(2009), ‘The empowerment and sharing of knowledge among mental health service users: bridging the gap between the users and the mental health institution’, *International Journal of Integrated Care*, 9(22) (online).
<http://www.ijic.org/index.php/ijic/article/view/URN%3ANBN%3ANL%3AUI%3A10-1-100585/685>
8. Dermentzi. M, (2008), The EMILIA Mental Health Services Users and Professionals Meeting: Bridging the ‘Us and Them’ Gap - Fighting for Our Autonomy, *Tetradia Psichiatris* 102, 50-52.
9. Roszczyńska-Michta J., Anczewska M., Waszkiewicz, J. (2009), *Zdrowienie – budowanie własnej narracji (Recovery: to Build One’s Own Narrative)*, Instytut Psychiatrii i Neurologii, Warszawa, 2009, ISBN 978-83-61705-01-7
10. Urek, M., Ramon, S. (2008), Uveljavljanje nacela enakopravnosti glede etnicnosti in spola v duševnem zdravju (Mainstreaming Ethnicity and Gender in mental health), *Soc. Delo* 2008, let. 47, 3(6), 177-186.