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THE DEVELOPMENT OF SELF-HELP GROUPS AND SUPPORT FOR THEM IN GERMANY*

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ABSTRACT

This article gives a broad overview over the development of self-help groups and support for them in Germany. Historic and political contexts of the German health and welfare systems are given. Reflecting the professional discussion in Germany, a basic typology of self-help groupings is suggested by definitions of anonymous groups, larger self-help organizations, and small self-help groups. The relationship between professional helpers and self-helpers, the remarkable change in attitudes over the last decades, are described in historic phases. The "*Kontaktstelle für Selbsthilfegruppen*" (self-help advice center), a widespread professional approach in Germany for promoting and supporting self-help groups, is presented. The latest development in German politics is reported, which leads to a strong commitment of sick funds to support self-help substantially. The article closes with a prospective view of possible further developments on Germany's self-help scene.

PREFACE

Germany is in a process of transition. Two crucial events were the fall of the Berlin Wall and the Iron Curtain in 1989 and the unification of the two German states in 1990. Politically there was no alternative, but the economic and psychological consequences were not predicted. People on each side of the border had drifted apart; habits and values, organizations and institutions, modes of production and

*This article is dedicated to Prof. Michael Lukas Moeller, an early promoter of self-help groups in Germany, who taught me a lot.

consumption, and views of history had become different over the decades of separation. There were new words which existed in only one of the two countries, describing phenomena which existed only there, and which were not understood on the other side. "Self-help group" was such a term, representing a completely new idea with which East Germans were confronted: self-organized groups of citizens had not been acceptable in their authoritarian political system. This article therefore refers partly, especially in its historic remarks, only to the old Federal Republic. A decade later, it is a huge subject for discussion in Germany whether this cultural and economic gap between the two former countries is closing or even still widening.

POLICY AND SERVICE CONTEXT

Unified Germany now has more than 80 million inhabitants, and is a highly industrialized society with a low birth rate and a dramatically ageing population. According to its constitution, it is "a democratic and social federal state" of 16 states (*Länder*) which have, among other things, constitutional responsibility for health and social affairs.

West Germany had established an extensive system of social security for its citizens which now straddles the whole country. It is basically not financed from taxes, but mostly from compulsory insurance contributions paid half by employees and employers to various schemes (covering illness, unemployment, and pension), sometimes subsidized by the government. While more than 400 statutory sickness fund schemes as public law corporations operate under government supervision, they are autonomous bodies with formal participation of those insured. They cover a wide variety of treatments in many settings, and the insured payed in 2000 on average 13.5 percent of their income, as well as extra charges for certain kinds of treatment. Almost 90 percent of the population benefit from these statutory sickness fund schemes. The total expenditure on benefits over all these schemes amounted in the year 2000 over 250 thousand million DM (roughly 120 thousand million $). The health sector is an expanding business in this country. Expenditure on sickness fund schemes is only part of the total Germany spends on its health services, namely 10.6 percent of GNP (1998), second only to the United States (13.6 percent in 1998), according to OECD.

Furthermore, historic and cultural influences determine the specific character of Germany's self-help scene (cf., Matzat & Oka, 1998).

THE SELF-HELP MOVEMENT IN CONTEXT

On Definition

It may be optimistic to speak of a movement since this suggests that different kinds of self-help groups have more in common than they actually do. But the

phenomenon in Germany is significant, with an estimated 70,000-100,000 groups (Matzat, 1997) with three to four million members. Some call it already "the fourth pillar of Germany's health system," beside hospitals, doctors in private practices, and a very limited public health service. Eighty nation-wide self-help organizations of disabled and chronically ill people cooperate under the umbrella of *Bundesarbeitsgemeinschaft Hilfe für Behinderte* (Federal Association of Help for the Handicapped). In more than 250 cities and districts, specialized self-help advice centers ("*Kontaktstellen,*" see below) exist.

