



The Bell Jar (Videointerview 22 min)

In 2015 Marie Obbel Bondeson had an Artist-In-Hospital Recidency at a department for psychosis in a hospital in Sweden. The mission was to observe the environment in collaboration with the staff. She wrote a diary and made it public. The result was a report to The Health Care Inspectorate (IVO), a governmental agency supervising healthcare. Their answer to the report was that the project had negatively affected on care in terms of not respecting the integrity, safety and autonomy of the patients. Carina Håkansson, Dr in Psychology, Associate Professor & Physiotherapist, has worked with alternative mental care for over 30 years. She was the founder of the Family Care Foundation and she works within the Extended Therapy Room Foundation. She is a lecturer and and a writer. This interview is about the diagnosis society, its bible, the psychotropic drugs and the impact of the culture of silence.

ABOUT THE DIAGNOSIS BIBEL

-This is it. It's rather heavy. This is what people want?

-Yes, but I am not sure that people would really have wanted a diagnosis if they knew about the alternatives. But this is in fact what we offer in our country, a diagnostic culture. Consequently people believe that this is the way everything is supposed to be. There is a tradition since some decades to not stigmatize people who are having mental or emotional difficulties. One way not to stigmatize is to think that it is okay to have a diagnosis. But people are more and more strating to realize the negative effects of diagnostics. Sooner or later, when you apply for a job or are getting into the military service for instance, the diagnosis appears. So we have started to talk about the disadvantages. But the most serious consequences I think is that young people start to identify with the diagnosis they have got. You tend to think of yourself that you are that way or the other because of your diagnosis.

-You start thinking about yourself according to the diagnosis? As an identity?

Yes, in a very static way. This is controversiel to say but I think it can become a way to avoid responsibility.

We seldom speak about the fact that if a person once has got a diagnosis, it is hard and almost impossible to get rid of it. Most people, that I meet in my work, never got this information.

Not always, I stress this, not always. But Mostly, there are reasons for us to act and be as we are. Of course it's more complicated to relate to and think about why we feel as we do, why we have an anxiety or fear. It takes more time, it demands more from the person in difficulties itself aswell as from the people surrounding. But this is what we have given up in favor of rather simple explanations and quickfix solutions. A result of this is diagnostics and psychotropics.

ABOUT THE PSYCHOTROPIC DRUGS

-There is no place where people can go and ask for advice if they don't want psychotropic drugs. Nor have we some place to turn to when we have ques-

tions about specific drugs, their effects and side effects. This is one of the reasons why we started startade International Institute for Psychiatric Drug Withdrawal.

-The most important reason for us to be careful with psychotropic medication is that there are so few studies and research from systematic practice, about how exactly the drugs affect us. There are short-term studies but we lack long term studies. What we do know is that some of the heavy drugs have severe side-effects on the human body but also on the psyche or soul so to speak.

- In Sweden, for the last 10 years, medication and the diagnosis of ADHD has increased badly in numbers. Very many young people consume on a daily basis drugs for a symptoms based diagnosis. Nobody knows yet the effects this is having. What we do know, about ADHD drugs, is that young people get physical symptoms like high blood pressure, weight loss, bad appetite, sleep disorder, worry etc. And this is the treatment that a majority of kids and grown-ups get. Psychiatry isn't organized to take care of people with complex life problemes. I am not sure that psychiatry is the right place for this.

ABOUT THE ALTERNATIVES

-In June 2017, a report was published in the UN (for Human Rights), where it was found that the psychiatric system has failed.

The investigation finds that we need alternatives to psychiatry.

It is a serious questioning of psychiatry that it may not be the system for people when having social, emotional, economic and mental difficulties. We need to come up with better systems.

What was the reaction of the report in Sweden?

Well, in Sweden there was no reaction at all what so ever.

-What I mean by this powerful expression is that today people still gather together in a department, with a long corridor and rooms on both sides. In these rooms there are different people with different concerns. Otherwise, they would not have been there. I am extremely doubtful whether this is the best way when people are in crisis. I think it's very strange that we haven't come up with something better in 2018.

-This is about the part of psychiatry that is not outpatient. As regards outpatient care, it looks very different in different parts of the country. What people testify to are that even in outpatient care, there is very much focus on medication. Not least, it is a fact that when you come to psychiatry, attending physicians must diagnose at the first, possibly at the second visit. This diagnosis is based on one hundred questions that largely cover a whole human life. This will be dealt with in a very short period of time and in relation to a person with whom you have no relation. That is, a doctor.

