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Lifelong Learning and Recovery: An Account from the Perspective of the EMILIA Project

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ABSTRACT The paper is based upon the accounts of mental health service users, who all suffered from severe long-term mental illness. The training intervention: “Empowering people in recovery” was developed during the Emilia project (see below). The training process in recovery at Middlesex University, London, an Emilia demonstration site, was accredited, took place over twelve weeks, four hours every session. At the Institute of Psychiatry and Neurology, Warsaw, the other Emilia demonstration site, there were twelve hours of taught training programme over three days in one week. The second phase was also twelve hours but at once a week intervals. The Emilia project also developed a “personal development plan” module for the training; both London and Warsaw demonstration sites assisted their mental health service users in using it. Many students taking part in this training found it to be a very positive experience. These results need replication and further work to identify what were the preconditions for making it such a worthwhile experience and how this could be replicated on a wider basis.

Keywords: Mental health recovery, Lifelong learning, Social inclusion, Education, Training, Empowerment

Introduction

The aim of this paper is to share with academics and mental health practitioners the experience of developing lifelong learning programmes undertaken as part of the EMILIA project—*Empowerment of Mental Illness Service Users: Life Long Learning, Integration and Action*—which is funded by the European Union under the Framework 6 Research Programme. The objective of this descriptive study is to know students' reaction to the lifelong learning received. The Emilia project has eight demonstration sites [or pilot centres] across eight European countries—namely the United Kingdom, France, Spain, Denmark, Norway, Greece, Bosnia and Herzegovina and Poland. This paper is based upon the accounts of service users experiencing lifelong learning in two of these locations: the Institute of Psychiatry and Neurology in Warsaw, Poland, and Middlesex University in London, the United Kingdom. The Institute of Psychiatry and Neurology is responsible for the improvement of health care in the fields of psychiatry and neurology. It is also responsible for conducting research in the fields of psychiatry and neurology and allied fields. Different disciplines are represented by 25 departments. The newest sector, Mental Health Centrum, is functioning as a community mental health care system, broadly implementing the idea of self help management of mental disorders. In 1992 the Institute attained the status of World Health Organisation [WHO] Collaborating Centre for Research and Training in Mental Health. Middlesex University is one of the largest universities in the UK and is located in North London. It has the largest School of Lifelong Learning in the UK, and also has an internationally recognised Centre for Learner Managed Learning, and a nationally recognised Centre for Excellence in Mental Health. It has an international reputation in Lifelong Learning and is a leading research institution in the field of Lifelong Learning. Middlesex is highly active in the following areas:

Lifelong learning and education	International and comparative education Work based learning
IT in education, especially the use of CD-Roms	Problem-based learning
Argumentation in education	Learner managed learning
Teaching and learning	Product design and technology

The major research and taught postgraduate programmes offered are:

- BPhil, MPhil and PhD; MProf and DProf
- MA for Lifelong Learning (distance learning and taught modules)
- MA Special Educational Needs; MA Specific Learning Difficulties
- MA/MSc in Work Based Learning.

The module these experiences refer to is the training intervention: “Empowering people in recovery”, developed by the first author. The other lifelong learning modules developed in the project focus on: dual diagnosis, post traumatic stress disorders, suicide prevention, recovery, social networking, ‘strengths approach’, user leadership skills, social networking competences and working with employers in the community. All these modules were developed through extensive consultation with service users. Again, they were either entirely taught by or at least part taught by service users. The goals of these modules are to increase the student’s sense of control, provide tools to cope with stigma and improve awareness both of the own users’ and the community’s resources. A sense of control over desired outcomes is a basic need of people, the deprivation of which has important consequences for well-being and health (Guinote et al., 2006). In order to increase the students’ sense of control they are taught through information processing strategies aiming at increasing understanding and predictability. The longer term aim is to empower the participants taking part in these programmes, all suffering from long-term mental illness, to discover their own sense of ‘recovery’, that their future life course is, to a great extent, in their own hands.