There are two reasons why the estimated number of self-help groups is imprecise. First, many of them are informal. They are not registered anywhere, they don't cooperate much with institutions, they don't demand money or other support, they don't put themselves on show in public, but are engaged with their own inner life as encounter groups. Sometimes they are referred to as "living room groups," to underline the privacy which puts them beyond the reach of official statistics. The second reason is about definition. What exactly is a "self-help group"? What has a right to be counted as one? Self-help groups are extremely diverse social phenomena, by nature hard to identify, complicated to describe, and fuelling battles of words. But an attempt is necessary to clarify a point of view and enable communication with others, if not agreement. The *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen*, an association of self-help supporters who are mainly professionals from psychology, social work, and similar fields, formulated the following definition:

> Self-help groups are voluntary, mostly loose associations of people, whose activities are directed towards 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).

This describes an ideal type. The reality of self-help groups is rich and colorful, as variable as human beings, their needs, and their talents. As a rough approximation in this jungle, a simple typology may be helpful: anonymous groups; larger self-help organizations; and small self-help groups in a narrower sense.

Anonymous Groups

AA (Alcoholics Anonymous) is the most prominent example, the prototype to which all anonymous groups refer. Others are EA (Emotions Anonymous), NA

(Narcotics Anonymous), OA (Overeaters Anonymous), GA (Gamblers Anonymous), etc. The latest examples in Germany, more popular in women's magazines than in reality, are "Shopping Anonymous," "Love-Addicted Anonymous," and "Messies Anonymous." These may seem rather odd, if not absurd to most Germans, but they demonstrate the growing popularity of the general concept of "addiction"—an illness, not the person's own fault—to explain all kinds of behavior disorders. And the concept of anonymous promises a tried and tested method of fighting addiction.

All self-help groups of the anonymous type are "open," which means people can join the group at any time—the only requirement being a desire to recover—and leave it whenever they want to. Thus, there is no formalized membership, and consequently no membership fee; no formal status for the group (unlike a registered club, association, society, or charity); and no board or committee (only a chairperson for one meeting at a time). Instead there are the "programs," "12 Steps," and "12 Traditions" representing the developed experiences of people with alcohol-related problems and self-helpers. They offer guidelines for daily life as well as for group work, and they might be regarded as a substitute or an equivalent of a therapist for these groups.

In anonymous groups, participants hold a series of monologues rather than dialogues or discussions. They tell their personal stories, their "narratives" (Humphreys, 2000). There is a close similarity to the confession rituals of Christian communities with their cathartic effects. They also explicitly relate to a "spiritual dimension" (cf., Kurtz & Ketcham, 1992) on the road to recovery, they "surrender" and hand over to a "higher power" (as they personally understand it). This, again, is a very clear reversion to Christian thinking and, psychologically speaking, to a "super-ego approach." This skeleton of a clear, strong program has obviously proved worthwhile for millions of people with alcohol-related problems as a means of compensation for lack of ego-strength. This style does not suit everyone, however.

Anonymous groups are far less common in Germany than in the United States (perhaps because European societies are much more secular), but their number is increasing, like everywhere in the world.

Self-Help Organizations

Self-help organizations in Germany include the large patients' associations, such as the League against Rheumatism, the MS Society, or the Psoriasis Alliance. They usually have a very formal structure and status, similar to the non-state and non-profit social welfare organizations which play a predominant role in Germany's social system (Matzat, 1989a). They function nationwide, at federal state level, and some of them have numerous local groups. They stress "outer self-help" by representing the interests of their members and others suffering from the same problem, acting as a kind of "patients' trades union." They offer legal

advice, publish journals regularly, and collect money to stimulate and support research. They employ professional staff, especially at their national headquarters. Members sign a confirmation of membership and pay a membership fee. These organizations seek private donations and public funding, and some are remarkably successful.

