

From alien to actor

*Lecture held during The Public Hearing on The Green Paper on Mental Health,
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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, 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.

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, where abuse may be undergone or witnessed and human rights may be violated. 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.

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.

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.”

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.

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I've used most of my time to give you some insight in what it is like to have a mental illness and to be a psychiatric patient. I shared some of my personal experiences with you, because Mr. Bowis explicitly asked me to. Normally, Mr. Bowis, I don't do that when I am the only woman on a list of male speakers all using their official titles. But here, today, I chose to do as you asked. Why did I do that? Why did I make an exception now?

Why did I not go into the fact that in many European countries psychiatry isn't about mental health care at all? We know that in many countries it's about the violation of human rights, about harmful confinement and about removing persons from society for the rest of their lives.

I also didn't point out the alarming, growing influence of the pharmaceutical industry. We don't need its dominance at European level, although this may seem tempting for many of you and your organisations. Don't misunderstand me: as many users I am grateful that I can use psychiatric drugs to help me fight my psychosis or my depression. It can be an effective additional aid in my recovery. But nothing more. I think modesty should characterize the pharmaceuticals in European mental health care and we have to make sure they behave like that.

I chose not to mention that we need good, evidence based community care, a safe environment to recover from our distress and a respectful and dignifying approach from the professionals who try to help us. We need recovery oriented care, user led initiatives and self help groups, good rehabilitation programmes and societies that welcome us.

I chose not to tell you all this, because of course you all already know. Every sensible person would come to the conclusion that we need food, a safe, caring and empowering environment, good support and an inclusive society. Because we are human. People, just like you. Sometimes we are in distress, we are confronted with mental health problems and we even need psychiatric care. Today it happens to us, tomorrow it can happen to you. We are people, just like you. With both good and bad traits, with talents and limitations, with dreams and a need for hope. And if we get the chance we learn to cope with our disabilities and we

develop knowledge and skills in combination with our experiential knowledge. If we get the chance we become researchers, policymakers, politicians. Just like you.

That's why I chose to do as Mr. Bowis asked. To show you that we are just like you. To tempt you to invite us in, to work with us, to talk with us instead of: about-us-without-us. I think talking about integration and social inclusion obliges you to act accordingly. I think it is your task to become role models. To show to the EU-countries and the people involved in mental health care that you want us among you, that you want to work with us and that you want to learn from us. I think it is your task to show to others that we are human.

Not alien, just human.

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