

*Experience Report*

**SELF-HELP/MUTUAL AID IN GERMANY—  
A 30 YEAR PERSPECTIVE OF A  
PARTICIPANT OBSERVER\***

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**ABSTRACT**

The aim of this article is to demonstrate the effects of national traditions, the health system, cultural transitions, and broader political movements on the development of self-help. Germany, where the author has been both observer and activist for over 30 years, is used as an example of self-help in one country. The students' rebellion in the late 1960s provided the historic and cultural ground for the emergence of collectives without professional leadership. The relationship between patients and doctors changed fundamentally; "experts through experience" showed up along side traditional "experts through formal education." From a grassroots movement of spontaneous self-helpers, organizations and institutions were developed. Academic research played a significant supporting role as "neutral witness." Attitudes and behavior of professionals, especially in the medical field, changed slowly, and, today, financial support for self-help is an obligation of Germany's statutory health insurance. Some see this as an "impact factor" of the highest relevance for our society.

\*This article is dedicated to my friend and former colleague Judy Wilson, who represented England in the international network of self-help group supporters for so many years, and to Dick Wilson, my friend and occasional language coach.

## INTRODUCTION

This report is written by one who has been a witness, a participant observer, and an activist in the self-help movement in Germany. It provides a personal view, based on historic facts and research results.

When I use the word “self-help,” I refer to collective forms of self-help in groups or organizations rather than to individual self-help such as buying an aspirin when you feel pain. In a brief trip through the last 30 years, I will mark important events, activities, and developments which have led to a relatively well developed and firmly established self-help scene in Germany (Matzat, 2004).

### **1953: The First AA Group in Germany**

One important root of the German self-help system lays in the 12-step movement. The first Alcoholics Anonymous (AA) group in Germany was founded in 1953 by and for American soldiers; later they integrated German alcoholics. Ever since, the AA program has been widespread and many other 12-step groups have emerged, such as Overeaters Anonymous, Emotions Anonymous, Borderliners Anonymous, Gamblers Anonymous, Co-Dependents Anonymous. AA is still the best known and quintessential of the self-help groups, even though 12-step groups represent only a very small sector of Germany’s self-help groups in the 21st century.

### **1968: The Bundesarbeitsgemeinschaft Hilfe für Behinderte (BAGH) (Federal Association for Aid for the Disabled) is founded**

1968 is a highly symbolic year for Germany. It was the year of the students’ rebellion formented by the widespread silence regarding the Nazi period and the Holocaust, the conservative tendencies in the German society, and, most immediately, the war in Vietnam. While it had specific German roots, it was also connected internationally with similar movements such as those in the United States or France. (Incidentally, in East Germany, 1968 has a completely different association, namely the “Prague Spring,” when Russian tanks flattened the upcoming “Socialism with a human face” in Czechoslovakia.)

In West Germany, the major societal changes that occurred from that point forward were in the society’s cultural structure—in the way parents deal with their children, teachers behave toward their students, women and men relate to each other, etc. A process similar to and not uninfluenced by what was happening in the United States in the late 1960s and 1970s. The cultural break was perhaps more significant in Germany as the excesses of National Socialism were but a single generation removed. The term “68ers” became a brand of an entire generation, at times used as an insult, at times a brand worn with pride.

1968 was also the year the Federal Association for Aid for the Disabled (BAGH), a nationwide umbrella for self-help organizations, was founded. This

umbrella organization that initially had eight member organizations grew very rapidly. Now, there are over a hundred member organizations with roughly one million individual members. BAGH and its member organizations also promoted the founding of local branches. Local self-help groups and/or nationwide self-help organizations cover practically every severe or chronic disease today. NAKOS (*Nationale Kontakt- und Informationsstelle zur Anregung und Unterstützung von Selbsthilfegruppen* = National Contact and Information Center for Promoting and Supporting Self-Help Groups) issues every year what we call the “green addresses,” the addresses of self-help organizations working nationwide. The printed directory is available free of charge and is available on the internet at <http://www.nakos.de/site/adressen/gruen/>