Only a minority of the members of these self-help organizations are really active and deserve to be described as "self-helpers." These few very often carry a tremendous workload and sacrifice limitless time, money, and energy. If one had the right to label their behavior, some might be called over-involved, possibly acting out a "helper syndrome," precisely as many professionals do. These active members demonstrate the positive effects of the "helper therapy principle" (Riessman, 1965) and of the healing power of doing good by helping others (Luks with Payne, 1991) that professional helpers benefit from every day. In the context of a collective self-help group process, however, it may be counterproductive. As "helper" and "helpee" are originally meant to be dialectic complementary roles for the same individuals here, over-involved members in self-help groups, rather behaving as volunteers helping "patients," contribute to some degree to the widespread passivity found among the majority of their co-members, about which they may indeed complain. Self-help organizations tend to be used or misused like any other agency in the care system. Their members, and even more so other sufferers, often behave simply as consumers (actually without paying a price!).

Small Self-Help Groups

Self-help groups in a narrower sense are in Germany often referred to as discussion groups or psychosocial self-help groups, reminiscent of professional group work, at least in the field of psychotherapy (Matzat, 1987, 1989-90). These groups are closed over longer periods, or what might be described as "slow open" (new members are only accepted at certain times to control and limit the number of participants for the sake of the group's functioning). Membership is clearly defined by self-declaration and mutual agreement, equivalent to a contract, and by regular, reliable participation and attendance, but not by subscription and fees. A limited number of people meet regularly, usually weekly, over a considerable period of time, preferably in a neutral venue, not somebody's home. Without following any written program or manual, they have an open discussion on very personal matters, their feelings and emotions, hopes and anxieties, conflicts and symptoms. They focus on their personal history (their "narratives"), their relations between themselves and with significant others outside the group. They try to be as frank and open as possible and to clarify their points of view. We find a rich variety of elementary therapeutic principles, techniques, or mechanisms applied in a kind of spontaneous common sense way by these laypersons (cf., Matzat, 1999). That is why Nathan Hurvitz (1974) characterized their work even as

"psychotherapy without psychotherapists." Perhaps an exaggeration, but psychological and emotional aspects certainly enjoy their special attention. The roles of helpers and those seeking help are not distinct in these self-help groups; they can be exchanged according to situation and demand. That's why they are also called "mutual aid groups."

THE ROLE OF EXPERTS

Experts who spent years acquiring training and professional experience often question how lay people can do everything themselves and wonder whether such groups will render them redundant. Pure fantasy; in reality most self-help groups seek contact to experts, asking for recognition and collaboration. Attitudes and behavior of professional helpers towards the developing self-help movement, however, have changed significantly over time.

The first phase was the Dark Ages of ignorance, lasting in Germany to the late seventies. Some self-help associations already existed, but they were practically ignored by experts, researchers, and politicians. AA was the only exception to this rule, known and highly regarded by professionals working in the field of addiction, as a most successful form of after-care after in-patient treatment for alcoholism. In professional education at this time the term "self-help group" was hardly heard except perhaps during practical training in psychiatric hospitals with wards for alcoholics.

The emergence in 1976/77 of the first big text books dealing with self-help groups in the United States (Caplan & Killilea, 1976; Gartner & Riessman, 1977; Katz & Bender, 1976) marked the beginning of a phase of awakening curiosity in professional communities. In Germany the early "bible" on self-help groups was published in 1978 (Moeller, 1978). And in 1977/78 three larger research projects on self-help groups were started at the universities in Giessen, Heidelberg, and Hamburg. All three were located in psychosocial medicine (psychosomatics/psychotherapy or medical sociology). These intersections between medical and psychosocial thinking was a soft point in the professional world which self-help ideas and lay people's activities could infiltrate. But nearly another 20 years were to pass before "self-help groups" showed up in the title of a sub-chapter under "Gruppentherapiemethoden und Selbsthilfegruppen" (Söllner, 1996, pp. 434-440) in the fifth edition of the German standard textbook on psychosomatic medicine (Uexküll et al., 1996). Earlier, to mention only one example, the relevance of this topic for physicians was reflected in an excellent textbook on "psychosocial competence in medical primary care," written jointly by specialists in general medicine and in psychosomatic medicine for the education of general practitioners (Helmich et al., 1991), in a chapter on "self-help and social network" (pp. 314-321).

