Variety Instead of Stupidity: About the different positions within the movement of (ex-)users and survivors of psychiatry *

Peter Lehmann

System survivors are more dissimilar than professionals might prefer to think. One person's survival is another's persecution – even recovery.

Fighting psychiatric assault, discrimination and stigma seems to work as an unifying element within the self-help movement of (ex-) users and survivors of psychiaty. Forming groups and organisations, in general it turns out that the variety of opinions about psychiatry and its methods among (ex-) users and survivors of psychiatry are not that great. It is amazing to realize that their experiences of psychiatry and their opinions are rather similar. It is especially easy to gather around a human and civil rights perspective. The experiences of paternalism, stigmatisation and oppression within the psychiatric system as well as in society as a whole are very similar everywhere in the world, even if the forms these might take are rather different (Lehmann & Jesperson, 2007, p. 367). Coming together, to experience compassion with dehumanizing psychiatric treatment is combatting the feeling of isolation and being an ugly and unworth mentally ill individuum. Often people with a psychiatric history for the first time develop self-respect and openess in a self-help group, which of course makes them vulnerable. Who would expect harm in such a closed space of solidaric people with so similar experiences and equal diagnoses like 'psychoses', 'depression', 'schizophrenia'?

But when it comes to activites beyond defence of human rights, different political and personal views get more important. Against the backdrop of past good experiences of solidarity and equal diagnoses, differences tend to undermine cooperation. Equality based on equal diagnoses turns out to be a phantom, a construct—like the nature of the psychiatric diagnosis itself. Even though differences and fights happen everywhere in groups and organisations, (also in those from psychiatrists and psychologists), in self-help groups of (ex-) users and survivors of psychiatry they are more destructive. They pull the rug out

* Translation by Pia Kempker

Peter Lehmann is a psychiatric survivor and publisher. He lives and works in Berlin, Germany

from under those people who just started to move without crutches. In his contribution to the book *Coming off Psychiatric Drugs*, David Webb from Melbourne took a critical look at the dark side of self-help groups:

> During my time of struggle, one of the most annoying things was all those people who believe that what had worked for them could also work for me. The path to peace and freedom is unique for each individual and very personal. (p. 165)

It seems more than overdue for the community of (ex-) users and survivors of psychiatry itself to address experiences like this. Until now, there has been no forum to discuss the dark side of the self-help movement. Egocentrism is only one facet of the problem.

Reforming or fighting psychiatry?

Take or abolish psychiatric drugs? Reform or abolish psychiatry? An insoluble contradiction? In the past I have delivered keynote speeches and published papers, where I describe the different trends within the movement of (ex-) users and survivors of psychiatry and advocated a respectful exposition. I am convinced that the problem is a universal one and still current. Moreover, a forum to discuss ideological differences within the movement, fights and insults is urgently missed. Wherever you address the dark side of the movement, people agree and add their experiences. But when you propose a public discussion, the answer is always the same: this is not the right place. But where is it?

'We want a different psychiatry' is – for example – in a flyer of the German Organization of (ex-) Users and Survivors of Psychiatry; 'we demand the development of efficient alternatives to the mentality in nursing and supervising of conventional medical psychiatry'. They are talking about 'cooperation as partners with equal rights', and as one of the tasks of the union the 'calling in of the duty of agreement for medical measures of treatment as for mentally ill people' is mentioned. In the chapter, 'More human conditions of life' 'less psychiatric drugs and more psychotherapies' are asked for: depression and psychoses were not to be suppressed by drugs but to be taken seriously in their meaning.

In 1995, the members of that German organisation where asked for their opinion of psychiatry and its future. As the opinion research poll about the improvement or introduction of quality in psychiatric treatment has shown, the differences in how the members imagine a different psychiatry were considerable.

There is no reason to assume that today the result would be different in Germany or other countries. Some want a psychiatry without psychiatrists, which means the abolition of psychiatry and establishment of a non-psychiatric care system instead. Others want better psychiatrists, more money for psychiatry so that more staff can be engaged, hoping that pleasant and therapeutic talks, nowadays generally missed, can be held. Some want delimitation, a completely

non-psychiatrically oriented self-help with securing of their civil rights and human rights as protection against psychiatric encroachments. Others want the development of a psychiatry that is determined by psychiatrists, (ex-) users and survivors of psychiatry and relatives together.