Lifelong learning and recovery

Lifelong learning is the development of human potential through a continuously supportive process which stimulates and empowers individuals to acquire all the knowledge, skills, values and understanding they will need throughout their lifetimes and to apply them with confidence, creativity and enjoyment in all roles, circumstances and environments (Longworth, 1999, p.2). Lifelong learning policy in the EU is driven by the belief that everyone should have equal and open access to high quality learning opportunities (Griffiths and Ryan, 2008). It acknowledges that learning is not just confined to the classroom and to the delivery and achievement of academic awards, but can be taught through many different means, in-

cluding using new technology. The European Commission (Com, 2001) defined lifelong learning as “all learning activity undertaken throughout life, with the aim of improving knowledge, skills, and competences within a personal, civic social and/or employment-related perspective.” A comprehensive approach to lifelong learning needs to emphasise “learning throughout the life time from preschool to retirement encompassing the whole spectrum from formal, non-formal to informal learning” (COM, 2003).

In May 2000 the European Commission issued a communication calling for the removal of environmental, technical and legal barriers to participation of people with a disability in the knowledge based economy and society. In October 2003, the European Commission published its Communication Equal Opportunities for People with Disabilities: a European Action Plan (Com, 2003). One of its aims is to improve access of people with disabilities to employment, lifelong learning, development of new technologies and the built environment. The use of information and communication technologies opens possibilities for overcoming barriers to access to education, training and learning faced by people with disabilities.

A lifelong learning policy in the mental health ‘services area’ (e.g. Denmark, France and the United Kingdom) empowers mental health service users to move freely between learning settings, opens up employment opportunities both in mental health training and in the delivery of services and optimises their knowledge and competencies (Stenfors-Hayes et al., 2008). This means removing the barriers, stigmas and obstacles that prevent mental health service users from entering the labour market and impede their progress within it, with specific strategies for tackling social exclusion and inequality. Lifelong learning is however about a great deal more than this: it promotes more inclusive, tolerant approaches in the workplace and encourages an inclusive approach to decision-taking.

The important goals of the recovery oriented mental health services are: the re-establishment of users’ roles in the community and the development of a personal support network. Recovery can be defined in many different ways but one approach is to see it as a process of individual discovery, experiencing life with one’s illness and its symptoms, recognising one’s vulnerability, encouraging hope and formulating realistic goals. Recovery involves a process of changing one’s attitudes, values, feelings, goals, skills and roles, as one grows beyond the effects of mental illness (Anthony, 1993). Deegan (1996), drawing upon personal experience, points out important elements which foster the process of recovery: hope and sense of control over one’s life. Liberman and Kopelowicz (2002) also mention hope, sense of autonomy and self-care as attributes which mediate the process of recovery. Essentially, recovery is not a process of external professional assistance. At its essence it is a private, personal process which originates in the indi-

vidual persons' choice to remake their future. Obviously, external assistance from mental health professionals can assist this process—or hinder it (Bertolote and Sartorius, 1996). In this sense the professional's role is beginning to resemble the role of trainer, teacher and instructor, where the patient is the expert, with their own unique experience of recovery. The professional assists this journey in as many ways as is possible.

The sample

In both demonstration sites service users were contacted through clinical services, local service user groups and through independent user groups. The decision to participate in the project was strictly voluntary, based upon the information provided by the Emilia project team. The samples in both demonstration sites include service users who have expressed an interest in learning. The researcher screened potential participants to ensure that they met the Emilia inclusion/exclusion criteria. Inclusion criteria were as follows: aged 18 and over, suffering from serious and enduring mental illness (specifically socially excluded/ unemployed mental patients suffering from schizophrenia (F20), and bi-polar affective disorder (F31)), with at least 3 years' contact with 'mental health services'. Exclusion criteria were as follows: people with dementia, people with a learning disability.

The training process and structure

The lifelong learning element of the training modules is based on: European standards, learner-centered, collaborative work on issues of common concerns to find fit solutions for diverse contexts. The modules prioritise a 'three-fold concept' of competence development: developing sensitivity and awareness, knowledge and understanding, individual practice. The training process in recovery at Middlesex took place over twelve weeks, four hours every session including a break for lunch. As well as recovery, there was an emphasis on developing personal strengths and competencies and on developing leadership skills. A personal development plan (PDP) was also part of the 'curriculum'. The three training modules on Personal Strengths, Recovery and Leadership were organically linked together and accredited at levels 0, 1, 3 and 4. All the training was by service user trainers and the emphasis throughout was on optimising student participation. The PDP was organically threaded within the first two modules (Personal Strengths and Recovery). The service user trainers used diverse teaching styles which all emphasised the importance of sharing, critical reflection and theoretical exploration.