As reports and articles about the self-help research projects were published, attitudes of ignorance could no longer be maintained. Instead, there was enormous

resistance among the experts (Moeller, 1992) during this first phase of curiosity, which manifested itself in two different ways. One was repressive and reactionary, indulging in fantasies of wild bunches of uncontrolled patients falling victim to alternative methods or even quackery. Doctors were worried about money shifting from their private practices into an emerging self-help sector. Even more important was the threat to their high social status. Suddenly people proclaimed their own competence and protested against "incapacitation by experts" (Illich, 1979). The traditional complementary roles were of an uninformed, uneducated, and naive patient facing a demigod in white who had both the knowledge and the ability to determine people's fate. This tradition began to change.

The other aspect of experts' resistance was disguised as progressive: the independence and autonomy of self-help groups should be respected absolutely. All contact with them was to be avoided as the only way of preventing them from coming under professional domination. In reality this meant refusal to cooperate with self-help groups, and resistance to learning from them. The benevolent paternalistic assumption was that members of self-help groups were helpless, passive, and weak, unable to protect themselves from professional infringement or to make their own responsible decisions.

The association of self-help supporters *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen,* which originated in the Giessen university research project, was an informal circle of interested scholars for several years before it was established as a registered society in 1982. Once it was a formal body and thereby in a position to receive public grants, the *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen* published the first brochure about self-help groups under the title *"Reden & Handeln"* ("Talking & Acting"), with many more to follow. Due to the competence and experience assembled here, it has been accepted since as an opinion leader in this field.

A phase of breakthrough, acceptance, and even idealizing followed from 1982-1987 and was the result largely of politicians' initiatives. Amidst a huge debate on new social policy, the crisis of the welfare state, and the exploding costs of the health system, self-help was a ray of hope on the horizon for those who wanted to reduce costs. To be fair we must add other, less cynical interests, such as more consumer rights, citizen participation, and the general democratization of society. The result was a broad coalition in which all political parties could find elements of their own value systems represented in self-help groups: the principle of solidarity for Social Democrats; "love thy neighbour" and compassion for conservative Christian Democrats; citizens' self-responsibility for Liberals; grass-roots democracy, empowerment, and participation for the Green Party/Ecologists.

The first impact was made in Berlin, a huge city and a federal state at the same time. Surrounded by the Wall and cut off from West Germany, it was a focus of societal conflicts and tensions on the one hand and highly subsidized financially by the Federal government on the other. The state government of Berlin invested very early heavily in self-help support, both through direct funding of groups,

initiatives, and projects, as well as through infrastructure support in the form of *Kontaktstellen*, explained below. The most relevant element of the "Berlin model" in the context of this article was the setting up and state funding of NAKOS (*Nationale Kontakt- und Informationsstelle zur Anregung und Unterstützung von Selbsthilfegruppen*) in 1984, Germany's national self-help clearing house, following recommendations by WHO-Europe (1982) (cf., Branckaerts & Richardson, 1989).

The decisive professional development during this phase of breakthrough was the development of the concept of the *Kontaktstelle für Selbsthilfegruppen* (self-help advice center or clearing house) by Deutsche Arbeitsgemeinschaft Selbsthilfegruppen (1987). Research had shown that not all self-help groups were the result solely of their own efforts. On the contrary, in many cases professionals had initiated or assisted in the founding of the group and remained important permanently through referrals of new group members and occasionally as consultants. Professional support for self-helpers seemed to be necessary or at least useful, and it seemed possible without being dominating or paternalistic, which had often been feared. All the research projects mentioned above acted on this by integrating practical support for self-help groups in their region as an element of action research, serving as forerunners of the later *Kontaktstellen für Selbsthilfegruppen* concept (Estorff, 1989; Matzat, 1989b). *Kontaktstellen,* as a specialist agency, were 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 professionalised service system and the developing self-help system; and
- informing those seeking help about alternatives (to self-help groups) in the professional service system.

