

The bright and the dark side of the self-help movement

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ABSTRACT: Lending on one's perspective and field of activity, a retrospective view of the beginnings of self-help in the psychosocial field in Germany after 1945 does not present a uniform picture (Lehmann 2009a; Brückner 2015; Stöckle 2022). In what follows, I focus on developments and ruptures that I took part in shaping and describe them from my perspective.

KEY WORDS: Human rights, advocacy, survivors

The German Psychiatry Enquiry of 1975 ignored the psychiatric disregard for human rights. If it was about the "equality of the mentally and somatically ill", it was not about equal human and civil rights independent of diagnosis, but about the alignment of psychiatric institutions with medical clinics (Lehmann 2016a). This was the initial situation when I founded the Irren-Offensive (Lunatic Offensive) with other former psychiatric inmates in 1980 (Lehmann 1981). In Tina Stöckle's diploma thesis "Die Bedeutung der Selbsthilfegruppen im psychosozialen (psychiatrischen) Bereich, aufgezeigt am Beispiel der Irren-Offensive" ("The importance of self-help groups in the psychosocial [psychiatric] field, shown by the example of the Lunatic Offensive") you can read what effect it had that we were together as former psychiatric inmates for the first time. Ludger Bruckmann enthused:

“The first meeting was so good and so beautiful for me. There I had found such a strong understanding. Everyone told about themselves and their story, everyone got a turn. There was so much empathy, a common ground, since we had experienced similar things, that was good.” (quoted after Stöckle 2022, p. 179).

I read in the same place my own long forgotten statement that we were just five people when the patient support group was founded. But that the exchange about psychiatric maltreatment was essential for mutual understanding, especially since we had excluded professionally active people. This enabled us to throw the concept of mental illness overboard quickly. The patient group became an association that actively resisted the psychiatric expert monologue with its claim to interpretative sovereignty. Self-help in the true sense, both mutual help and psychiatric-political self-advocacy of one’s own interests, became important (ibid., p. 181), especially the struggle for human rights, the search for the meaning of madness, and the striving for autonomy and personal development (ibid., pp. 176-189).

How it went on

Soon the Lunatic Offensive sought contact with other human rights-oriented groups (ibid., p. 194), travelled together with (non-affected) members of the Berlin Advocacy Centre for Complaints about Psychiatric Maltreatment and Abuse to events of users and survivors of psychiatry in Denmark, Italy, Yugoslavia and the Netherlands. It also maintained contacts with organizations in England and the USA, and worked on the establishment of international associations: in 1989 the Forum Anti-Psychiatrischer Initiativen (FAPI); in 1991 the European Network of (ex) Users and Survivors of Psychiatry (ENUSP); and in 1991 the World Network of Users and Survivors of Psychiatry (WNUSP). The goal of ENUSP, to which some German self-help organizations belong, was and is the representation of common interests and support of the autonomy and right of self-determination of users and survivors of psychiatry (Lehmann & Jespersen 2007).

ENUSP is still active on many levels today. Among other things, I represented ENUSP as its chairperson at the WHO-European Commission’s Consensus Conference in Brussels in 1999, when it was decided that, between others:

- Developing innovative and comprehensive, explicit mental health policies in consultation with all stakeholders, including users and carers
- Development of new non-stigmatizing (that was the term for “non-psychiatric” – P.L.) and self-help approaches, and
- Development of mental health legislation based on human rights, emphasising freedom of choice, were central key principles and common goals and strategies to advance mental health promotion (WHO & EC 1999).