Similar differences appear in the valuation of psychiatric drugs, the most important treatment method in psychiatry: some people take psychiatric drugs with the conviction of not being able to live without them, whereas others decline them with the conviction that psychiatric drugs are pure poison for the nerves.

These two principal conflicts always played a part in the past and led to antagonism. Representatives of radical positions from both sides did not become members of the organization of (ex-) users and survivors of psychiatry, or they left it again with the opinion that the organization was too antipsychiatric on the one hand or too reformist and believing too much in psychiatry on the other. What is in this controversy? Are the conflicts of such a fundamental nature that further arguing is programmed, that the danger of more and more frustrated members leaving organizations is inevitable?

What do (ex-) users and survivors of psychiatry want?

From my experience I know that many generally tend to wish to enjoy their lives, to be left alone, to have contact with like-minded people and to live tolerable lives. A change of psychiatry is not on their agenda, either because they think psychiatry is o.k. or because they are alone and do not see a chance for them.

For others there is generally an attitude of central importance that can be described best as 'empowerment'. (Ex-) users and survivors of psychiatry want to preserve or win back the control over their own lives. It is the criterion that is brought by many (ex-) users and survivors of psychiatry all over the world, when they characterize alternative or emancipatory psychosocial institutions, no matter if they are psychiatric institutions or self-help groups.

In the opinion research poll in 1995, the members of the organization declared what a changed psychosocial area should look like. Over 100 members participated in the poll. In their statements, psychiatry received an almost crushing refusal. Only ten per cent of those answering stated that they found help for solving their problems in psychiatry. Often (wo)man's dignity was injured. In spite of being prescribed by law, there was no extensive information about treatment risks. For being able to talk of a qualitatively acceptable psychiatry, the following fundamental criteria have to be fulfilled:

Observance of the dignity of (wo)man, warmth and human contact, individual company, a relationship full of confidence instead of fear. There are many useless things in psychiatry: for many (ex-) users and survivors of psychiatry the whole institution together with the psychiatrists is useless. In general, the following factors were found to be useless: violence, the use of psychiatric drugs, coercive measures, electroshocks and fixation on diagnosis. Medical (wo)men who believe that they know more about their patients than

they themselves, are useless. Alternatives are important for giving options to choose from. Concerning the question what these alternatives should be like, the following suggestions were made: alternative drugs, e.g., homeopathic remedies, self-help, runaway houses, alternatives according to Mosher and Laing, soft rooms à la Soteria (Peeck et al., 1995).

Abolition or reform: A conflict that devides?

In practice, this controversy about 'Reform or abolish psychiatry' is there in theoretical and ideological discussions, in the kind of mainstream or alternative institution that each single one prefers. And in theoretical discussions the conflict 'Reform or revolution: abolition of psychiatry' is important for getting clarity of where oneself stands, where the others stand, to understand where the differences are and what the others want, even if it is not the same as oneself wants.

But 'Abolition of psychiatry and provide alternatives instead'—the one extreme—will look ridiculous if the corresponding positions do not relate to the interests of (ex-) users and survivors of psychiatry, and 'reform attempts' will also fail if they are only about improvement of psychiatry.

When we see all the demands, projects and hopes, the different imaginations tending to 'reform' or to 'abolition and alternatives' are always noticeable—but why should a coexistence be impossible as long as there is no fighting? And why not also reciprocal support?

How conflicts are to be solved was exemplarily shown in the controversial discussion about the so-called 'treatment contract' and 'the psychiatric will' in Germany. First it seemed as if the treatment agreement—as it is called now—would stand in aggressive competition to the psychiatric will. The treatment agreement is a document signed by a user of psychiatry and psychiatrist where the user agrees to treatments in a later situation where his or her decision is not considered competent anymore. This form of advance directive is developed for people who trust in psychiatry. The psychiatric will is a document written and signed by a user or survivor of psychiatry where he or she determines how he or she wants to be treated or not treated in a later situation where his or her decision is no longer considered as competent. This form of advance dircetive is developed for people who mistrust psychiatry. Finally there was a respectful discussion, taking the arguments of the opposite side seriously, that now admits the (ex-) users and survivors of psychiatry a fair decision to choose the kind of beforehand instruction which they think is best in their situation. Some trust in psychiatrists, others mistrust them, some feel dependant on them, others feel offended by them. Which of us want to command which feelings the individuals shall have?