The distribution of money was *not* seen as part of the *Kontaktstellen für Selbsthilfegruppen* activities, being perceived as something which might interfere with the counselling approach adopted. It was felt that *Kontaktstellen* should rather be independent professionally-run services, not part of other routine administrative services. Whereas professionals had previously supported self-help groups only in their specific field as a kind of appendix to their original activities, a new broader

perspective of self-help groups promotion emerged. This required staff to have certain skills and techniques as well as good organization (Balke & Thiel, 1991).

The self-help movement became idealised e.g. in over-optimistic books such as "On the Road to the Self-Help Society?" (Vilmar & Runge, 1986), which tended to be quoted with the omission of the question mark. And it was the same with the publication of findings such as that 35 percent of the German population were potential members and prepared to join a self-help group if faced with illness or crisis (Grunow et al., 1983). (In a most recent survey done by one of the big sickness fund bodies (DAK, 1998) even 76 percent (!) declared their readiness to join a self-help group in case of an illness. This shows clearly the striking increase in public acceptance of the self-help approach and a very positive attitude to it in the German population.)

The growing acceptance of self-help groups was also reflected in declarations by professional associations, particularly of physicians, about the value of this approach, welcoming patients participation and the new partnership. It became fashionable to have self-helpers participate in expert meetings and conferences, even if only in the form of a self-help fair where the groups could present themselves by means of exhibitions and information stands outside the hall. It is questionable, however, how significant was the change in the professionals' every day practice. Occasionally, one could observe the other extreme: the abuse of self-help groups as a dumping ground for awkward and difficult patients.

The years from 1987 till 1992 can be seen as the phase of institutionalization and professionalization, when professional support of self-help groups and interested individuals was accepted as a new field of psychosocial work. Most experts agreed on the *Kontaktstellen* being the ideal method to achieve adequate support and information: a development not caused, but reinforced by a program of demonstration models funded by the Federal Ministry for Youth, Family and Health Affairs. Twenty *Kontaktstellen* were funded from 1987 to 1991 in the old western Federal Republic, and from 1992 till 1996 a similar program of 17 *Kontaktstellen* was run in the new federal states, former East Germany. The research team studying the whole process found out, in summary, that in regions with such a *Kontaktstelle,* the number of self-help groups grew, more citizens joined them, and they were longer-lasting (Braun, Kettler, & Becker, 1997). This initiative from the highest political level increased the number of *Kontaktstellen* in Germany by about 20 to 25. (Some had already existed before and were chosen to be part of the program in order to bring in their experience.) Most of these models survived the ending of federal funding, although still today there is no regular financing guaranteed for *Kontaktstellen für Selbsthilfegruppen* in Germany, and most of them rely on a patchwork funding from several sources, including states (*Länder)*, districts or municipalities, sickness fund schemes, sponsors and private donations. Fourteen of the 16 states (*Länder*) developed a policy of supporting self-help through *Kontaktstellen* since then. In a survey by the national self-help center NAKOS (Thiel, l999), these 14 *Länder* declared a total amount of 10 million DM

(approximately 5 million $) as support for *Kontaktstellen* in 1999. (Further state money went to self-help groups and self-help organizations.) Given the annual planning of budgets, this creates an almost permanent struggle, absorbing energy and resources which should be devoted to their original purpose of self-help support.