Each teaching session lasted about 4 hours with opportunities for short breaks. Lunches were provided. The teaching was in blocks of four consecutive weeks with a gap of one week between each four week block.

In Warsaw the structure was different. There were twelve hours taught over three days in one week, which covered workshops on: experience of mental illness, social attitudes, stigma, recovery and empowerment. The second phase was also twelve hours but at once a week intervals, covering topics on self-esteem, combating stigma, and developing a personal recovery plan.

The module is designed to be delivered in six sequences. The first sequence is a 45- minute PowerPoint presentation on the contextual framework theoretical background of the training programme. This was followed by five sequences of workshops run in maximum 10 persons groups. *Workshop 1 "Interviews" and "Metaphors"* has four exercises: 'Spinning wheel of name', 'Attitudes towards the people with mental health problems', 'Experiencing illness and hospitalization' and 'Metaphors'. *Workshop 2 "Recovery and empowerment"* has two exercises: 'Continuum of recovery', and 'Personal Recovery Plan'. *Workshop 3 "Destigmatization"* has four exercises: 'Stereotypes concerning people with mental illness', 'Redefining self-portrait', 'Experiencing discrimination in friendly environment', and 'Coping with discrimination'. *Workshop 4 "Responsibility"* has three exercises: 'Exploring the term responsibility', 'Leading the blind,' and 'Fields of responsibility'. *Workshop 5 "Being empowered or empowering oneself"* has two exercises: 'Finding one's positive traits', and 'Personal Recovery Plan.'

The EMILIA project also developed a personal development plan (PDP) in order to help service users review and plan their future effectively. Both the Warsaw and Middlesex sites assisted their service users in using the PDP. The Personal Recovery Plan (PRP) was launched as a complement to the PDP.

Results

Students' reactions to the Emilia training

At Middlesex, at a meeting convened to review their experience of the Emilia training, students made a number of comments. One student felt that he had been encouraged to think positively about himself, and this was a big change compared to how he usually viewed himself:

It was difficult to begin to think positively about myself since this was an entirely different thinking pattern for me so it was difficult to get my head

around it, but it did help me to come to terms with what my life had been and what my future potential was. It was good to have the opportunity to begin to reflect that there was a possible positive future.

On the other hand, another student said that this shift in focus was very difficult:

However well intended the message and methods, it was difficult for people with mood disorder to feel empowered or ‘strengthened’, since you were trying to deal with mood swings all the time and you were not necessarily guaranteed to be in a positive frame of mind. I sometimes felt better after attending an Emilia session and it certainly helped that process of feeling good about oneself. Some good experiences do ‘seep through’ but for some reason the black bile does arise and continues to do so. Emilia sessions didn’t put paid to the black dog and did not result in instant reflection on one’s life, but being in a safe environment definitely helped the process.

Another student mentioned that they had expressed their experience of being a user in a more conscious and reflective way than before:

Before the Emilia training I felt a bit like I was sitting on my capacity. Someone else said that ‘I felt the goal setting process was a bit artificial’ and ‘didn’t feel like me’ but on the other hand there was a huge amount of student support amongst Emilia students.

Someone else commented that they actually didn’t like the term “recovery”, as it was “too American” and redolent of the artificial and misleading use of a language of excessive and unrealistic optimism:

I don’t like the word recovery—it sounds weird that I’m on the road to recovery. Its tied in too much to Americanisms and the false use of positive terminology and positive thinking which I have an allergy about. I know it’s used a lot and people are trying to spread it amongst psychiatrists and it’s important to get people to think in terms of recovery, but ...

However, most students derived much benefit from listening to other people’s accounts of their own recovery:

What was good is that I got a sense of other people’s recovery and how that compares to mine. As for me, I never had the idea that I would recover. But a lot of people here seem to feel that recovery isn’t out of the question.

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I know that I recovered. It's like a stew. People put different ingredients in and as far as I am concerned they have all recovered.