### **During the 1970s and 1980s Self-Help Organizations of Disabled and Chronically Ill Persons Mushroomed**

In the beginning, many self-help groups were organized in private living rooms, focusing on the personal encounter of people affected by similar diseases; at the same time others were demanding better services. It was virtually unknown for groups to provide services for others, possibly even for non-members, or to employ paid staff. Money was not available and mutual aid was the idea. In some cases, professionals, mainly physicians, who were themselves dissatisfied with the medical system, encouraged patients to organize and supported them by offering rooms, office facilities, and medical information. The influence of these godfathers (rarely godmothers) varied in importance and duration. But the term *Selbsthilfegruppe* in German clearly implies that the activities are decided and carried out by those affected; a professional has no business attending an ordinary meeting of a self-help group unless he is an invited guest—to give a lecture, for example. “Support groups” led by professionals (e.g., social workers or nurses) would *not* be regarded as *Selbsthilfegruppen*. (Today, some of the nation-wide self-help organizations have advisory councils of experts, usually physicians.) In the years following 1968 many self-help organizations of the disabled and chronically ill persons came into being on local, regional, and federal levels.

It was also in 1968 that the German Federal Supreme Court ruled that alcoholism was a disease. This decision led to the development of a defined *professional* counseling and treatment system financed by public money. Once a condition is determined to be a disease, a person is entitled to be covered by the statutory health insurance and to be treated free of charge. Earlier, many people had regarded alcoholism to be bad behavior or even a sin; and, traditionally, philanthropic activities in the field of addiction were embedded in the social work of church-run welfare associations which had started to drift toward more and more “self-help.” Thus, non-12-step groups far outnumber AA groups in Germany (cf. Hüllinghorst, 2006; [www.anonyme-alkoholiker.de/index](http://www.anonyme-alkoholiker.de/index), 7, Jan. 2009).

### **1978: The First Textbook on Self-Help Groups in Germany**

In 1976 and 1977 the first American textbooks on self-help groups were published (Caplan & Killilea, 1976; Gartner & Riessman, 1977; Katz & Bender, 1976), most valuable references for those who had started to explore, support, and promote self-help groups in Germany and other European countries. But having a textbook in one's own language is very important for the development of a national self-help movement. It becomes a beacon around which people can coalesce and networks can form. In 1978, Prof. Michael Lukas Moeller (Matzat, 2007) published the first book on self-help groups in Germany: *Selbsthilfegruppen. Anleitungen und Hintergründe* [Self-help groups. Guidelines and backgrounds (Moeller, 1996, new edition)]. In 1981, Moeller's (2007) second book followed: *Anders helfen. Selbsthilfegruppen und Fachleute arbeiten zusammen* [Helping in a different way. Self-help groups and experts working together (Moeller, 2007, new edition)]; new edition: 2007. To this day, his two books are milestones and beacons for anyone in Germany who wants to learn about the dynamics and psychological mechanisms of self-help groups or about opportunities and obstacles for cooperation between self-helpers and professionals. He has had a lasting influence on the academic discussion in Germany and through his public speeches, articles in daily newspapers, and appearances on TV programs he has promoted the self-help idea among the general public. Prof. Moeller was a psychoanalyst and, more importantly, a group therapist. When traveling in the United States he had learned about self-help and wondered whether it might be beneficial for his own patients. An important aspect of the German cultural milieu was that encounter groups— *Selbsterfahrung*, “self-experience” was the common term there at the time—were very popular (at least in certain intellectual milieus), as was psychoanalytic thinking.

Psychoanalytic thinking is still quite widespread in Germany. While Sigmund Freud's work has widely vanished from departments of psychology, and his ideas are scarcely taught any longer in universities, he is still referred to by the laity when talking about psychology.