Quite a new perspective was opened through changes in health legislation (*Gesundheitsstrukturgesetz*) implemented in January 1993. The most positive results of the model programs (increase in the number of self-help groups in regions with *Kontaktstellen,* increasing number of participants, and longer life-span of groups) led to a new clause enabling "sickness funds to support self-help groups and *Kontaktstellen* with health promoting and rehabilitating objectives through financial contributions." For the first time self-help groups and *Kontakt-stellen* were recognized in law. But there were two limitations: the restriction to health-related topics, and the enabling and non-mandatory nature of the clause. In fact no insurance systems provided really significant financial support for self-help then, especially not for *Kontaktstellen*.

Looking at the matter as it affects self-help groups and organizations, the main problem arises from the fact that not all members belong to the same sickness fund, which are naturally obliged to act only for the benefit of their members. Furthermore, enabling group processes does not fit with the conventional concept of treatment of a sick individual (or even of a sick organ only) by specific medical interventions which are remunerated separately in the German system. Another difficulty arises when larger self-help organizations apply for contributions for professional staff, which calls their self-help character into question.

Sickness funds also fear being abused if they pay for *Kontaktstellen* infra-structure, considering that this should be a public responsibility. They therefore refused to fund staff salaries, office rent, etc. What they like most is to pay for well-defined small items like printing a poster or a brochure, best of all carrying their logo. They would prefer this to be combined with an advertisement for themselves in the face of intensifying competition between sickness fund schemes. Only very hesitantly have they started to sponsor, at least in some cases, the consultation services or the institution as such in a lump sum. According to a survey by the national self-help center NAKOS (Balke, 1999) 104 of the local *Kontaktstellen* have received altogether only 0.6 million DM (approximately 0.3 million $) from statutory sickness fund schemes in 1998—that's peanuts. All major sickness fund schemes have developed guidelines for implementing this enabling self-help clause. Unfortunately they concentrate only on how to handle technically applications from self-help groups and *Kontaktstellen*. Clearly, the insurance schemes do not yet understand self-help promotion as a perfect means of re-orienting their health policy from curing to caring, from high tech to high touch, from experts' dominance to patients' participation, from treatment to prevention and health promotion, from hospital to community, from pathogenesis to salutogenesis.

In Autumn 1998 the national election brought a new "red-green" coalition of Social Democrats and the Green Party/Ecologists to power. One of their reform projects was a so called "health-reform" which included a re-formulation of the self-help clause mentioned above. After long and vehement political struggles with the opposition (who dominated the *Länder* governments which are, according to our constitution, very influential in health matters) at least parts of the originally planned "health-reform" came into force on January 1, 2000, among them the section on self-help support through sickness fund schemes which says:

Code of Social Law, Book V
(Sozialgesetzbuch V)
Statutory Health Insurance
(Gesetzliche Krankenversicherung)
Section 20 (4) Prevention and Self-Help

1 The statutory health insurance fund *(Krankenkasse)* shall support self-help groups, self-help organisations, and self-help advice centres *(Selbsthilfe-Kontaktstellen)* whose aims are the prevention of, or rehabilitation of patients from, any of the diseases included in the list pursuant to clause 2.
2 The central associations of the statutory health insurance funds shall jointly adopt a uniform classification of those diseases that qualify for financial support in regard to prevention or rehabilitation; they shall involve the Federal Association of Panel Doctors and representatives of the principal associations responsible for promoting the interests of self-help initiatives.
3 The central associations of the statutory health insurance funds jointly adopt uniform principles regarding the concrete nature of support for self-help initiatives; over and above the funding of projects, grants can be given to support the activities of self-help groups, self-help organisations and self-help advice centres that are health-related.
4 The representatives of self-help initiatives specified in clause 2 are to be involved.
5 Expenditures incurred by the health insurance fund in executing the tasks specified in clause 1 shall, in the year 2000, amount to one Deutsche Mark per person insured; in subsequent years, such expenditures are to be adjusted in the light of changes in the percentage of the monthly reference amount in accordance with section 18(1) of SGB IV.
(Translated by the author.)