ENUSP was also involved in the European Commission’s Action project against

“Harassment and Discrimination Faced by People with Psycho-social Disability in Health Services – A European Survey” (Action Project 2005) and in the adoption of the “Münchener Thesen und Forderungen für eine soziale Psychiatrie in Europa” (“Munich Theses and Demands for Social Psychiatry in Europe”) in 2007 at the annual meeting of the Deutsche Gesellschaft für Soziale Psychiatrie German (DGSP; German Society for Social Psychiatry). In the manifesto, the executive boards of the DGSP, ENUSP and the German Bundesverband der Angehörigen psychisch Kranker (Federal Association of Relatives of Mentally Ill Persons) demanded, among other things, that the right of users and survivors of psychiatry to physical integrity be respected, that they and their expertise play a decisive role in psychiatric teams and in the training and further education of psychiatric professionals, that independent self-help and alternatives to psychiatry be promoted, and that users and survivors of psychiatry as well as relatives who are independent of sponsorship by pharmaceutical companies be recognized as experts (Lehmann 2008a, 2008b; “Dialog und Selbstorganisation” 2008). However, the board of the German Bundesverband Psychiatrie-Erfahrener (BPE; Federal Association of Users and Survivors of Psychiatry) distanced itself from this agreement in 2008, as it was not involved in its conclusion and distrusted the relatives’ association (GV-BPE 2008). Subsequently, it was ignored on all sides.

Back to Berlin: Here, within the framework of FAPI, we organized an international congress in October 1990 in East-Berlin together with the AG Ökologie & Menschenrechte (Ecology & Human Rights Working Group) of Netzwerk Arche (Network Ark) (former GDR) with the theme “Alternatives to Psychiatry” (FAPI 1990). Among other things, lawyer Hubertus Rolshoven presented the Psychiatric Will, whose legal effectiveness was strengthened in 2009 by the Patientenverfügungsgesetz (Mental Capacity Act) and which later served as the basis for the Psychosocial Advance Directive (Lehmann 2023).

In 1989, members of the Lunatic Offensive were also involved in the founding of the Verein zum Schutz vor psychiatrischer Gewalt (VzS; Organisation for the Protection from Psychiatric Assault), the overseer and trustee of the Runaway-House, which opened in Berlin in 1996 (Kempker 1998). In 2002, we ex-members of the VzS founded the “Für alle Fälle” (FaF; In Any Case), which was dedicated to further education and research in the psychosocial field (Klafki 2006, pp. 136-138). In 2005, we ex-users-and-survivors-of-psychiatry-members of the FaF were also founding members of the Berliner Organisation Psychiatrie-Betroffener und Psychiatrie-Erfahrener (BOP&P; Berlin Association of Users and Survivors of Psychiatry). As an association in the state of Berlin, this organization took over both the representation of psychiatric policy interests in the state of Berlin and, from 2016 to 2019, the legal representative of four events of the Psychexit-AG to develop a compendium for competent support in withdrawal antidepressants and neuroleptics (BOP&P 2016, 2017, 2018, 2019).

Successes came quickly. Critical voices could no longer be so easily suppressed,

isolation was broken up, critical knowledge and the first psychiatric patient directive were published. The Lunatic Offensive was given a senate-funded meeting place with well-paid half-time positions, its members travelled to concerned-led events in Germany and abroad, and learned about runaway houses in the Netherlands and Loren Mosher's Soteria facility (Stöckle 1983; Wehde 1991). The organization spread beyond Berlin, and there was cooperation with critically minded psychiatrists, lawyers and relatives.

Problems, problems

Simultaneously, with this development, problems arose without being discussed or even discussed in a consensus-oriented manner. Differences of interest usually led to disputes, to competition over who was more affected by psychiatric maltreatment and to insistence on one's own psychiatric "experience" as the measure of all things.

Here the question plays a central role for me, why actually psychiatrized people should be better than others and from the beginning and without exception interested in each other, wanting solidarity, compassionate, able to criticize and capable of "real human relations" as well as open discussion. Why should the original psychiatric diagnosis, which led to psychiatrization, convey a quality seal of "experience" and thus a special competence? Why should relatively meaningless psychiatric pigeonhole diagnoses such as "psychosis," "schizophrenia," or "depression" result in those so diagnosed having more in common than those very diagnoses? Aren't those affected by an assumed equality or comparability of, for example, the "psychosis" experience under an illusion that literally drives them into hopeless disputes and disappointments when they first experience a different perception or evaluation? Especially when they have opened themselves up in their weaknesses in the securely believed supposedly protective space of a self-help group and now experience ill-will and baseness among themselves as particularly hurtful?

