

# The Right to Live in the Community

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## We Are the Community

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### - Overwhelming experiences -

I was not yet twenty when my first psychosis emerged. I was convinced that we were on the verge of a world war. The public defence sirens were tested every first Monday of the month. To me, those sirens meant that the cruise missiles had already been launched. We had just minutes to do what had to be done: find each other and wait to die. Sometimes I could actually feel the radiation taking effect. I felt nauseous and believed that my hair was falling out. The rest of the world pretended to carry on as normal, but I could see that everyone was afraid. They knew that we were all about to suffer a slow, painful death, but nobody knew how to prepare for it. And so we all continued our daily lives with stolid determination.

A psychosis is far-reaching and overwhelming. Many psychiatric complaints are far-reaching and overwhelming. They involve a severe distortion of meaning. They render the world unfamiliar, unrecognizable, a threat. Psychiatric suffering can turn life into a living hell. Just 'being' can no longer be taken for granted. Nothing can be taken for granted. Once you know that life will become unbearable beyond a certain boundary, once you know that you have such a boundary, very little can be taken for granted again. A psychiatric disorder is also accompanied by a sense of estrangement. What you *have* is often closely allied to who you *are*. The manifestations of the disorder sometimes dominate your entire personality. The distinction between the individual and the disorder is soon lost, and it is very difficult to regain.

### - When psychiatry takes over -

One of the consequences of serious psychiatric suffering is that you will find yourself as a patient in residential psychiatric care. This too is an overwhelming experience for many of us, especially the first time. It is difficult to cope with being a patient in a psychiatric hospital. This is a place where traumas are likely to be experienced, and where even abuse may be undergone or witnessed. My stay in the institution damaged me in several ways. When I look back at how undignified it was to be a psychiatric patient, the self-respect for which I fought through the years feels shaky. When I remember the humiliation inherent to being a patient, I feel so angry that I am liable to forget my resolution that it will never happen again. No matter how you look at it, psychiatric institutions are reservoirs of human suffering. Other people's misery you see there is added to your own. This, to me, is one of the contradictions of psychiatry: we herd together people who are suffering and then expect them to feel better.

The longer you are a psychiatric patient – becoming 'chronic' in the jargon – the more likely you are to forget how to lead a normal life. An admission to a hospital means that you exchange your familiar, trusted surroundings for the hospital life and routine. You can no longer call upon

the person you were. Your main role in life becomes that of a patient. This role should not be underestimated: it demands certain skills, such as the ability to adapt. As a patient, you have to fall into the rhythm and routine of the large hospital organization. You have to comply with the rules. Unfortunately, the dividing line between adaptability and submission is not always clear. And it can easily become less so over time. Once the sense of resignation has taken hold, you have absolutely nothing to help you regain your former life. A situation develops which could well endure until the end of your days.

The longer you remain a psychiatric patient, the more likely you are to forget the rules of normal life. You forget that life itself has its ups and downs, and you forget that you used to be a person with both good traits and bad. As a patient, you learn to blame all the negative aspects on your disorder. During my career as a patient, I learned to attribute every setback and every little disappointment to my disorder. I now know that everyone has the occasional bad day when nothing seems to go right and the entire world seems to be conspiring against you. But for a long time, that sort of day would set alarm bells ringing for me because I thought that it was the precursor of a relapse. I had forgotten about life's everyday irritations.

For a long time I did not dare to take matters into my own hands, to lead my own life. I relied on the professionals: they were the experts. Other people knew how I should lead my life. I did not. When you are a psychiatric patient, it is extremely difficult to retain your self-esteem, your own values and opinions. And it is nearly impossible to explore or develop them.

#### **- The 'warm and welcoming' society -**

We wrestle with our mental health and with the unpleasant side-effects of the psychiatric system. We also have to contend with the social consequences of our disorder. We face prejudice and ever-decreasing tolerance in the community. That affects us in our social contacts, in the neighbourhood, in education and in finding a house or a job. There are regularly rants in the media denouncing our attempts to participate in society. Negative images are presented, based not on any facts but on emotions and the 'rights' of whoever can shout loudest. Those images present us as unpredictable, homicidal maniacs for whom the only answer is restraint and permanent confinement. There is no consideration for the social injustices, such as abuse and violence, which turned our vulnerabilities into serious psychiatric suffering to begin with. In many European countries there is a political climate in which the burden of the economic recession is shifted onto those people with least money and the poorest health. I could go on. It is certainly not only our own individual problems which we have to contend with. We must also learn how to deal with the causes and consequences of those problems.