### **1977-1979: Research Projects in Giessen, Hamburg, and Heidelberg begin**

Prof. Moeller started the first research project on self-help groups in Germany at the University Clinic for Psychosomatic Medicine and Psychotherapy in Giessen, and I, the author of this article, then a young psychologist who had just finished his studies, was a member of the team (Matzat, 2007). We named the specific type of self-help groups we explored “psychologico-therapeutic” to avoid the term “psychotherapeutic” because we were afraid that this might create considerable problems with professional group therapists. However, it expresses the idea that self-help groups can offer people something akin to psychotherapy. We wanted to learn about the inner life of such groups, their

way of working, their effects and benefits (possibly also side-effects), and about beneficial kinds of professional support—support that would not take away their ownership. In order to do so we used a mixed-method approach: standardized psychological tests, ad-hoc constructed questionnaires, and interviews, as well as our personal observations as trained psychologists and (group) psychotherapists. This research project, in fact, formed part of the large scale reform of psychiatric care in Germany (Matzat, 1987). The research report (Daum, Matzat, & Moeller, 1984) was published by the state, displaying “the Federal Eagle,” the state’s coat of arms, on its cover. The Federal Ministry of Health and Social Affairs supporting research on self-help groups! That was quite a message to the public and to the professional world. Self-help was no longer something illegitimate, tucked away in a political red-green, alternative, and anti-authoritarian corner.

The research project in Giessen was followed later by others in Heidelberg (also based in the Clinic for Psychosomatic Medicine and Psychotherapy) and in Hamburg (based in the Department of Medical Sociology). Whereas the Giessen team focused on “psychologico-therapeutic” groups, the Heidelberg team tried to transfer a similar approach to people with somatic diseases. The Medical Sociology Department in Hamburg used sociological methods like questionnaires, interviews, and focus groups to find out how many self-help groups existed in Hamburg, which topics they tackled, how they cooperated with professionals, and so on (Trojan, 1986).

I was a member of the research team in Giessen, and developed a severe “self-help dependency” with the highest personal and professional interest in the capacities of “ordinary people” to support each other mutually, to cope with crisis and illness, to become competent patients, to become more “empowered” in their interaction with professionals, and to influence health and social policy as well as professionals and their institutions. In 1987, I became the full-time director of a (now officially established) self-help support center, still based in the University Clinic for Psychosomatic Medicine and Psychotherapy in Giessen, where I am still working.

All three research projects had an action research philosophy. The researchers were not just collecting data to put into computers to produce numbers. They wanted to see how they could support people in forming self-help groups. What kind of guidance or supervision could we offer them, while still respecting their autonomy? We were participant observers, participating not during the group meetings but through all kinds of support and encouragement, convinced of their value and far from being “neutral” or “objective.” (What a sin for proper researchers!) Besides our academic and psychotherapeutic knowledge, the self-help group members were our most important teachers.

At the time of these research projects (in the late 1970s/early 1980s) we developed what we now call a “clearing house.” Of course that term didn’t exist

at the time, nor indeed did the German word “*Selbsthilfe-Kontaktstelle*.” But we simply wondered what kind of support activities we could offer.

The next step was the development of *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen* (i.e., German Working Group [for the Support of] Self-Help Groups). In the beginning it was only a very informal circle of people devoted to self-help groups coming together partly from these research teams, but including other interested persons as well—“Friends of self-help groups” you might say. Mostly, they were professionals working in universities, psychotherapists in private practice or in hospitals, staff of various counseling centers, etc. A minority were members of self-help groups; some were both. We met whenever we could; we used conferences, which some of us were attending for other purposes, organized our own workshops there, to sit together for an afternoon or a day and exchange ideas. What about self-help groups? How to define them? Can they really work without professionals? What are the risks? What will they do (commit suicide or refuse ordinary treatment?) if we are not there to supervise them? Dare we, on the other hand, cooperate with them as professionals, or should we completely withdraw and avoid any contact? Are we going to poison them as soon as we meet them? It was highly moralistic thinking in those days. Of course this excessive caution was, from a psychodynamic point of view, a “reaction formation” against the apprehension of our own professional dominance.