Another student expressed some concerns about recovery but ended up feeling it was OK:

There are a lot of valuable things going on but I am not sure about this recovery term—how it fits into the treatment I am actually receiving from mental health services, and so on... I am in a holding situation because of not being hopeful about my future and all the medication which is necessary to prevent me going into hospital. On reflection I got some answers. The recovery concept does hold water.

So far as the personal planning aspect (PDP) of the recovery module was concerned, one student said:

I thought the PDP was very useful. I think the problem with the word is that the mental health industry has highjacked it. A day centre is now a recovery centre without changing what it does at all. Maybe we need a new term because we all understand that we are on the road.

Other people found the personal planning aspect of the recovery module intimidating but on balance useful:

The PDP was very difficult for some people. It is a quite upsetting concept, but it's good in order to help you get to somewhere you want to get to.

PDP comes with a lot of baggage—its about where are you now in your life— and sort yourself out ... It has taken so many years to get where I'm at now in my life. It's now about taking one step at a time. The PDP is worth it. It addresses the key things in one's life...

In Warsaw service users formulated individual action plans to accomplish a Personal Recovery Plan (PDP). A variety of different plans for the future were identified including: to look for a job, learn a foreign language, become more active physically by for example taking up a sport; improve social networks or increase social relationship; and to find ways to accept their illness. Although in some cases these plans were rather difficult to accomplish (buying flat, move abroad) it should be pointed out that they started to emerge. According to the students' feedback, Personal Recovery Plan (PRP) implementa-

tion gave them hope and helped them to move towards their goals:

Finally I found job, but since it is not very satisfying one—you know—just simple work [carrying advertisement leaflets] now I feel I can go and try to find another one. It is difficult to set the goal...leave the illness behind and fight, but it is like seeing light in the dark.

I was unhappy with different aspects of my life: health—not so good, condition—I wish to be better; work—I haven't been working lately; knowledge accessibility—poor; illness makes one's fulfilment difficult, only relations with peers—quite good, so this gathering makes sense for me.

There were also some bitter comments regarding stigma and social exclusion:

When they [people] know about my psychiatric hospitalisations they are not friendly and do not trust me, even my parents don't believe that I could be independent and self-managing. I have social disability payment, which is for being hungry, what shall I do? Training is fine but doesn't bring money for decent living.

Conclusions

In traditional models of mental illness, recovery is understood as an improvement in symptoms and other deficits to a degree that they would be considered within a normal range. This is called the service-based definition of recovery (Schrack and Slade, 2007). The user-based definition of recovery is not only symptom remission or a return to normal functioning but a process of personal growth and development together with regaining control and establishing a meaningful life. This is exemplified by the National Institute for Mental Health in England's definition of recovery as the "achievement of a personally acceptable quality of life" (NIMHA, 2004). Many of the Emilia students began to identify with the possibility of recovery thus expressed, and made through attending the programmes as described above substantial progress in their own sense of personal direction and recovery. There seems little doubt that many students taking part in this learning experience, all of whom suffered from severe long term mental illness, found it to be a very positive experience—in most cases useful and inspiring. These results obviously need replication and further work needs to be undertaken to identify what precisely were the preconditions for making it such a positive and worthwhile experience and how this could be replicated on a wider basis.

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To empower in recovery by lifelong learning is to ensure the person's right to choose his or her own future. There should be ongoing assessment of service user's needs and achievements to adjust learning modules.

What is important when discussing policies and strategies of lifelong learning is that it is not the learning per se that can be sanctioned or mandated, but only the conditions for it (Griffin, 2000). It is arguable that de-institutionalization and the emergence of the recovery model have generated a greater need for lifelong learning in mental health service users. After all, very little new learning is required for an institutionalised life; there is little environmental change and the patients have little control over their lives. In contrast, life in the community involves experiencing continual change and requires mental health service users to have a greater degree of control over their lives; therefore, more extensive lifelong learning is required. In her paper discussing mental health recovery Anthony (1993, p. 536) stated that "any person with severe mental illness can grow beyond the limits imposed by his or her illness." It may be that this potential to grow beyond any limits is partially determined by access to and the ability to acquire and apply lifelong learning.

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