Since the psychiatric field ranges from psychotherapy to forensics, i.e., covers a large and heterogeneous area (Lauveng 2018, pp. 120-121), the question of dispute becomes who is "properly" genuinely most affected? Moreover, people draw different consequences from similar experiences. Some want to reform psychiatry, others want to abolish it. Many treat this conflict as an insoluble contradiction, form factions and ignore, despise, or fight each other. And when it comes with activities beyond the defence of human rights and to design something new, then different political and personal options develop their own explosive power (Lehmann 2009b).

Activists in the self-help scene, who focus on differences in attitudes rather than commonalities, find an extensive field of activity for bullying, belittling and marginalizing others while making their own convictions absolute. A popular method of damaging one's reputation is to misunderstand and scandalize an arbitrarily selected content deliberately, disregarding the background of an action or statement, in order to present oneself on the morally and psychiatrically correct side (see, f.e., Lehmann 2014). The more

eloquent and manipulative such activists appear, the more they contribute to poisoning the climate in self-help associations, dividing and weakening them and demotivating or even demoralizing committed affected persons.

Cracks and breaks

The first cracks appeared early in the Lunatic Offensive, without leading to any productive discussion. To this day, such conflicts play a central role in the self-help movement. The document “Warum ich aus der Irren-Offensive austrete” (“Why I am leaving the Lunatic Offensive”) from 1981 exemplarily addresses the contentious claim to competence in the concept of psychiatric experience:

“I think it is an arrogant presumption for the Lunatic Offensive to pretend that it has the patent remedy – as opposed to the ‘experts’ – for solving psychic problems. I also think it is a fatal error to believe that just because we have experience in the loony bin, we are our own experts and don’t need the others” (Anonymous 1981; quoted in Lehmann 2022, p. 295).

People who did not fit the stereotype of the washed-up psychiatric victim but were smartly dressed, came “from a good family” or defined coercion experienced in their own crisis as helpful were regarded as foreign bodies in the association or – as is still the case today in some affected persons’ organizations – as traitors and collaborators or as dimwits seduced by psychiatry (Lehmann 2015a, 2015b, 2016b).

Disputes increase when activities in the self-help sector are paid for and decisions are made about the use of the money. Some insist that work involving time and responsibility must be paid for, while others suffer from decreasing transparency in the flow of money and decision-making processes. When the group planning the Runaway-House was promised a donation of one million Deutschmark in the early 1990s, the Lunatic Offensive fell apart (Lehmann 1998). By the early 2000s, the Runaway-House was generating significant additional revenue: Some wanted the decision-making power over finances to remain with the overseer and trustees who were responsible for all financial issues and controlled by ex-users and survivors of psychiatry via a veto right, while others wanted the staff to have decision-making power; the dispute over this led to a break with the founding generation.

Incompetence, arrogance or pursuit of self-enrichment are further problems in connection with funding. For example, the Berlin Senate funding of the meeting place and the workplaces of the Lunatic Offensive ended when funds were misappropriated (Windén 1994). FaF fell by the wayside because of attempts to gain self-serving access to financial resources for user-controlled research. Most recently, the Psychexit event series was on the verge of collapse because of months of delay by a new board of BOP&P, through which the conferences were billed (Lehmann 2019a); members of

the Psychexit-AG were scared away or expelled (Lehmann 2019b). However, with the Landesverband Berlin – Angehörige psychisch erkrankter Menschen (Berlin Association of Relatives of Mentally Ill Persons), a supporting association was fortunately found that was interested in continuing the work on how to help people competently who have decided to withdraw their prescribed psychotropic drugs (Psychexit-AG 2020, 2021, 2022).

Finally, I would like to mention structural problems in the self-help sector. It is difficult to compare the same experiences over decades. People change, and so do their interests. New members join, and the older you get, the younger the new members seem. What younger members bring to the table in terms of digital knowledge is scary for some. Again and again, people affected by psychiatry are elected to boards, even though they have little competence for these tasks. Populist demands go hand in hand with the desire of some to relinquish responsibility. People are happy to have someone else do the job, and if he or she does it well, there is a danger of burdening that person with more and more tasks – to the point of burnout.

