

Lifelong Learning, Social Inclusion and the Empowerment of Service Users

My interest in mental health dates back to 1997 when the editor of a general-interest Black and Minority Ethnic magazine asked me to assess ethnic variations in the rates of mental ill health and service experience. It was clear the magazine was concerned at the time about a comparatively sharp rise in the number of young Black British men and women in mental health institutions in the United Kingdom. After three months mulling over—and literally chewing—policy documents, official statistics, and conducting interviews, I published an article (Ogunleye, 1998) that significantly raised the awareness of mental health issues in the BME communities; the article also engendered some soul-searching in local officialdom. In many respects, it was my own clarion call to action, an action to address a rolling and pressing issue of concern to mental health service users, practitioners and the BME communities.

Of course a lot has changed in mental health care delivery in the United Kingdom since 1998; there is now in place the National Service Framework for Mental Health and the NHS Plan. The approach to diagnosis, prognosis and in deed to general management of care is more holistic and joined-up. There is also some indication that service experience for BME users is improving even if it is patchy (see Department of Health, 2007).

'There are nuggets of evidence that suggest a link between recovery and lifelong learning'

Yes, we should welcome a more joined-up, holistic approach to the management and delivery of mental health care especially where there is a balance between the medical approach and the recovery approach and where our understanding of 'causes and effects' is not empirically cut and dry. Yes, should welcome these developments if it now means that service users with long-term illness can tap into social and professional networks of support every step of the way in what is often for many a long and tortoise journey to recovery.

Another development we should all welcome is the increasing acceptance in recent years that service users are a particularly disadvantaged group and that their particular needs, desires and aspirations deserve a high priority in the government socio-economic policy agenda, an agenda that places emphasis on social inclusion and economic and professional integration of all. A case in point was the setting up of the Social Exclusion Unit in 1999 and a decision to locate it [initially] in the Office of the Prime Minister, which significantly raised its profile.

PROLOGUE

James Ogunleye PhD FRSA

Of course the United Kingdom is not alone in addressing the issues of exclusion of service users. Countries across Europe are singing the same song. The songsheet is created by the European Union through the instruments of the Lisbon and Copenhagen treaties, better known as the Lisbon and Copenhagen processes.

Through the Lisbon and Copenhagen processes, lifelong learning literally received a facelift (see, for example, Ogunleye, 2007); it also added a new dimension to the so-called European social model. So, in the United Kingdom as indeed across Europe, lifelong learning became a linchpin for the empowerment and social inclusion of service users (Ogunleye, 2009).

But lifelong learning is more than a tool for tackling the exclusion of service users. There are nuggets of evidence that suggest a link between recovery and lifelong learning (Griffiths and Ryan, 2008; Lanham et al, 1997) and between mental health/emotional wellbeing and lifelong learning (Hafford-Letchfield, 2009; Aldridge and Lavender, 2000).

What is more, service users who have participated in Emilia training—either as trainees or trainers or both—have attested to the therapeutic benefits of lifelong learning. The writers of this special issue of *Service User Empowerment*—Paulette Case-Robinson, Peter Sartori and Torill Klevan Nilsen—are living witnesses; they are amongst users and users' network leaders who have been involved in the Emilia project.

Paulette's, Peter's and Torill's experiences are by no means isolated. At Emilia demonstration or pilot sites across Europe, service users, practitioners and researchers are reporting the positive impacts of Emilia's unique approach to user empowerment through Emilia lifelong learning training modules. For example, colleagues in Paris have reported an increased service users' self-confidence in their abilities and capacity to train and to get work following Emilia training. We also know from colleagues in Barcelona that Emilia intervention has made it possible for a largely mental health day hospital to transform into a learning organisation for both mental health professionals and service users. And we know from colleagues in Warsaw that Emilia intervention has raised the bar in *personal recovery plan* training for service users. In Vilnius, colleagues noted that the involvement of service users as both trainers and researchers

at a major university psychiatry clinic is changing perceptions about service users' capacity to engage. In Bodo, we know that participants in Emilia user representation [powerful voices] training have put their new skills into good use by setting up a local user council.

Yet we must not underestimate the challenges that lie ahead. The fact is that the road to social inclusion and economic and professional integration of service users remains pretty bumpy. Paulette Case-Robinson and Peter Sartori remind us in the following pages that the age-old stigmatisation is real as is the 'failure' of social agencies and intermediaries in addressing and meeting the needs of service users. But, as Chinese philosopher Lao Tzu (c 604-c 531 BC) once said, the longest journey begins with a single step; the Emilia project's approach to user empowerment is a very significant step in the right direction.