#### **- Survival and life-art -**

I was not yet twenty when my first psychosis emerged. Twenty years have since passed. That first psychosis was not the last. I am still not rid of it. Am I expected to wait another twenty years until cure descends upon me? Well, to be honest, I am not willing to do so. I have decided that I will not wait for the doctor to give me a pill that will cure me. I have decided that my condition and I are two separate entities. I am *not* my disorder.

My life – and that of many other people with a psychiatric disability – is all about learning to cope with that which cannot be cured. We have not yet experienced the miracle of cure. For many of us, waiting for it to come along is a complete waste of time. The psychiatric system is not able to cure nearly as much as it likes us to believe. Waiting for it to do so keeps us submissive and passive. It is better to ask: 'What are the obstacles in my life, and how should I

deal with them?' The question to be answered is: 'What do you want to do with your life and what care and support do you need to make that possible?' We are not psychiatric disorders with care needs: we are *people* with lives to be led, some aspects of which may require professional care or assistance. It is relatively unimportant who provides such assistance or where we get it from. The prime aim of psychiatric care should be to enable us to lead our lives in the manner we wish. Care is a means to an end, not an end in itself.

To maintain an existence with a psychiatric disability is difficult enough. To build a life around that condition demands courage, perseverance and creativity. People with a psychiatric disability are true 'life artists'. We tell each other about that life art in our stories, and in doing so we face the things that overwhelm us. Through our stories, we are able to see the difference between who we are and the problems we have. We learn to formulate for ourselves what care we need. We develop stories in which we recognize ourselves. We search for the right words to do justice to our experiences and in doing so we regain our own identity. Through our stories we say, "this is my life, that is who I really am and this is how other people can help me."

### **- User movement knowledge -**

We help ourselves with our stories. We do a lot to help ourselves. We have a wealth of experience in doing so. We learn to see the true value of our experiences and to see them in a meaningful way. We try to learn from them what we all have in common and what the differences are. We attempt to identify what will help us and what will stand in our way. We develop knowledge: experiential knowledge. We pass that knowledge on to others: to the next generation of care service users, to give them strength and hope; to professionals in mental health care, as for them to learn to hear our voices; to people outside mental health care altogether, so that our human face can be seen.

We help ourselves in many ways. User initiated projects are gaining in popularity and in substance. In countless areas, we have initiated activities on the basis of our own 'helmsmanship'. The underlying motivation is the conviction that our experiences will lead to renewed insights regarding psychiatric disabilities and their symptom. We are also confident that we can contribute to a better type of psychiatric services than those currently in place. Self-help and user initiatives are a response to the fact that our individuality, our experience and our knowledge are not yet adequately represented within mainstream mental health care services. For us, the emphasis is increasingly being placed on self-determination, our own responsibility and personal effort, rather than devoting our strength to railing against the power of others and their agendas.

The psychiatric survivors' movement has a lot to offer. Perhaps more than we have been aware of thus far. We initiate new and creative projects which strengthen our position and offer a different perspective of living with a psychiatric disorder. We develop training courses for professionals and for fellow users, and we start new self-help groups. We educate and train our fellow users who want to integrate their experiences in professional roles. Yet, hitherto, there has been no general overview of the various European user initiatives. There is no account of the strategies we use, the experiences gained have yet to be collated and no solid scientific basis for our methods has been established.

### **- Facilitating recovery and empowerment –**

To contribute to the development of knowledge in the area of user initiatives, in the Netherlands, long-term mental health care users in cooperation with Trimbos-institute, developed the TREE-programme. This programme combines the strategies and methods of user initiatives which are thought to account for their success. These are among others: self-determination, self-help and mutual support, the creation of new roles based on positive labelling of psychiatric experiences, giving meaning to experiences of distress oneself instead of accepting 'the doctors' view'.

### **- TREE: ... -**

The TREE-programme aims at enabling people with psychiatric disabilities to support each other *towards recovery, empowerment and experiential expertise*, thus enhancing their abilities to manage their own lives and to counter their marginalization in society.

### **- TREE Programme ... -**

To this end, the programme enables its participants to exchange experiences and offer mutual support. It also encourages them to develop knowledge and to use such knowledge by making it available to others. Last but not least, the programme promotes user led change within mental health care organisations in the direction of recovery-based services.