Out of this informal circle of no more than about a dozen people from all over West Germany, all fascinated by the self-help group idea—and not feeling we were loners, lunatics, or outsiders—the first generation of *informal* self-help clearinghouses emerged. Anyone who was able integrated the promotion and support for self-help groups into the routine activities of his or her respective institution.

### **1980s: Moral Support from the WHO-Europe**

By the 1980s, we also had some international support for our thinking from the WHO-Europe (i.e., the WHO regional office in Copenhagen, not the world headquarters in Geneva). In 1983, they published a book on “Self-Help and Health in Europe,” edited by Stephen Hatch (from England) and Ilona Kickbusch (from Germany), and they brought together an international task force in Höhr-Grenzhausen, Germany, and in Leuven, Belgium. Their most important recommendation was that professionally run self-help clearinghouses should be established on national, regional, and local levels. Whenever we went to German politicians, thereafter we could mention that WHO was supporting our ideas. The fact that there were activities in other European countries was a support and encouragement to those of us who were among the forerunners in Germany.

In that most beautiful Adriatic city, Dubrovnik (then in Yugoslavia), the International University Centre, an umbrella organization of hundreds of

universities from all over the world, organized international courses for scholars in all fields of knowledge. As part of the program “Health for All” under the patronage of WHO, courses on self-help groups took place annually. Alfred Katz from the United States was one of the master minds, and I had the honor to follow him as one of the directors of these courses. Self-help group supporters and researchers—mainly from European countries (including some colleagues from the Eastern Block) but also from the United States, Canada, Australia, and Japan—assembled to exchange their ideas and experiences in studying, promoting, and supporting self-help groups under the national, cultural, and medical service system conditions in their respective countries.

### **1977-1982: Phase of Curiosity and Resistance**

A small minority of professionals—often connected to the 1968 rebellion and/or with a strong psychological cast of mind—were quite interested from the beginning. On the other hand, self-help became a threat to others. The President of the German Doctors Association, for example, publicly warned that support for self-help could lead to lower income for doctors in private practice. That was, of course, an over-simplified remark, but at the time it was an important expression of resistance, a voice that found listeners.

Another field of resistance was formed by the psychotherapists. “Psychologico-therapeutic” self-help groups looked very similar to “group psychotherapy without a therapist.” Some psychotherapists believed, wrongly, that self-help groups might become rivals.

During that period we elaborated what a self-help clearinghouse is supposed to do. We created the model for a new type of institution. And the *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen* as a professional organization promoted this approach to the public, to politicians, and to possible sponsors.

“*Selbsthilfe-Kontaktstellen*” are meant to provide a certain region, a district, or a larger municipality, with the following services:

- promotion of the self-help group approach in general, offering a contact to this new field, making it visible, and giving continuity to its development;
- information about existing self-help groups in the area, both for professionals and for sufferers, and enabling access to the groups;
- support and backing for the founders of new groups;
- consultancy with existing groups, giving support in critical situations, in conflicts, or at times of transition;
- providing or finding adequate meeting rooms, office facilities, access to funders, etc.;
- acting as an intermediary between the official professional service system and the developing self-help system;
- giving those seeking help information about alternatives to self-help groups to be found within the professional service system (e.g., psychotherapy).

### 1982-1987: Phase of Acceptance and Idealization

In 1982 the informal circle of *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen* became a registered society with charitable non-profit status. There had been some discussion whether we should remain informal, grassroot minded in the spirit of self-help, but the concerns were outweighed by the fact that in Germany it is much easier to receive money as an association (a tax deduction for donors, and a familiar organizational form for public funders). Later I served as a member on the organization's board for 13 years.