References

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Service User Empowerment

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The Strengths Approach to Recovery and Lifelong Learning

The EMILIA Project at Middlesex University has been running the Strengths Approach to Recovery training module since 2007. We are among the Service User Trainers who have facilitated 2 cohorts and each student has a mental health condition.

The Strengths Approach to Recovery and Lifelong Learning is a research project which provides a course for people with mental ill-health. The theory on which the course is based is Maslow's hierarchy of needs. Individuals with mental health conditions may have some or most of their basic needs for clothes, shelter and safety met, however, the higher needs are rarely addressed and their aspirations for self-actualisation are often unmet.

The inspirational Professor Peter Ryan is the Europe lead of the EMILIA Project. At Middlesex University, he forms an important part of the course, taking part in the process and counselling students for whom the work touches hitherto-unexplored emotions. Professor Ryan is supported by a number of academics and practitioners including Janet Holmshaw and Helen Matheson, of the Department of Mental Health and Social Work and the Centre for Excellence in Teaching and Learning (CETL) in Mental Health and Social Work, and the Middlesex University's School of

EMPOWERING SERVICE USERS Paulette Case-Robinson & Peter Sartori

Health and Social Sciences as a whole.

The Supervisory Group is largely made up of Service User/Trainers from a wide span of inner and outer North London, and are regarded as 'experts' in their own right.

Recovery does not mean cure. However, people with mental conditions are able to learn, grow and change if they find a recovery pathway that takes their individual and collective needs into consideration.

The Strengths Approach to Recovery is accredited in the United Kingdom and has four modules:

Strengths: examines past achievements, hopes, abilities, aspirations and a Personal Development Plan (PDP) is created by each student.



Inspirational: **Professor Peter Ryan**, EMILIA Project Co-ordinator

Empowerment and Recovery: personal development, ambitions, self-esteem and the future as positive.

Advocacy and Leadership: self-advocacy, peer advocacy—speaking and acting on behalf of a group, public speaking.

Trained Service Users as Future Trainers

Service user/trainers have been 'shadowed' by former EMILIA students who may then become trainers. Service user/trainers have also been heavily involved in the training of pre and post-registered mental health nurses plus social workers. Their work is not merely appreciated, but valued in real terms—they receive payment for

their contributions. This underpins Middlesex University's School of Health and Social Sciences and the Centre for Excellence in Teaching and Learning (CETL) in Mental Health and Social Work's policy of service user involvement and a demonstrable belief in equality.

'Emilia Emphasises User Experience and Representation'

I would like to say something about my own experience as a user representative in EMILIA. The project emphasises user experience and representation. I have felt that I have been included, heard and respected as a user representative.

I have experienced the collaboration from the staff trainers on an equal basis.

I believe such a genuine sense of equality gives positive signals to training participants—that their involvement and experiences in the project are really valued.

When I got involved in the

EMPOWERING SERVICE USERS Torill Klevan Nilsen, Bodo, Norway

Emilia project, which emphasises empowerment, I had found a foundation which carried me despite experiencing it [the training] at times as being 'fragile'. I think that most people who are recovering are anxious that there might not be a continuity.

So, in many ways, my participation in EMILIA has increased my own empowerment.

I have experienced a more meaningful life by being trusted, given challenges and believing in my own skills.



'I have experienced a more meaningful life by being trusted'

— **Torill Klevan Nilsen**

'Hope is Central to any Recovery Process'

A central theme of any recovery process is hope, be it caused by physical, emotional or mental trauma, or any combination.

The aftermath of mental health crisis, more often than not, leaves one distraught, institutionalised and wondering whether we will ever return to how we were, or even how to start again.

Confounded by stigma, we are perceived as 'damaged goods', or [even] 'sub-human'. We are also perceived as 'violent' [even though we are more likely to hurt ourselves than others], thereby creating fear of those who experience mental health problems.

To compound this, it is more frequently expected that we will never recover, which leads to apathy, dependency, which in turn creates feelings of hopelessness, lack of self-worth, and leaves us grieving for our loss.

This sets up the *revolving door* syndrome. That is, periods when our conditions are controlled by medication, followed by relapse, when we are hospitalised. Without the hope of recovery, we live a 'half life' between hospital admissions, appointments and no other specific purpose.

Apart from the 'natural' resilience

'Hope is a pinpoint of light on a stormy, rugged, dark, and dismal landscape.'

EMPOWERING SERVICE USERS Paulette Case-Robinson & Peter Sartori

of some service users (some service users recover, but keep their experience of mental illness hidden), how could we be encouraged to take up the reins of our lives again?