Now the law decides clearly that

a) self-help support is a legally required task of the statutory sickness fund schemes;
b) the budget to be invested is 1.0 DM per insured per year (i.e., over 70 million DM, approimately 35 million $ nationwide) with an annual increase according to inflation; and
c) self-helpers have to be involved in the processes of decision-making.

Of course, this is an enormous break-through, politically as well as financially. Self-help is recognized, esteemed, and financially supported on a completely new level! At least that is true for self-help dealing with health matters, prevention, and rehabilitation. Perhaps it is no coincidence that this was achieved under a she-minister, actually of the Green Party, Ms. Andrea Fischer.

To dampen possible euphoria it has to be added here that the translation into practice failed in the year 2000: only 0.2 DM was expended by the sickness funds instead of the prescribed 1.0 DM.

PROFESSIONALIZATION OF SELF-HELP

Professionalization can be observed in two corners of the self-help scene, one being in the larger self-help organizations themselves. Several are becoming service providers, more and more similar to conventional welfare organizations. Services such as medical and legal advice, visits at home or in hospitals, books and brochures with patient information, conferences and seminars, and lobbying for changes in legislation and in professional service systems are often produced or performed by paid full-time workers, mostly with professional training. Some sufferers are also involved nearly full-time in such organizations or groups as volunteers. Somewhat cynically they are described by some as "professional patients." Their whole life concentrates on their handicap or illness, and they are always ready to offer a listening ear or a helping hand. They exploit themselves (and sometimes their family) and are, deliberately or not, exploited by others, sometimes until they are burnt out. They proclaim their "sufferer competence" acquired by going through illness and crisis, in contrast to "expert competence" acquired by going through formal education and professional training.

In terms of supporting self-helpers, professionalization is also connected with the *Kontaktstellen* concept. The first generation of self-help supporters in Germany were highly qualified experts in well established institutions like university hospitals, schools for social work, counseling centers, etc. They were personally fascinated by the new self-help thinking, which was only a side-line for them, with which they were involved with joy and curiosity, feeling like pioneers exploring the unknown. They did so nonetheless from a very solid base of expertise in their traditional fields, equipped with theories and knowledge on psychopathology and psychotherapy, on coping mechanisms, on groupwork, and on the psychology of the relationship between helper and those seeking help. Since then, working in *Kontaktstellen* has become more and more an ordinary job, mostly for social workers, often young novices in the field, who fit best with the traditions of the organizations running the *Kontaktstelle* and with their desire to pay low wages. The majority of those owners belong to the so-called "free welfare sector" (*Freie Wohlfahrtspflege*), another principle specific to Germany (Matzat, 1989a). In extreme difference to American voluntary organizations, or state-run social welfare systems elsewhere, there are six large umbrella organizations in

Germany which are vested with privileges by the state. According to the so-called "principle of subsidiarity" (*Subsidaritätsprinzip*) (cf., Matzat, 1989a, p. 5), these big six have priority in providing all kinds of social services (for the youth, the elderly, the handicapped or chronically ill, the poor, the homeless, the addicts, the immigrants, etc.), run independently but largely financed by the Federal Government, by states (*Länder*), and by municipalities. Only when they show a lack of interest in doing a certain task the state is used as a stopgap. Some critics argue that the "free welfare" thereby takes the pick of the bunch, leaving the unattractive, hard-to-finance jobs to public authorities. Those who are ready to justify this system stress how competently and flexibly these organizations perform their functions and how close they are to the citizens (not quite how most people usually see bureaucratic public services). An alternative view is that these welfare organizations themselves for the most part are formalized to such a degree that to their users they appear like public agencies themselves. It is not yet clear whether their involvement in the new field of self-help support will open the gates for self-help thinking, changing their professional medical or social work on a larger scale, or will bind a new movement into a traditional system.