THE CULTURE OF SILENCE

-Criticisms about the direct side effects and the lack of follow-up of psychotropic drugs, when criticism is presented -nobody answers. You do not get an answer. I think that psychiatrists have a low status among doctors. Psychiatrists also have a low status among many of us who are not physicians, as myself. In fact I do not understand why you should meet a psychiatrist when you have social, psychological or emotional worries. Obviously, when a person seeks medical care, for example psychiatry, one also has to exclude somatic diseases. Sometimes bodily symptoms can make you think it's psychic. For all people, one should rule out that there is something physically wrong. But when you have ruled out that there is nothing physically wrong, I do not understand why you should meet a psychiatrist. We don't talk about this.

-The psychiatrists I know, both in Sweden and in other countries, which focus on relationships, complexity, life-style and human phenomena. Most of them are also psychotherapists.

They have come to the conclusion that the education of psychiatrists is not sufficient to meet people in crisis or in difficult situations.

I think this is one of the things, speaking of your book "The Elephant in the room", which we are not talking about. Why do we need a psychiatrist at all when the physical examination and the review is done? I have not received an answer to that. I do not understand. In Norway, for some years now, a law has been introduced that psychiatric hospitals must also offer drug-free alternatives to those who so desire. A year ago I was in Tromsø at one of the first hospitals that introduced this. There is no such thing in Sweden, and there is not even a discussion about whether this could be an opportunity.

- How can we initiate a discussion? How do we break through in this culture of silence?

-I think we may need, including myself, become even more emotional. Even more insistent, even more clearly ideological.

INTEGRITY AND AUTONOMY

-My Artist-In-Hospital residence in a psychiatric department resulted in a report to IVO- The Health Care Inspectorate, a governmental agency supervising healthcare. Any comments?

-Yes, that the confidence in the patient is so terribly low that you don't think he or she is able to understand. Patients are supposed to handle being in a department where you meet 35 staff and agency locum physicians one day which the next day are replaced by new doctors or nurses. This goes for day care staff as well as night staff. This is totally horrible, I think. It shows the double standard that we depend on. On one hand, words of honor are used; Respect for the patient and Integrity. On the other hand the words are used within a system that implies the opposite. With this in mind, to claim that patients wouldn't handle that an artist, who comes with the intention to make people's reality distinctly visible, this I find disgraceful. It's a shame.

-Do you have more comments to IVOs answer to the complaint?

-Of course on one hand, secrecy is extremely important. People must feel safe that what they say in deepest confidence is not spread to other people. At the same time, what most people say has been harmful to them is introversion, not transparency. In their own family but also in care professional contexts. This idea of privacy at all costs, may perhaps more be a question about the interests of the staff. In order not to expose us, not to show our weaknesses and what we may not be good at managing or coping with. So we say it is in the interest of the other, in this case, a considerably weaker other. You put words in the mouth of people that I do not believe come from themselves. It would be so much more sympathetic if they would have said

that, as a staff member of this department, we find it difficult when you come here and we feel inspected and disguised. We are not sure what you want. But this is not what they say, instead they are saying that it's the patient who cannot handle it. This is an extremely common phenomenon, not only in psychiatry, but in many places that involve people.

ABOUT THAT ANOTHER CARE IS POSSIBLE

-It is extremely important to initially try to receive the person who comes with what he or she brings. To my long experience it is usually important to give something from yourself to the other. You can also give something from yourself without words.

-To give something with or without words, what does that mean to the person in front of you?

- It means everything I believe. I think it makes us feel less alone and scared. Less strange. Most people that I meet are terrified that they might be or become mad. Of course it goes without saying that it has a crucial importance if I receive a person with an attitude of investigator putting questions or if I meet the person along with showing something from my own madness, my own fear, my doubts or my weakness. Not necessarily from my own life, but that included. What is good healthcare? There is something about openness in it. I more and more come to the conclusion that the "room" where I receive persons in crises, this space have room for many other people. A part of good care is to get help from other people and their experiences. This is a reminder for myself as well as for others that things are possible to change. The state of things is not completely hopeless. So that there may be life!

july 2018