To maintain hope, find purpose, take risks, and move on with our lives—or as Oprah Winfrey puts it, people need to find "... something to do, someone to love and something to look forward to ..." for maintaining wellbeing and a meaningful life.

We are speaking about a part of the population—according to a report 1 in 4, probably 2 in 4 in the inner cities—totally disenfranchised because they dared to become unwell because they could not withstand conditions they have had to endure!

Life experiences that have devalued their humanity: sexual predators inside and outside of home—where safety, food, clothes and shelter should be assured; inequalities, due to one's gender; racism; social and economic barriers; and a prevailing national culture that is [sometimes] indifference to physical and emotional abuse of service users.

The failure of social agencies to respond to crisis, ensuring that children of service users have/maintain normal socialisation—emotion, education and communication wise—and developmental needs are met, is an-

other case in point.

All the above may lead to vulnerability over-and-above that of being human.

The EMILIA Project is pan-European with 8 demonstration sites spread across Europe and is being funded by the European Union. Currently, the project is funded up until February 2010.

Research findings are not yet fully complete. However, we have already seen its impact on service users and similarities of mental health conditions across a whole continent comprising different countries and differing cultures.

From our own teaching and learning experience and the positive impacts on the students, we are hopeful that the EMILIA Project will not only continue, but grow and be appropriately supported and funded.

Meet Paulette and Peter

Paulette Case-Robinson has been a service user for the past 16 years. Her professional qualifications and experience are in medical nursing, mental health advocacy, assertiveness and personal development, psychology, and counselling. She became involved in a successful campaign that saved the Day Hospital in a North London Mental Health Trust. In 2006, Paulette and Peter Sartori joined the EMILIA Project and were responsible for re-working the *Strengths* training module. In November 2007, Paulette teamed up with Peter to form ACTIVEEIGHT, a UK registered social firm.

Peter Sartori has been a service user for the past 13 years. Peter is a graduate of economics and a former company sales director. He has also been a civil servant, designer, professional musician, and a songwriter. He became involved in the same Day Hospital campaign as Paulette. Both Paulette and Peter are involved as service users in the Haringey User Network. They present to professionals and service users alike through ACTIVEEIGHT and are available as mental health consultants.



Paulette Case-Robinson and Peter Sartori: 'A central theme of any recovery process is hope'

Free Interactive Lifelong Learning and User Empowerment Seminar at Middlesex University Trent Park Campus

Dr James Ogunleye, Paulette Case-Robinson and Peter Sartori will give a presentation on lifelong learning, empowerment and service users. Paulette and Peter will also share their experiences on the positive impacts of *Emilia intervention* at an interactive seminar to be held on Tuesday 15th September 2009. Time: 11-12.30pm.

Mental health service users, professionals and Practitioners, and others interested in attending the *Empowerment* seminar are asked to give an indication of their intention below. You will be contacted via email nearer the time.

Name Occupation [optional]..... *Cut out and return your completed slip to:*

Organisation/Address o/c Emilia—Room M215
School of Arts & Education
Trent Park campus
Middlesex University
Bramley Road
London N14 4ZY

Email [very important]

• Trent Park Campus, Middlesex University: the empowerment seminar will take place here on September 15th, 11-12.30pm.



EMILIA – Empowerment of mental illness service users: Lifelong learning, integration and empowerment

The EMILIA project is a Framework 6 European Union project, funded at €3.4 million over a four and a half year period; it is the European Union largest ever funded research and intervention project on mental health and lifelong learning/social inclusion. The project has 16 partners in 13 European countries. A central aim of the project is to explore the use of lifelong learning as a means of achieving improved social inclusion of mental health service users with enduring, long-term mental health difficulties.

Emilia Project main contractor is Middlesex University.

For information about the Emilia Project, visit www.emiliaproject.net.

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Emilia Partners (demonstration sites in red ink)

Bosnia and Herzegovina:
HealthNet International

Denmark: Department of Education, Psychiatry in Midtjylland, Aarhus Region

Denmark: Psychiatric Research Unit Sealand Region

Finland: The University of Tampere

France: Hospital Maison Blanche, Paris

Greece: Scientific Association for Regional Development and Mental Health (EPAPSY)

Lithuania: Vilnius University



Norway: Nordland Hospital, Bodø

Poland: Institute of Psychiatry and Neurology Warsaw

Slovenia: Faculty of Social Work, University of Ljubljana

Spain: The Fundació IMIM, Barcelona

Sweden: Karolinska Institutet, Stockholm

United Kingdom: Middlesex University (Project main contractor)

United Kingdom: King's College, University of London

United Kingdom: Skylark Project Consultants Ltd

United Kingdom: Wealden Computing Services

