

Expertise. Adam James learns about a European training initiative for 'experts by experience' Mental Health Today (2007) Vol.7 (Issue 3): 14–15.

Expert advice?

Service users and patients are now heralded as "experts by experience", and one project is collating user expertise from around Europe with the aim of producing a qualification enabling users to work in mental health. But is it all worth the time and investment, asks Adam James?

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"Experts by experience" has become one of the concepts of the moment in mental health.

It refers to the knowledge that patients, service users and carers have acquired through either the very experience of distress, or caring for someone with mental health problems. Organisations from the government's National Institute for Mental Health to user-led charities have embraced the idea. Training departments of universities, mental health service providers and the police regularly commission such service user experts by experience to run courses for their staff.

Now the European Union is taking up the mantle of trying to assimilate this expertise. The European Commission's Leonardo Da Vinci Program has been using 375,000 euros to fund a two-year project, called Ex-In, with the aim of creating a service user knowledge-base and developing an "Experts By Experience" qualification which will springboard users into mental health employment. Standing for "experienced involvement", Ex-In has been harnessing service user experience and know-how from six participating countries to inform its template Experts By Experience course. Ex In says such a qualification would be a recognition that people who have experienced mental illness and been treated by services have "vast knowledge".

"A growing number of training bodies, universities and services are involving experienced [service user] people," explains Jorg Utschakowski of the Initiative for Social Rehabilitation in Bremen, Germany, and one of the Ex-In partners.

"The problem is that, in many cases, users have, due to the lack of structured training for their work, no acknowledged status."

Ex-In's UK partner is The University of Central England. Its professor of community health, Mervyn Morris says knowledge by experience is qualitatively different from traditional psychological and psychiatric science. "It is more practical and life-orientated," he says. "It's not knowledge that is about controlling diseases."

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Morris cites the example of the Hearing Voices Network, credited for showcasing user-knowledge of voice-hearing.

"A voice-hearer will often talk about coping and managing strategies, but he/she will not start from the perspective that voices are a symptom of mental illness and are part of a disease," says Morris. "But this is what a psychological cognitive behavioural perspective of voice-hearing might do. From the user's perspective it's about living with voices and finding their own understanding of voices. That's a shift of perspective about the core nature of the problem."

The planned Expert By Experience qualification is tied in with Ex In's grander vision that increased use of "experienced involvement" will encourage a "more user-orientated, more satisfying and less discriminating and degrading provision of mental health services."

In February this year delegates at a "Broadening Our Horizons" conference at Birmingham University got the opportunity to hear first hand about some of the user-led projects which will form the basis of the modules of the proposed qualification.

Inevitably, some of Ex-In's participating countries have more mature service user-led services than others. Holland has hundreds of state-funded user-led advocacy, peer-counselling and support projects already in place. One service is a user-managed hotel, Zorghotel de Pit-Stop, in Haarlem, offering people in distress a non-hospital refuge. But Slovenia, for example, has no comparable service. It has just a handful of community mental health services, none of which are user-led. Petra Videmšek, a social worker, told conference delegates that the only state-funded mental health services were traditional psychiatric hospitals. Any community mental health service that did exist was run by non-government organisations.

There are 10 planned modules for the Expert By Experience qualification. All material is being supplied by service-user organisations and universities from Holland, England, Slovenia, Norway, Sweden and Germany. The modules will focus on empowerment, recovery, the assessment of clients using person-centred or narrative approaches, training professionals on user perspectives on voice-hearing, peer-advocacy, peer support, and the preparation of service user training and presentations.

Conference delegates also heard about a form of "community mental health forum" popular in Germany. Known as triologue seminars, these are when people diagnosed with psychosis (the experts by experience), their family members, carers, friends, and professionals meet informally in neutral settings and in their spare time to discuss mental health issues, ranging from prejudices to neuroleptic medication. At the conference, triologue seminar representatives said such forums – reportedly widely supported by service users in Germany – offer a "mutual education" where "everyone is regarded as an expert with respect to their own role

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and experience”.

Since the first triologue seminar in Hamburg in 1990, there are now 130 working seminars, involving 5000 people. One module of the Ex-In curriculum is devoted to triologue, and students will learn will learn to take into account the perspectives of professionals and carers.

Ex-In partners are markedly enthusiastic about triologue, and Prof Morris was impressed by a Hamburg seminar he visited. “There were 30–40 people at the seminar. Triologue seminars, in effect, make a community out of people involved in mental health. They create possibilities through dialogue.”