One year later, in 1983, we were able to open a national clearinghouse according to WHO-Euro's recommendations. West Berlin was, as Berlin is now, both a city and one of the 16 federal states which comprise Germany. The reader may remember that in 1983 West Berlin was surrounded by walls and fences: it had enormous social and political tensions—squatters took over housing, violent demonstrations in the streets were frequent, etc.—and an “alternative party” gained enough supporters to win seats in the state parliament. A conservative politician believed that the particular situation in Berlin could best be dealt with by cooperating with the new approaches offered by self-help groups, citizens' initiatives, the voluntary work of non-governmental organizations, the alternative health movement and so on; but the policy makers needed a respectable organization that could be part of this new program, and they found the *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen* (because we were a charitable registered society, and the famous Professor Moeller had been the founder). They offered us money under the condition that our activities were to be carried out in Berlin. That was *the* opportunity to open a national clearinghouse and the reason why it happened in Berlin, which was an island then, far away from the rest of the country.

Rising naturally from social movements in the German society, a registered society of self-help supporters and promoters was formed, and then an institution founded. To categorize the hybrid character of self-help clearinghouses, my friend and colleague Wolfgang Thiel coined the term “*Bewegungs-Institution*” (movement institution). The staffs belong to two cultures (cf. Parsons, 1951) at the same time (to the self-help movement with their hearts and to their respective professional communities by training).

In 1987, *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen* coined and published a normative definition of “self-help groups” which became widely recognized and accepted in Germany: Self-help groups are voluntary, mostly loose associations of people, whose activities are directed toward coping in common with illnesses, psychological or social problems, by which they—either themselves personally or as relatives—are affected. They do not seek to make a commercial profit. Their goal is a change in their personal lives and an influence on their social and political environment. In regular, often weekly, meetings they stress authenticity, equality, a common language, and mutual aid. The group is a



means to counteract outer (social) as well as inner (psychological) isolation. The goals of self-help groups focus on their members, and not on outsiders; in that respect they differ from other forms of citizens' action groups. Self-help groups are not led by professional helpers, although some consult experts now and again on particular questions. (Matzat, 1993, p. 32)

### **1987-1992: Phase of Institutionalization and Professionalization**

By 1987, rumors about self-help had reached the federal government which made inquiries to find out what they could do to support it. According to the German constitution, most health and social matters are regulated not at the federal but at the state level (Matzat, 1989); we, therefore, recommended that the federal government carry out pilot projects. These projects are evaluated by independent experts in order to determine their usefulness. Out of numerous applications, 18 projects were chosen, one of them in my own town of Giessen submitted jointly by *Deutsche Arbeitsgemeinschaft Selbsthilfegruppe e. V.* and the clinic for psychosomatic medicine and psychotherapy. The projects were quite well financed by the federal government for 4 years. Was their effectiveness proved? Of course, one could not prove effectiveness in the strictest scientific sense like in a randomized controlled trial. However, those evaluating the projects could show that in areas with clearinghouses the number of groups increased significantly, the number of people participating in self-help groups increased, and most of the groups were stable over time, which was essentially attributed to the clearinghouses' support (Braun, Kettler, Käsmann, & Becker, 1997).

From then on we could say that to support self-help groups in general through local clearinghouses is indeed useful and valuable. In some federal states the clearinghouse idea was taken up, in others not. That's how it is in a federation.

In 1992, after unification, a second similar government program was introduced in former East Germany where there were very few self-help groups. No groupings independent of state organizations had been allowed by the old regime. But very quickly, with a little help from the West, the same self-help approaches developed.

The number of *Selbsthilfe-Kontaktstellen* (local clearinghouses) in Germany has since grown to approximately 300. Their addresses are published yearly in a free brochure by NAKOS (see above) and can be found on the internet under <http://www.nakos.de/site/adressen/rot/>. In almost every large city or district you find one today. Some are very small, with perhaps only one part-time worker, and some have a very fragile economic basis. Large ones in major cities may have a staff of three or four (part-time) workers; in Berlin and Hamburg you find more than one clearinghouse. However different the clearinghouses may be, there is at least one point where information on self-help groups is collected and all support possible is provided to those who want to join or to found a self-help group, as well as to those who are prepared to collaborate as professionals with

them. There is consensus in Germany that *Selbsthilfe-Kontaktstellen* (self-help clearinghouses) have professional staff, usually social workers or psychologists.