There is a debate about what qualifications are needed and what kind of further training should be provided for professional self-help supporters. Through *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen,* experienced colleagues offer seminars, training courses, and annual conferences. The latest stage is the development of a curriculum defining the skills which a proper self-help supporter working in a proper *Kontaktstelle* should have. It may even be rewarded with a certificate. A "state-certified self-help supporter" holding a diploma is the vision of some, the nightmare of others.

Practically all experts involved in Germany agree that adequate support for existing self-help groups or founding new groups requires attitudes and skills which are not included in traditional professional training. Leaving it to volunteers is not enough. Whereas work *in* self-help groups is seen as "expert-free," the enabling of and support *for* self-help groups is seen as a professional job. It should be done as well as possible, following certain standards, and paid for adequately. *Kontaktstellen für Selbsthilfegruppen* are on course to create a distinctive institutional image by providing such services, and by serving as a bridge between the professional and the self-help sector.

PROSPECTIVE VIEW

Looking into the future, self-help work in all its forms is on its way to becoming a small but well established element of the medical and psychosocial field in Germany. With the support of *Kontaktstellen für Selbsthilfegruppen,* small independent self-help groups will grow in number and importance, representing an effective antidote against the increasing isolation and loneliness in modern Western societies (cf., Putnam, 2000).

Nationwide self-help organizations will become even larger and form more local branches. More such organizations will emerge, developing as "service providers" similar to traditional institutions and competing with them. Consequently, they will be confronted with questions for quality assurance, a possible guise of influence from the outside. Market mechanisms will consequently gain ground, and various self-help organizations in the same field may compete with each other for members, money, and influence. But as these organizations grow and become more complex and formalized, members will generally feel more alienated from them. Some of the larger self-help organizations in Germany are already well aware of this danger and therefore are trying to establish or to revitalize small local groups in which members become directly active in their own affairs. The possible influence of interest groups like the pharmaceutical industries, hospitals, publishing houses, religious sects, etc. on self-help organizations is something to keep an eye on.

Patients' rights, independent patients' information, and patients' participation are high on the agenda in Germany nowadays. Members of self-help groups and self-help organizations will be invited as patients' representatives to all kinds of commissions, bodies, assemblies, "round tables," etc. in order to make the voice of users of our health and social care system be heard. What a chance; but also a danger that a new caste of self-help apparatchiks may emerge.

The number of *Kontaktstellen* in Germany had reached a plateau in the nineties. Maybe the availability of new resources from the sick funds and other statutory insurance schemes (see below) will bring new founders on the scene—hopefully some with the right self-help spirit, and not only fare-dodgers. Maybe *Kontaktstellen* will be detected also by other institutions as a comparatively cheap investment promising a large yield in terms of health promotion and the creation of a civil society. Anyhow, the questions of quality assurance provided mainly through further training and a clearly visible profile distinguishing them from other medical and psychosocial service agencies will come to the fore.

Furthermore, support for self-help groups by experts will in the future not only be provided through specialized *Kontaktstellen* but more and more in all sorts of service and care institutions, each in their specific field and for their specific clients. Supporting self-help initiatives will become a quality mark for social and health institutions in general. The *Kontaktstellen* should therefore encourage, support, and supervise colleagues in other institutions as they start to integrate self-help thinking and action in their services.

Other statutory insurance schemes (pension, partly also responsible for rehabilitation, and accident) will be obliged in the future to support self-help in Germany, according to a new law on rehabilitation (Code of Social Law, Book IX, *Sozialgesetzbuch IX,* Section 23) that came into force July 5, 2001.

All these processes together could contribute to a general shift of perspective in experts service systems, from deficit orientation toward more resource orientation,

from paternalism toward more partnership, from experts' dominance toward more patient participation.

One day, in the land of Utopia, experts will even appreciate being taught by their clients who are members of self-help groups and organizations, because this additional perspective and personal knowledge will make them wiser, more successful, and more human in performing their tasks.

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