Away from the conference, there is, however, scepticism about the Experts By Experience qualification initiative. Laurie Bryant, service user lead for the government’s National Institute for Mental Health, believes many service providers would not appreciate the worth of an Experts By Experience qualification.

He says: “Such a course may produce highly motivated people with a qualification, but a chief executive [of a service provider] will be operating to a completely different agenda – that of controlling budgets and ticking boxes.

“What I would not want to see is for such a course to raise people’s expectations, only for them to go out into the real world and find work for them is not there, so their hopes are dashed... Sometimes we, as service users, are allowed to go so far, and then we bang our head on a glass ceiling.

“I would prefer attention to be spent on preparing the ground first – i.e. for the people running such a course to work with the decision-makers first, and ask them how they are going to use and embrace the people who take such a course. As service users we do not work enough with service providers and those who commission services – but it is they who are the power brokers.”

Bryant, a member of the International Initiative For Mental Health Leadership, believes service users might spend their time more productively in learning leadership qualities. “To make an impact we have to develop [service user] leaders who can sit down with chief executives and change their thinking,” he says.

“We need to teach people to talk the professional talk. That’s where I see the future. The question I always ask is where does the decision-making power lie? I think service providers should be commissioning 50 per cent of services. We need a complete paradigm shift.”

Sara Stanton, of mental health charity Together’s service user directorate, argues that rather than offering Expert By Experience courses, energy might be better invested on integrating service user knowledge into training for professionals such as mental health nurses and psychiatrists. “This would be better than developing separate curriculums and courses for service providers,” she says.

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Ex-In's funding ends in September, and Prof Morris says it will be down to individual European countries to develop Ex In's template course in whatever way they see fit.

As for the UK, Prof Morris believes health organisation and service user groups have to decide whether putting together an Experts By Experience qualification is worth pursuing. "It is now about finding out whether there is a market for such a course," he says. "Maybe organisations such as Mind will take an interest.

"My view is that such a course should be run and accredited within the higher education sector – and it should be of a certificate level. I trained as a nurse and I then did a teaching certificate qualification that enabled me to teach. Such an Experts by Experience course could operate along the same lines."

While Ex-In's partners are uncertain what in the long term will become of the work they have put in, the very idea of an Expert By Experience qualification hit the mark for some conference delegates. Tracey Holley, of the Worcestershire Mental Health Network, said: "I have had depression and really struggle with the idea that I am an expert. But this course is just what I am looking for. When can I sign up for it?"

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The Dutch perspective:

Harrie Van Haaster heads IGPB, an Ex-In partner and a user-run research company based in Amsterdam, Holland. In conjunction with a higher education institution in Eindhoven, IGPB runs its own smaller scale Experts By Experience courses. Van Haaster, 54, is also a psychologist who has witnessed both his wife and mother being admitted to psychiatric hospital.

"In 1996 our government made it a law that one per cent of national health care expenditure in each health region had to be spent on user initiatives. So there are now around 200 user-led mental health initiatives in Holland. These vary from user-run research companies and day centres to smaller projects such as a service user-run kennel for dogs and cats of people who are in [psychiatric] hospital. This may seem a small thing – but, for some people, pets fulfil an important need, and someone in hospital will want to know their pet is being well-cared for.

"Most user-run projects in Holland receive between 250,000–500,000 euros. It's not massive– but enough to do small things. Moreover, most progressive mental health organisations in Holland are supportive of these user-run projects and will, in turn, provide funds. We also have a national service user organisation, called Voice.

"We have found that through these user-run projects people want to learn more and improve their skills and competencies – this was a big stimulant for running

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these [Experts By Experience] courses in Holland.

"There is user expertise, and users have a lot of experiential knowledge. It's important we make it explicit. For example, there is all the knowledge gained through the self-help movement. It may not be written, evidence-based knowledge, but self help is full of knowledge. Some may consider such knowledge to be too anecdotal. And while it is important that knowledge is connected with individual stories, it's also important to find the "intersubjective" knowledge. I prefer to use the term "we-knowledge". We-knowledge is different from intuition. We must provide this we-knowledge and develop our own validation strategies. Psychiatrists tell us they know what is good for us, and how we should look at the world. But we want to do it ourselves. It's not about being against professionals, but about building our self esteem.

"Three or four modules from the Experts By Experience course already run in Holland. And what, for me, is most important about the courses is that they are creating jobs. Around half of the 150-200 service users who have completed the courses have then found jobs.

"I had hoped Ex In would have been a bit more successful in having a Europe-wide course. But it is complicated. Different countries have different ways of doing things."

* This article first appeared in Mental Health Today magazine