The internet, of course, is a source of growing importance, as far as information is concerned, but it remains limited when it comes to counseling and personal contact, when self-help groups are rather informal; e.g., “psychologico-therapeutic” groups are often not found on the internet, or when specific local or personal circumstances are relevant.

A convincing proof of the effectiveness of self-help clearinghouses was provided some years later by Jürgen Stremlow (2006), a researcher in Switzerland. He collected data on all the clearinghouses in Switzerland obtaining the number of staff members they had and how long they had been in existence. He also counted the number of self-help groups per 100,000 inhabitants in the respective catchment areas.

The results showed a clear statistical relationship between the number of groups per 100,000 inhabitants and the number of staff members per clearinghouse and the length of time they had been operating. The message is simple: the more staff members operating over a longer time, the more groups you will have. Moreover the diversity of groups increases; that is, there will be a specific local self-help group for more issues. This is a very simple research finding, but if you show it to a politician, he gets a very clear message: if you are interested in this form of “social capital,” that is the way to acquire and to enlarge it.

Another interesting finding comes from Bremen (a city and port in the north of Germany). Over the years the number of people contacting the *Selbsthilfe-Kontaktstelle* (self-help clearinghouse) there because of psychological problems had been increasing, whereas the proportion of those calling with regard to chronic disease and physical disability had been decreasing. What does this mean? I don’t think that the number of disabled persons has come down in Germany. It rather means that nowadays people can find a lot of information on diseases and conditions on the internet (including the websites of self-help organizations), instead of turning to human beings in a self-help group. However, the amount of information found on the internet is now starting to become a problem: users can easily be “over-informed” and confused by contradictory information. It is becoming clearer that much of the information on the internet is simply wrong or commercially biased, and there is a lack of external, neutral validation and assessment of this information. (This is also true of online groups which do not as yet play an important role in Germany’s self-help scenario—and which are controversial whether they should be seen as self-help groups at all in the strict sense of the term.) Secondly, it indicates that more and more professionals do give information about self-help, particularly in “advanced” fields like alcoholism or cancer.

The prominence of requests by people suffering from psychological distress led to a joint project recently conducted by the *Selbsthilfe-Kontaktstelle* and the University Clinic for Psychosomatic Medicine and Psychotherapy in Giessen, which dealt with

self-help groups for persons with mental disorders, treated in specialized hospitals (Meyer, Matzat, Höflich, Scholz, & Beutel, 2004; Schäfer, Meyer, Matzat, Knickenberg, Bleichner, Merkle et al., 2005-2006).

As the clearinghouses receive an increasing number of calls concerning rather unclear, vague psychological states (Matzat, 1989-1990), an additional function of them is to provide a minimal level of psychological counselling service for screening and clarifying psychological problems in order to point the way through the jungle of the German health and social services systems. (The reader should know that cognitive behavioral therapy and psychodynamic therapy by licensed psychotherapists is covered by the statutory health insurance in Germany. In every city or district you will find publicly financed counseling centers for youth, for adults, for families, for the addicted, for the mentally ill, etc.) I call this the “piloting” or “signposting function” of *Selbsthilfe-Kontaktstellen*: pointing people to a more appropriate professional service outside the self-help sphere. Only 5 or 10% of the people suffering from various diseases use *self-help groups*, and often people seeking *help* call self-help clearinghouses. They need to be assisted and directed—as competently as possible.

