

User and Family Expert (UFE) – Help Others, Help Themselves

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I'm happy to be here to give a presentation. I am not confident to speak English, so if I have difficulties, please help me. Today I will introduce a programme called "Oou Fay" – U-F-E - not UFO!

A Train from Venice to Beijing

It's a long story...a train from Venice to Beijing. October 2008. On this train there were over 200 people. One third were people with mental disorders. One third family members. One third the mental health care providers. The initiator of this journey was an Italian psychiatrist. It was crazy! A train from Europe, to Russia, to Mongolia, lastly to China, to Beijing. It took two weeks. He just wanted to show that people with mental disorders can do anything they want. I don't believe that! I can't do anything I want. I think it is incredible that they did it! But they did it! This is a photo of all the passengers on that train.

After they arrived in Beijing, they contacted the Ministry of Health. The Sixth Hospital of Peking University was the only mental health institute in China directly affiliated to the Ministry of Health. So we discussed with them and started a programme from the year 2011. The second phase started from 2014 and ended by 2017. This photo is the first training course in Beijing. There were three groups – patients, family members and care providers.

Users and Families are experts by experience

Okay. "Oou Fay". The pronunciation is "Oou Fay" not "You Fay". Do you know Italian language? ("No"). "Oou Fay" are family experts.

They can be regarded as experts to help others. Or help themselves. So how to be an expert? From my understanding from the Italian colleague, we are the experts of knowledge and users and families are experts with experience and the illness. So UFE is a unique resource of the mental health system. They cannot be replaced by the experts of knowledge. So the tour group of experts should work together.

In Italy UFE's work in almost all the mental health care departments, such as receptionists, day care units, inpatient units, social advocacy, family intervention, employment assistance, etc. One lady was schizophrenic and had a strong delusion of persecution and she was hostile to us. But surprisingly, she worked in the community mental health centre very well. I think in China she could be hospitalised.

The Italian UFE gave us lectures and they had a lot of emotional stories on recovery and how to help others. The culture and the language was completely different but the experience and the illness was the same, so some of the audience from China were moved to tears. This lady, the "youngest" but actually the oldest, 80 years old, lived with her daughter who was schizophrenic. She said that her daughter refused her at the worst time of her illness, so she went to UFE rehab centre. She hoped and believed that others could help her daughter. That is exactly the motto – "All for one and one for all".

We established our UFE Association in 2010. Here people who have red certificates for care assessment and regular treatment and work in some positions in our hospital. This is the lobby of our out-patient department. Several years ago the capacity

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was 300 people and now we have 1,200 patients per day, so very crowded. And the nurse who handles the information desk is extremely busy.

Now we have UFE here to help with the workload. Another job for UFE is to stay with the inpatients. In the hospital the doctors and nurses are very busy and we have no social workers, no psychologists, like most hospitals in China. So UFE plays an important role to listen to the patients, talk with them, take activities with them and reduce their feeling of loneliness. We consider this a kind of group therapy hosted by UFE just for the new patients to help them adapt to hospital life and improve their treatment.

These are the positions of UFEs (Figure 1). And this is a book written by UFE for the second anniversary of the UFE Association in 2012. Now we have just 100 UFEs. The average age is 37.5 years and 70% are schizophrenic. The average course of illness

is 10 years and the average time of working for each UFE is 20 minutes. 13 of them relapsed and 8 were rehospitalized. 31 were employed and 1 was hired by our hospital. Currently we have 18 working in our hospital. The total hours working per day was 27.5 hours, equivalent to 3.5 full-time staff.

We promote UFE work in the community. The district in which our hospital is located, Haidian, has over three million population. We have the UFE Association and now we have 150 UFEs working in the community day care center. Here is the China Association of Persons with Psychiatric Disability and Their Relatives (CAPPDR). This is the biggest NGO just for psychiatric disabilities. That is like NAMI (National Alliance on Mental Illness) in America. We collaborated from 2013 and promoted UFE to other provinces. We hold training programs each year and published this book, Guide for User and Family Expert (UFE) (Figure 2).



Figure 1: UFE's work

China Disabled Persons Federation is not an NGO and not a department of Government. It is more influential than Government. CDPF issued documents to promote the UFE model all over China. This year they started pilot projects in Beijing, Nanjing, Kunming and Harbin. UFE groups were established in these

four cities, providing UFE service platforms, meaning CDPF offered paid jobs for UFEs, supervised by the rehabilitation center of our hospital.

This is a map of China. Each flag shows a city where our UFEs have been and given lectures (Figure 3). Their

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presentations were very welcome and hopefully in the future there might be one in Hong Kong.

Help others, Help themselves

I will finish by reading some entries from UFE diaries. “I used to be a puddle of mud during my illness and UFE makes me reborn.” “UFE opens a

window to my new life, a brighter passway to my future.” “A patient told me that my words were more persuasive than the doctor’s. She became confident to her recovery staying with me.” “I will dedicate my particular experience to the particular group of people.” “To be an UFE, I feel no longer to be cared for but energetic to care for others.” Thank you for your attention.



Figure 2: Guide for User and Family Expert (UFE)

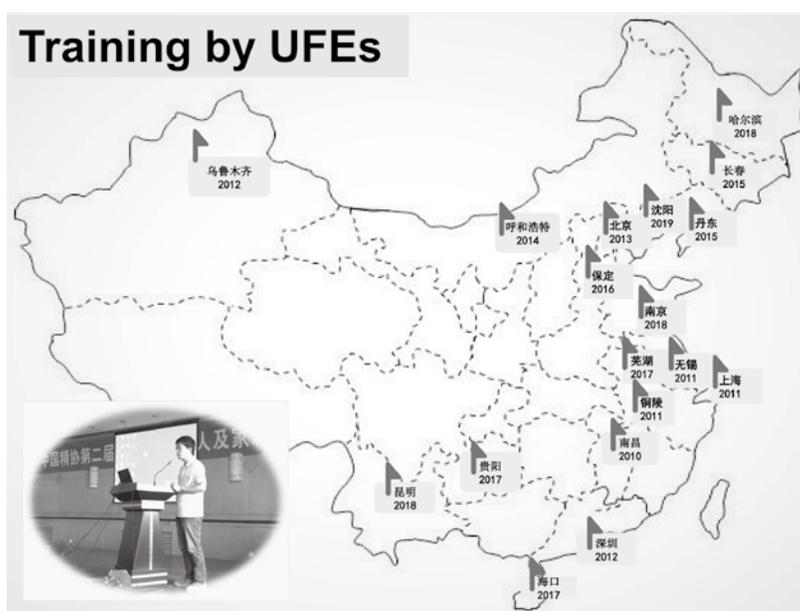


Figure 3: Cities in China with Trainings by UFEs