

## **“Getting on with your life”. A user’s experience of participating in the EMILIA project**

My name is Torill Klevan Nilsen, and I have been a user’s representative in EMILIA.

I think it is great to be given this opportunity to talk about what it has meant to me as a user to participate in EMILIA, and what significance it has had for me personally. This may be a digression, but I do however miss contributions from some of the other participants in the project. What significance participation has had for them, and what challenges they may have encountered involving users.

In February of 2006 Mental Health in Bodø (a user’s organization) was contacted regarding providing a user’s representative for an EU project. The project was called EMILIA and the Nordland Hospital Trust, psychiatry, was responsible for the Norwegian part of the project. I was at that time asked to participate, and joined the project in mid February 2006.

I attended the first meeting not knowing what to expect. Having no knowledge of the project, what its purpose was, the duration of it, and so on. To be completely honest, I was somewhat frightened, somewhat confused and not sure if I could do this. The fact that all written material was in a foreign language - English – was a challenge in itself. Expressions such as lifelong learning and empowerment, designations such as WP 1, 2 and 3, and names like Peter Ryan, Shula Ramon and Tim Greacen were buzzing in the air. Everything was new, and nothing made sense to me. It was also not clear to me as to what was expected of me as a user’s representative, or what predefined role I was to have. However, I decided to give myself, and the project, some time, allow myself to wait on the sideline to see whether things became clearer in time.

Mental Health as a user’s organization had been given the opportunity to participate in this project, and on behalf of the users this opportunity was worth embracing. So I clung on, and gradually I saw the contours of a project that in time would be of great significance to me personally, and hopefully to other users as well.

For 4 years I have been a user’s representative in EMILIA. At the outset I was part of the Bodø steering group, gradually I was given more tasks and responsibilities.

My first meeting with other participants in EMILIA was the annual meeting in Barcelona in October 2006. To be given the opportunity to participate in the annual meeting was an accomplishment in itself. There is no longstanding tradition for the involvement of users. Realizing I was the only user’s representative present I felt both disappointment and frustration. The table was encircled by professionals, determining what users needed.

Lifelong learning can be a lot of different things. I believe that the project itself had to learn letting users participate to a greater extent, starting at the planning stage. In my experience there is a kind of arrogance to a project focusing on users, and to such a degree emphasizing user participation, taking so long to involve users. I do believe that the project would have benefited from involving users as early as the first kickoff

meeting in 2005. But, change in thought and action do take time. In this instance, for both the users in the project and for those responsible for the project.

As a professional you have to dare let some of your authority go, and as a user you have to let some of the security that lie in passively accepting help go. These are challenges for both parties.

As mentioned, I have held different positions in this project. First and foremost I have been part of the Bodø steering group and participated in the Bodø meetings. This in turn led to me participating in the annual meetings in Barcelona, Sarajevo, Vilnius and Bodø.

In Vilnius, 2008, it was decided that there should be a user's representative on the project board, and I was elected. In my opinion this was a correct and important decision. It is, of course, debatable whether there should have been more than one user's representative, and whether users should have been more involved initially. Personally, I do not feel I contributed much on the board, but it is of importance to me that users are represented. Involvement of users yields positive signal effects. As a user this is an extensive process as well. Most users are unaccustomed to being involved, involvement is unknown territory and it takes time to dare use the "power" bestowed upon one. There may also be some insecurity regarding the authenticity of the "power" bestowed.

In connection with this final conference here in Paris, a scientific committee was appointed. In this instance too, a user's representative was included, and that was to be me. The well known feeling returned; am I only an alibi? Having said this, the insecurity felt, or lack of self-esteem, may be the responsibility of users, and part of the challenges users are facing in the future. We have expressed our desire to participate. When given the opportunity we must seize it. The process will take time and no one can stand it alone.

Bodø has been one of the demonstration sites in the project, and has thus been testing some of the training packages developed. The thought behind most training packages was that there should be two trainers, and that one of these was to have user experience. In this regard I got to travel to Århus to learn more about this training and I have since been a trainer for two of the training packages in Bodø (Powerful voices and Social network support). The training was given in fall of 2007 and spring of 2008. Doing this work I felt I could contribute. Cooperating with the other trainer, a professional, was a positive experience. Interacting with participants of the training packages felt meaningful and good. The training packages did bring about substantial work, but the work yielded in terms of positive and good experiences.

Based on my experience as a trainer, I have taken part in a cooperative development of "Interactive European Lifelong Learning Programmes" between Århus and Bodø. Something that has resulted in a lot of traveling and work, but in my experience it has been informative and productive. In this instance I experienced what I would term real user influence. Real user influence I define as participating on equal terms as other group members, where the divide between users and others is non-existent. The focal point is how you can contribute, not who you are.

At several occasions I have contributed in presentations of the project within Norway, where I have talked about the project from a user's perspective. There seems to have been an increasing interest in EMILIA, and I would have to say my personal belief in the importance of the project has grown over time.

I have personally experienced the importance of learning in secure surroundings. I had a hard time finding such safe surroundings when I needed them. Either expectations of users would be overwhelming, as in the municipal programs. Or, there would be neither expectations nor demands, as in the psychiatric health care programs.

EMILIA offered the combination of safety and demands I was looking for. However, in my opinion, for a group to function optimally, it ought to be compiled based on functionality and not diagnosis, as has been the case in EMILIA,

**I have been asked to share some of my experiences participating in this project, and to share what significance some of these experiences have had for me personally.**

When talking about change and to what degree change has taken place, one has to take a step back. It is looking back I realize what change has taken place. As the process took place, being present in the moment was more than sufficient.