Power and counter-power are not only two poles in the relationship between psychiatry and self-help, but also in the internal relationship of self-help organizations. Just as organizations need people to take on responsibility, leadership positions and representation, they also need a living democracy and transparency so that internal power structures do not become entrenched. What inadequate democratic practice leads to can be seen when board members sit at the lever for decades and build up rope networks that use formal tricks to push through decisions at general meetings. Dogmatic attitudes, claims to infallibility, exclusions and expulsions of non-compliant members and, above all, disrespectful cooperation or, better, antagonism reinforce the tendency for such organizations, even if they basically have great potential, to become weaker unfortunately instead of stronger over time (Kaiser-Burkart 2021).

Recommendations for a togetherness

The problems of the self-help movement in the psychosocial field occur worldwide. In order to find a common approach to limiting them, recommendations for cooperation were adopted at the World Congress of ENUSP and WNUSP in Denmark in 2004 as the “Vejle Declaration”, named after the town Vejle where the congress took place. Its central theme is mutual respect (Lehmann et al. 2007). However, as with the UN Declaration of Human Rights or the UN Convention on the Rights of Persons with Disabilities (UN CRPD), the road from proclamation to implementation is rocky, and here as there, the number of obstructionists is large. How could it be otherwise?

P.S.

So much has been achieved in Germany and abroad in the last four decades, including a variety of self-help groups in states and communities; self-help funding (albeit still too

modest and costly); the institutionalization of advocacy in national and international bodies and congresses; a still functioning Runaway House; the recommendation for support in discontinuing antidepressants (Bundesärztekammer et al. 2022, pp. 78-81) and neuroleptics (DGPPN 2019, pp. 59-65) in treatment guidelines (albeit provided with insufficient information); the first inpatient offers for withdrawal from psychotropic drugs (Kaufmann & Lehmann 2023; Lehmann & Newnes 2023); the legal strengthening of the psychiatric will through the Mental Capacity Act; the UN CRPD with its paradigm shift from proxy to supported decision-making (Lehmann 2017); and the inclusion of the requirement for psychotropic drug withdrawal support programs in Guideline 14 (“Freedom and security of the person”) of the UN CRPD (CRPD 2015).

To conclude with a positive example: In Germany, the Bundesnetzwerk Selbsthilfe seelische Gesundheit (NetzG; Federal Network Self-help Mental Health) strives, among other things, to take part in psychiatric policy-making processes, to strengthen self-determination in treatment and to prevent coercion and violence (NetzG 2015). The NetzG issues statements on treatment guidelines and is a member of the “AG Menschenrechte” (“Human Rights Working Group”) of the Aktion Psychisch Kranke (Action for the Mentally Ill) and of the “Kontaktgespräch Psychiatrie” (“Contact Group Psychiatry”), an association of associations and organizations in the psychiatric field. However, the NetzG’s efforts to be involved in decision-making processes regarding statements on the withdrawal of psychotropic drugs in the treatment guidelines are still expandable – after all, these should correspond to the state of science and the requirements of the UN CRPD. What prevents the NetzG from insisting on an end to the violation of human rights by withholding information about discontinuation and withdrawal problems and on support programs for withdrawal is unknown.

Acknowledgement

This article originally appeared under the title “Anti- und nichtpsychiatrische Selbsthilfe in Deutschland ab den 1980er-Jahren” in: *Soziale Psychiatrie* (Cologne), Vol. 46 (2022), No. 1, pp. 30-32, in: *Newsletter Seelische Gesundheit* on January 17, 2022, and in: *Schattenblick*, online edition, 7/21/2022.

I updated the text for the book *50 Jahre Aktion Psychisch Kranke und Psychiatrie-Enquête* (edited by Kirsten Kappert-Gonther, Peter Brieger & Matthias Rosemann. Vol. 2, Tagungsdokumentation 08. September 2022 in Berlin, Cologne: Psychiatrieverlag 2023, pp. 71-82. Online-Ressource www.antipsychiatrieverlag.de/artikel/selbsthilfe/selbstorganisation.pdf), translated it into English and updated it on December 26, 2023. All internet accesses took place on that date.

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