### **2000: Financial Support by Statutory Health Insurance Funds**

A very big change occurred when money from Germany’s *gesetzliche Krankenkassen* (non-profit-making statutory health insurance funds under public law) became available. The German health system is not paid for by tax money but by the contributions of the insured. Almost everybody in Germany has to be insured in one of these statutory health insurance funds of which there are some 200 covering approximately 90% of the population. People are free to choose a particular fund; but, in practice, they all provide the same services. The traditional situation is that the working father is the “member,” i.e., from his salary a certain percentage (approximately 15% at time being) is taken as his contribution, and his wife and children are insured as his dependents. A public law regulates what is covered by the statutory health insurance (drugs, treatment in practices and hospitals, rehabilitation, prevention, psychotherapy, etc.). In 1999, there was a change from a conservative to a red-green federal government. The new health minister, a woman from the Green Party, supported the self-health concept and initiated a law which stipulated that the *gesetzliche Krankenkassen* (statutory health insurance funds) have to support financially “*Selbsthilfegruppen*,” “*Selbsthilfeorganisationen*,” and “*Selbsthilfe-Kontaktstellen*” one Deutschmark (i.e., 60 US cents) per person per year. The definitions now written into the code of social law (Matzat, 2001-2002, p. 317) are: self-help groups are defined as small groups, acting on local level, offering face-to-face communication; self-help organizations are larger, nationwide and more formally organized; self-help clearinghouses are professional agencies promoting and supporting self-help

groups, informing and counseling interested citizens, and fostering the collaboration between professional helpers and self-helpers. The law states that when the statutory health insurance funds spend their money on self-help, they must consult representatives from one of four associations for self-help: one umbrella organization for disabled people (*Bundesarbeitsgemeinschaft Hilfe für Behinderte* = Federal Working Group Aid for the Disabled) (see above); one from the field of addiction (*Deutsche Hauptstelle für Suchtfragen* = German center for addiction matters); one umbrella organization of NGOs for social welfare (*Deutscher Paritätischer Wohlfahrtsverband* = German non-denominational welfare organization); and *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen* (German Association [for the support of] Self-Help Groups) to which the author is affiliated.

Germany has 82 million inhabitants, of whom about 90% (over 70 million) are insured in these systems. Thus, the health insurance funds have to spend 70 million Deutschmarks, approximately \$50 million dollars, on self-help. This was a large increase in funding and also in terms of recognition as well. The German state had obviously agreed that self-help has positive effects and started to support it substantially. It had become a public affair.

To illustrate the leap forward in terms of the recognition of self-help, I refer you to the cover of *Deutsches Ärzteblatt*, May 2003 edition, the official journal which goes to all German physicians (ca. 250,000) every week. On the cover is written “*Ärzte und Selbsthilfe: Zusammenarbeit verbessert sich*” (i.e., “Doctors and self-help: collaboration is improving”). That was, of course, not so much a description of the actual situation, but rather a political message from the Medical Association: this is what we want to happen! In this issue there are articles describing the four most important umbrella organizations in the self-help field and information about self-help structures. Since then, every doctor has had a route to the addresses of self-help groups and clearinghouses for their patients. The physicians’ own professional umbrella organization was in favor of self-help; this, hopefully, will be an influence on their attitude toward self-help.

#### **2004: Patient Participation in the German Health System**

For many years, all decisions in the German health system were made by a closed circle called the “Joint Committee” (*Gemeinsamer Bundesausschuss*; <http://www.g-ba.de/institution/sys/english/>). Under public law, the state does not interfere between the providers and the statutory health insurance funds. The Joint Committee negotiates which health technologies—drugs, diagnostic or operational methods, psychotherapy, etc.—are accepted as effective and will be paid for. This is not a political or governmental issue, it is decided between the care providers, doctors, and hospitals and those who pay, the health insurance funds; the patients themselves were not represented in the decision-making process. A crucial new structure came into being in 2004: *Patientenbeteiligung* (i.e., “patient participation”), a representation of/for patients on the

joint committee. The law states that they are *sachkundige* (i.e., well informed) persons, drawn from organizations (for cancer, rheumatism, diabetes, etc.) or by professional organizations working in the field of self-help support (i.e., self-help clearinghouses) or consumer advice. I was among those nominated by *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen*. The idea was that these persons bring together not only their own experiential knowledge, but the experience of their respective organizations in its totality. The second qualification was that they have experience in committee work, negotiations, etc. They needed to have a broad understanding of more than their own issue and be knowledgeable about the health system—which is extremely complex—including its financial limitations. Later on, another requirement turned out to be relevant: understanding the scientific and technical language of evidence based medicine (randomized controlled trials etc.) and statistics (e.g., the concept of probability). So the expectation was quite high.