To take or to decline psychiatric drugs?

The valuation of the prescription or taking of psychiatric drugs is a very controversial topic. The taking of neuroleptics, antidepressants, mood stabilizers and tranquilizers can lead to apathy, to emotional plate lining, depression,

suicidality, paradox phases of excitement or confusion, intellectual disorders, lacks of creativity, concentration or memory problems, status epilepticus, weakening of the immune system, hormone or sexual disorders, chromosome and pregnancy damages, damage to the blood, disorders in the regulation of body temperature, heart problems, damage to liver and kidney, skin and eyes, Parkinsonism, hyperkinesia, muscle cramps, movement stereotypy and much more. On the other hand many (ex-) users and survivors of psychiatry suggest that they cannot be without psychiatric drugs in their situation, or that drugs shorten a mental crisis and so avoid being brought into psychiatry, where would probably be given psychiatric drugs for a long time.

There are very often irritations when people who decline psychiatric drugs meet those who take them. In fact it is the decision of each individual person if he or she wants to take these substances, for whatever reason. Indeed, there are arguments against the free reasoning or a liberal basic attitude:

1. The organisations of (ex-) users and survivors of psychiatry do not participate in drug-monitoring, and single psychiatric patients are normally not informed about the existing, the possible and the not excluded risks. They do not know that some substances were taken off the market in some countries, but are available without restrictions in other countries: e.g. penfluridol (Semap) because it can lead to cancer, remoxipride (Roxiam) because of blood damages, triazolam (Halcion) because of amnesia and black-out actions.
2. The burden of proof in cases of compensation demands is only borne by the (ex-) users and survivors of psychiatry. The – financially assured – producers do not have to prove that damage is not caused by their risky substances, but the – generally poor – damaged have to prove in a complicated proceeding that damage is only to be attributed to the substance given to them.
3. The dispensing of psychiatric drugs to women of child bearing age happens very often without considering possible pregnancies or dangers to the fetus.
4. More and more defenceless old people get these substances to manage nursing shortages. More and more children without the possibility to choose get psychiatric drugs to make them match the not-very-fond-of-children world better via chemicals. More and more women get psychiatric drugs to neutralize their disturbing reactions to patriarchal situations of life chemically. More and more people who got into conflict with the law get psychiatric drugs to stay calm in their inhuman prisons or to break their resistance when deporting them.
5. Because of inter- and intra-individual differences in the effects, it is impossible to predict with assurance how a certain dose of a preparation

will work. All known damage with psychiatric drugs come principally independent of the dose and after a relatively short time, sometimes after taking a small dose once.

6. More and more people get combinations of different effects through incompatible psychiatric drugs.
7. All psychiatric drugs produce bodily dependence, and the prescribers deny this effect of the substances (except tranquilizers), and conceal the phenomenon of withdrawal or redefine rebound phenomena, supersensitive reactions of the receptors as well as possibly irreversible damage caused by psychiatric drugs as symptom changes.
8. There are nearly no statutory institutions necessary to support problems with withdrawing neuroleptics, antidepressants and mood stabilizers.
9. All the time, there are attempts by psychiatric unions and Big Pharma to enforce especially the life-long taking of psychiatric drugs, the perfecting of community-psychiatric supervising systems and new forms of dispence.
10. There is neither the right to drug-free help or user-controlled institutions nor non-psychiatric crisis institutions or financially well-supported self-help groups.
11. None of the psychiatric drugs mentioned solve social problems. Generally they aggravate solving these problems. After withdrawing these substances the conditions for solving the problems which led to the use of psychiatric drugs are normally even worse.

For all these reasons, the use of psychiatric drugs is to be judged with skepticism. Nevertheless the decisions of the users about taking psychiatric drugs are to be respected: especially if they help to overcome escapeless conflict situations, which would end in psychiatry, with a very short, very low-dosed, very low burden of risks by reflected and self-determinate taking of psychiatric drugs. Also to be respected is the decision of users to take psychiatric drugs, no matter for what reason, in what time period and with which grade of content of information about the risks. Special sympathy and solidarity are due to the (ex-) users and survivors of psychiatry who are forced by nerve damage caused by psychiatry or social conflict situations to take psychiatric drugs to be able to live in any way. Particularly people affected by addiction make clear that user-controlled institutions for crisis cases are needed, so that the first taking of psychiatric drugs can be prevented.

