

EMILIA

First I would like to say something about how I became involved in the EMILIA project.

The user organisation in Bodø "Mental Helse" was asked if they could provide a user representative in a EU financed project which Nordland Hospital was participating in.

I became a member of the local steering group of the project in February 2006. My experience as a user is based on 16 years contact with the mental health services. I have experience of being ill, needing help, in periods quite a lot of help. I am among the lucky ones that got the help I needed and which makes it possible for me today to say that I am a previous user.

Within the EMILIA project there has been developed a number of training packages which have been tried out over a period of time. In Bodø it was decided that we should try out three of these training packages: Powerful Voices, Social Network Support and User Research Skills.

One of the aims of these training packages was that one of the trainers should be a user, in the beginning in close cooperation with a professional. Gradually as the user trainer gained experience they too could run the packages on their own.

In the autumn of 2007 we started the first training package called "Powerful Voices" which was developed by Middlesex University in England. We renamed it "User Representation" in Norwegian. We wished to focus on users own experiences and work towards how they could represent themselves and possibly others in their contact with society. It was about everything from daring to say something to their therapist what they thought about their own situation and to maybe becoming engaged in a user organisation and talk on behalf of other users. The aim after the training was completed was that each participant could hold a 5 minute talk about their own experiences or a theme they were particularly occupied with.

I would like to say something about the group that participated in this training and it's composition. The target group for EMILIA is people with suffer from a serious mental illness like schizophrenia, Bipolar and other psychosis. The inclusion criteria was based therefore on a given diagnosis and not their functioning. This gave a clear consequence in our group of 7 users. There were users who had previously had worked and others that had never had a job at all. Some coped very well in their daily life's while others were clearly hampered by their illness. Regarding their background and previous knowledge of user representation there was also great variations, some had some experience while others were unsure what it really was.

One of the main aims of EMILIA is empowerment, give the participants more belief in themselves and what they are capable of and make use of it. One of the participants said the first evening:

"I thought it was going to be difficult to participate in this training, but I already know something about user representation."

To make the participants aware that they actually had prior knowledge which was important to share with others did something to their confidence. The discovery that their experience was important and that they were in fact “experts” in certain areas was new for some of them.

The training comprised of 8 sessions consisting of 4 evenings of training and 4 supervision sessions for those that wanted help with homework. The training was based on homework between the training sessions. In consultation with the participants we adapted the training sessions both in length and the way we “taught”. We used a lot of time to practical exercise which popped up. The hospital wanted their logo on the side of the cars which was used by the staff of the Rehabilitation Team. Some of the patients reacted to this and felt that it was stigmatising. This resulted that their commitment made a difference. In one way they put theory into practice. Their engagement was enormous and their pride that they had achieved something in a bureaucratic system was visible. They saw that it helped.

As previously stated there was a large variation amongst the participants as far as functioning was concerned. However they all worked towards the last evening and their individual presentation.

One of the most experienced meant that she could talk to an audience for many hours as she had so much she wanted share with them. Another didn't dare to say anything in front of a group of people. He had problems saying anything at all so he asked if he could share his experiences through his own music. The last evening he let us hear how he experienced being ill, being psychotic through his own music. It meant so much more for him than he could share his experience without words. And we talked about how different forms of expression can be used to carry ones message.

In January 2008 we started the second training package called “Social Network Support” developed by Barcelona in Spain.

Some of the participants had participated in the first training, while some were new. 6 all together. This training was carried out during the day, 5 sessions in all.

Also here we are talking about a very complex group from those that had very little or no network to those that some established network. Personally I have experienced how easy it is to lose you network when you become ill, either because you withdraw yourself or your network disappears of various reasons.

The aim of this training package was to define ones own network, look at the challenges and barriers when trying to establish and uphold a network. To talk about expectations to ones surroundings and which demands should be put on ones own role in this. There was a focus on stigma and some discussion on how oneself could work towards lessen this.

The topics were well known and the participants felt they were more aware of their own networks after the training. Sharing experiences was also this time very important.

EMILIA has a main aim to counteract social exclusion of people with serious mental illnesses. Within a framework of lifelong learning one wishes to improve this groups possibility for paid work or other meaningful activity.

The participants were all followed up in order to measure the effect of the intervention.

Personally I have thought a great deal about how one can document such effects and who defines what is change. Now and again it can difficult to say what helped, what made a difference when one is measuring recovery.

In the end it is a subjective experience of the individual from their own place which is the most important documentation.

Already during the training a comment came from one the participants who said “I told them at the day center today that I didn’t have time to sit there, I was busy, I am on a training course”. She said it felt good to have something to go to, something that gave hope that things could change. She talked warmly about EMILIA and said that it was a major reason why she felt she had a better daily life. Her dream of getting a job wasn’t achieved yet, but she had a hope that it would be.

Another participant could tell us that changes that seemed insignificant for many, in his case it was a victory. After EMILIA he had managed to invite friends home to have pizza, something he was very proud of.

A couple of the participants are now working. EMILIA wasn’t the only reason but was a good help on the way.

A clear and really visible effect of the training in “User Representation” was that one of the participants after the training was finished had taken the initiative to establish a user council at the day center in town. And it works very well.

I think both of these training programs have been based on experiences and knowledge which the participants had with them, but they weren’t clear about. It made them aware of the potential they had themselves, increased their believe in themselves. It gave them hope.

The changes are maybe not that big seen from the outside, but change takes time.

As far as the training programs are concerned maybe the result had been more visible if the target group had been different, for example milder forms of mental illnesses and the function level of the participants more the same.

Both programs have had two trainers. One a member of staff from the Rehabilitation team at Salten Psychiatric Center who have contributed with their professional knowledge and a user with their experience.

Feedback from the participants that a user has been one of the trainers has been undivided positive. They appreciated that a trainer had experience from being a user and it felt that the trainer had a genuine understanding of what they shared of their own experience.

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

I have been trusted by the others and experiences the collaboration from the staff trainers as a equal cooperation, they with their professional knowledge and me with my experiences.

I believe it gives positive signals to the participants in such training when they see that it actually there is a need for user's experiences.

There is a fine dividing line between being a trainer and a user. I have tried to be conscience when it was necessary to have the role as a user. For my own part I have tried mostly to be a trainer.

When I got involved in this project which emphasis empowerment, I had found a foundation which carried me despite experiencing it at times as being fragile. I think that most people who are recovering are scared that it won't hold. So in many ways my participation in EMILIA has also increased my own empowerment. I have experienced a more meaningful life by being trusted, given challenges and believing in my own skills.

As I said at the beginning Bodø choose three programs. The third one, which is running at the moment, has a focus on research skills. I am not involved in that one.