My participation in EMILIA was based on my experiences from being mentally ill and it was this special competence as a user who was in demand.

When asked to participate in the project in February 2006, my circumstances of life were somewhat different than at the present. I had recently embarked on the journey returning to a meaningful life, not sure where the road would take me.

In 1990 my life changed dramatically. At the time I was 40 years old and married and was the mother two children. I worked full time and was actively involved in the community, in addition to being a mother and housewife. I lived what you might call a normal life, apparently successful. Deep down I had known for a long time that something was not right, that I carried a baggage from early years filled with traumatic experiences. I have spent a lot of energy keeping those memories at a distance through the years. In 1990 I hit the wall, the dam burst and I went down.

The following 10 years it felt as if I was moving through a dark emptiness. I previously thought of myself as a sensible, able human being independent in almost everything. Suddenly, I found myself dependent in most things. I had given up on life, my goal was to end it. Finding an end to life was my project for years. I lived through an existential voidness, an absence of life, abandoned by both people and God. Keeping up an existence in this voidness was not possible and I realized that if I chose life, I had to "find life" some place. I had to venture into the world and dare take part in it.

I was lucky. I had some good people around me, who had faithfully been there through all those years, who never gave up on me, who saw my strengths and not only

my weaknesses. They believed in me, and with their help, and as others joined in, I embarked on the long road back to life.

It was a strenuous process. I had lost so much in the span of those years. I had gotten a divorce and moved on my own. I had left the workforce, and become a receiver of disability pension. Thus, my personal finances had taken a turn for the worse. I had isolated myself socially for long periods at a time. I suffered from a lack of concentration, and even reading became difficult. A big sorrow for a book lover like me. None the least, I had lost all self-confidence and self-belief. As a human being I was worthless, not sure I deserved to live.

Put simply, it was no easy task I had ahead of me, but I had started and was well on way when I joined EMILIA.

### **What has EMILIA done for me, and where am I today?**

A lot has happened in my life the past 4 years, events that have shaped my life, encounters with people of great significance. Isolating the factors making a difference is no easy task. Was one event more significant than another? It may be a mix of everything. But I do know that my involvement with EMILIA has been of great significance to me, and that I would not have been where I am today without EMILIA. The word “recovery” has become particularly meaningful to me, it is a suitable equivalent for what has happened to me the last years.

When I first joined this project, I encountered some unfamiliar terms for which I had to spend a fair amount of time to find understandable definitions and good Norwegian translations. The latter has been a challenge, and there is a tendency to use the English expressions in Norway. What first comes to mind is “empowerment” and “lifelong learning”, both key-terms in EMILIA.

For me “empowerment” consists both of using ones potential and neutralizing what is hindering one in using ones potential. In my mind, empowerment cannot be given to a person, it is a want that has to come from within. Surroundings can help fight harassment, stigmatization, neglect, etc. and thus make it somewhat easier. But each one has to clear his own path.

My challenge then was realizing what was holding me back from using my skills and abilities. Could I at an adult age dare use myself, believe in myself? To achieve this I needed arenas where I could challenge myself. My participation in EMILIA became such an arena.

Ever since I first became a user’s representative in EMILIA I was met with respect, and I was taken seriously. I do not think I will ever forget the moment when I was invited to join the annual meeting in Barcelona. That was a great honor I thought and a real self-confidence boost, both for me personally and on behalf of other users. From social, and professional, isolation over years, I was suddenly part of a community. I had things to talk about, experiences to share. Life became richer in so many ways. I almost felt “normal”. With the same obviousness I was invited to Barcelona, I was also challenged and faced with demands. I was given tasks and relied on to such a degree it initially scared me, but I chose to believe I was capable.

To be given the role as a trainer was a new and incredible rewarding experience. I may have wished I had more knowledge and training, but I did OK. Cooperating with the professional trainer was very positive, I perceived we were a team. I got to use facets of myself besides those of a user, something that also gave a boost to my self-confidence. Working with course participants was a real source of motivation.

**In what way can I relate lifelong learning to my personal experiences from participating in EMILIA, and what significance has it had on who I am today?**

To be given the opportunity to visit other countries, to get a peek at other cultures and to hear foreign languages, has both been informative and of importance to me in social settings. I have actually gained knowledge and experiences that I can share with others.

I have been given the opportunity to actively use a foreign language to the extent I would never have achieved without participating in the project. A real benefit to me. Old knowledge I thought was long gone, has come back to me, another self-confidence boost.

After years of social isolation, being forced to cooperate closely with others and also to function socially, have been a learning experience and a demanding process. This may be where I have noticed the greatest change in myself.

I have on several occasions been required to deliver written materials, which has led to a re-discovery of old computer skills, and the acquisition of new skills within the context of the ever changing digital world. This has all been really inspiring

The examples mentioned above are visible, tangible results of learning. A learning that has been of importance for me feeling included in present day society. Less tangible are results of learning in the heart and mind. The challenges, not visible to anyone else, encountered and conquered, the anxiety I have had to combat to move on to experience personal growth.

I have gained confidence in myself. I have found the courage to face new challenges, the courage to try and to fail. I have found courage to demand my space, to be more visible. I have allowed myself to dream, and to realize some of my dreams. Last fall I went back to school to realize an old dream. I studied history of philosophy and could experience the joy of learning, the gratefulness of improved concentration and with that improved memory.

I have more dreams, and I will not abandon them.

I will remember EMILIEA as much more than a project. Through EMILIA I was given a new beginning. I have been being relied on, something that has made me believe in myself and lead to me today having a meaningful life.

From this point on, it all depends on me.