The government accredited four “patient organizations,” one of which was our *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen*. These accredited organizations have to agree on the “well informed” persons they have chosen to send to the Joint Committee, creating a stronger democratic legitimization.

Patients’ representatives have three rights. The first is the right to speak out whenever they have something to say. That is different from public or parliamentary hearings in the past when lawmakers could ask for an opinion, but if they did not, one could not offer their experience or opinions. The second right is to put topics on the agenda. As a patients’ representative I can propose a topic, and the other partners cannot say that is rubbish. The third right is to be present when voting takes place. Patient representatives cannot vote but their presence makes a big difference. A new element changes systems, and patients’ representatives are something new.

### RISKS AND SIDE-EFFECTS

Money can be an incredible resource but it also can trigger unattractive human behavior, including envy, rivalry, corruption, etc. This is true not only of financially subsidized self-help as a whole but also for the role of patients’ representatives. Are the people who want to work on the joint committee the elite of the self-help movement? Have they a certain type of personality? They will always be subject to some sort of influence, perhaps, even at risk of corruption. Perhaps, the persons coming from self-help organizations are not “the best,” but rather “the loudest,” “the most ambitious,” or “the most querulous.” Some of them are sent from self-help organizations which gives them a certain legitimacy; but, often they belong to the paid staff of larger self-help organizations. Some, like myself, are professionals sent by associations (in my case *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen*) and are at one and the same time citizens, patients, insured persons, and self-helpers. Professionals working in the self-help field are not only knowledgeable about self-help but have a basic

knowledge of statistics and study design. The classic personal testimony, so common among self-helpers (and often quite impressive to outsiders), is irrelevant in these formal bodies where decisions are being made about the quality of drugs in reference to scientific studies which exclusively rely on “evidence” (as defined in the framework of “evidence based medicine”).

Discussion on such questions culminated in the “big pharma” debate that went on for some time in Germany. To what extent are self-help groups influenced by pharmaceutical companies? As far as we know, at the time being, only a few nationwide self-help organizations receive (according to their own declaration) a substantial amount of their budget from the pharmaceutical industry; some receive a minor percentage which may not create dependency, but the vast majority do not receive any (relevant) sponsorship. (Local self-help groups are not (yet) relevant in this context anyway.) On the other hand, discussions show that many self-helpers are quite naïve about this question. The opinion leading umbrella organizations in the self-help field have developed ethical codes on industrial sponsorship to which they are themselves committed and most self-help organizations have adopted (<http://www.bag-selbsthilfe.de/news/60/verabschiedung-der-leitsaetze/>). The statutory health insurance tries to make this a prerequisite for their own funding. *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen e.V.*, to which the author is affiliated, also tries to promote the debate within the self-help community by critical articles in its *Selbsthilfegruppenjahrbuch* (self-help yearbook), by lectures and workshops, both on the local and national levels.

To U.S. readers, it must be pointed out that in Europe pharmaceutical companies are not allowed to advertise drugs available to patients only on prescription. Therefore, it is an obvious strategy to influence organized patients (e.g., self-helpers) to put pressure on doctors, health insurance, and politicians—to the benefit of the industry. We know such “conflicts of interest” all too well from doctors and medical researchers.

Thomasina Borkman (1999), in her book *Understanding Self-Help/Mutual Aid*, had already asked the prophetic questions: “Do the institutionalized, and often rich and powerful, mainstream players help or detract from self-help/mutual aid by providing resources? Under what conditions do they try to control and subvert or facilitate the self-help/mutual aid process”? Good questions, a broad subject, which must be monitored closely in the future.

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