### **- Principles .... -**

People with psychiatric disabilities can take part as a member of a self-help group, as a student of one of the courses, a volunteer or as a paid experiential expert. The programme offers the opportunity to:

- communicate with others about experiences that are overwhelming;
- create some distance from these experiences and reflect upon them (develop your own narrative);
- make a we-story out of several I-stories (experiential story);
- make the experiential narrative useful for knowledge dissemination to fellow users of psychiatry, mental health care professionals and others;
- participate as a (paid) trainer or lecturer in training programmes.

The underlying principle is that an important element in recovering from long-term mental illness is to develop and pass on narratives. To make and to tell a narrative enables us to overcome whatever it is we are overwhelmed with, for instance a psychosis, because it enables us to recover our sense of self. Through the story telling we grow from being a disorder to becoming a person trying to deal with life. And it enables us to learn to formulate what it is we need to recover. To develop your own narrative and compare it with the narratives of other users of psychiatry is the beginning of building experiential knowledge. A collective story is made out of several individual narratives. To this end we look for underlying principles, for what we have in common and for what distinguishes us from one another. And finally the experiential story is transformed and used for knowledge dissemination in training programmes and courses.

In the TREE programme participants develop, transform and disseminate experiential knowledge. They perform these tasks themselves, as volunteers or in paid jobs in the mental

health care organisations where the programme is implemented. If necessary they hire others, mental health care professionals perhaps, as prostheses to enable them to perform their tasks.

#### **- Contents: ... -**

The programme consists of:

- self-help groups and working groups;
- one day training, courses and group discussions for fellow users of psychiatry;
- training programmes for professionals;
- consultancy and coaching in organisations that wish to implement the programme.

#### **- Programme of/with ... -**

The programme is for and with persons with severe mental illnesses and psychiatric disabilities. They often struggle with multiple and complex problems in several domains of life and most of them have impressive patient careers in psychiatry.

#### **- Consequences –**

As a consequence they face dependency, lack of self-confidence and self-esteem, loss of control over their lives, loss of meaningful identity and greater social vulnerability. There are no other criteria to enter the programme than to have (the courage to have) some interest in what the programme is about. We don't know what factors predict success. Perhaps it is better not to know. The programme is developed in order to create opportunities for recovery and empowerment and to facilitate whoever wants to make use of these opportunities. Inherent to this goal is that everybody can participate. Practice will show for whom it is a successful opportunity and for whom it isn't. The programme is open to all users of long-term mental health care. There are no criteria, no demands, no examination and one can use it as often and as long as one likes.

#### **- Evidence based?**

In the Netherlands the TREE-programme, or parts of it, is becoming more and more popular among people with psychiatric disabilities themselves as well as among care providers. Several mental health care organisations have started to facilitate their users to implement the programme. A nationwide operating team of experiential experts is now hired frequently to provide for kick off meetings, support fellow users in their recovery and in making recovery narratives, coach persons with psychiatric disabilities to become experiential experts, train fellow users and professionals, give lectures, design new programme parts and guide the implementation of the programme. Four implementation sites, throughout the country, with models of the TREE programme are being studied on its effect. On two sites a quasi-experimental design is followed and on two sites a randomized controlled trial design is followed. Outcome indicators are identity, confidence in mental health, empowerment and connectedness. The study started in 2004. Results will be available in 2007.

#### ***Blanco***

I come to the end of my lecture. I have tried to explain what it is like to be overwhelmed with a mental disorder and its consequences. I showed what it takes to build a life when facing

psychiatric disabilities. I have mentioned the enormous amount of valuable experiences and experiential knowledge present within the psychiatric user movement. And I gave an example of how we try to develop evidence that the wisdom we share within the user movement is effective for our healing and recovery.

I believe that from within the user movement we have set in motion a development which will prove irreversible. We put forward our own experiences and are able to reflect upon them. We listen to the stories of other people with psychiatric disabilities and we integrate those stories into our collective body of knowledge. We are coming to realize what themes and topics are of importance to us all, and we recognize the obstacles that face us. We are becoming aware of the (importance of the) history of our user movement. We are developing an understanding of power relationships and constrictive social structures. And against the dominant perspectives, we are demanding attention for the social aspects of individual psychiatric problems.

We are developing various initiatives and through them we transfer our knowledge to others. We train and advise users and professionals. We pass on the baton to those who follow us, supporting them in their recovery process. We are presenting examples of hope to those who consider their situation hopeless. In doing so, we open up choices to people who did not realize they had any choice at all. And we help to find the resources which can bring those choices to fruition. That is the strength of our user movement. Sharing a sense of unity, passing on our knowledge to each other and feeling solidarity in difficult times.