The Vejle Declaration

To promote a respectful co-operation in self-help organisations and to encourage people to resist dogmatism, hierarchies and claims to power from wiseacres, at

the Joined Congress 'Networking for our Human Rights and Dignity', run by the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) and the World Network of Users and Survivors of Psychiatry (WNUSP) in July 2004 in Denmark, the 'Vejle Declaration' was developed and approved by the General Assemblies of ENUSP & WNUSP. In all organisations (ex-) users and survivors should:

- build a constructive, welcoming, friendly, attractive atmosphere, respectful of all the opinions of others, not trying to decide what is good for them and support each other in developing our individual and creative capacities
- underline the importance of transparency, good governance and responsibility in financial matters
- integrate minorities in a proactive way and combat any discrimination, whether it is based on origin, gender, age, disability, economy, religious or sexual orientation
- be patient to each other, try to see the whole person behind the label and emotional and physical problems and not to judge others
- be careful in the election of representatives and consider their experiences and prevent ourselves and our colleagues from burning out and subsequently leave the organisation
- appreciate the work of all people who honestly try to improve psychosocial treatment as well as those who work to establish alternatives to psychiatry and resist any unilateral approach to the understanding of mental health problems
- respect the work of volunteers and recognize the need for paid jobs as well as looking for allies – because we face a vast and complex task
- demand that psychosocial services are made for the users/clients/survivors/people in recovery, under our influence and with respect to our equal rights as citizens in a democratic society.

Necessary reflection of the differences

Being a member of the movement of (ex-) users and survivors of psychiatry, I claim to speak not only for myself, but for a large community and move from 'I' to 'we': We have to be aware of the stress that exists between the individual needs of the (ex-) users and survivors of psychiatry, who have a right to define their conflicts, needs and risk readiness, on the one hand the danger that comes from the power demand of psychiatry (both biological psychiatry and community psychiatry), politicians without responsibility and the profit-oriented drug industry.

This stress can only be mitigated if the consumers of psychiatric drugs as well as the people who are forced to take these substances have guaranteed

human rights not depending on the diagnosis, simple access to financial compensation in case of needs, a right to help without psychiatric drugs and an alternative offer of non-psychiatric help.

If we want to change something and if we want understanding by psychiatrists, therapists, politicians or whoever, we can only demand this understanding authentically if we try to understand ourselves. How do all the structures that we want to build up help the solidarity amongst each other if we saw at their basic pillar day and night? The fact that we were in a psychiatric institution, have a psychiatric stamp, may be something we have in common, but we are too different in origins, beliefs, political interests and personal preferences to let the psychiatric community – a community primarily defined by the outside – solve all the problems of being together. Moreover, if we want respect, no matter from whom, we have to respect ourselves and treat different-thinking persons with respect, even if we do not share or understand their opinion in some cases. As well as demanding choice for help, we have to concede to each other the right to wish and work on the form of changed psychiatry or alternative that we choose to be the most reasonable one for us. If the basis of our ambitions is a change in the direction of more humanity, sensible alternatives, in the direction of equal rights and better life conditions: why should different strengths lead to unbridgeable differences? Only together can we carry through our demands.

References

Lehmann, P. & Jesperson, M. (2007). Self-help, difference in opinion and user control in the age of the internet. In P. Lehmann & P. Stastny (eds), *Alternatives Beyond Psychiatry*, pp. 366–80. Berlin, Eugene, Shrewsbury: Peter Lehmann Publishing.

Peeck, G., von Seckendorff, C. & Heinecke, P. (1995). Ergebnis der Umfrage unter den Mitgliedern des Bundesverbandes Psychiatrieerfahrener zur Qualität der psychiatrischen Versorgung. *Sozialpsychiatrische Informationen, 25* (4), 30–4.

Webb, D. (2004). 'Please don't die'. In P. Lehmann (ed), *Coming Off Psychiatric Drugs: Successful withdrawal from neuroleptics, antidepressants, lithium, carbamazepine and tranquilizers*, pp. 164–73). Berlin, Eugene, Shrewsbury: Peter Lehmann Publishing.