Ingo Ilja Michels

3. The Role of an NGO Self-Organisation of Drug Users in Germany

Dedicated to Celia Bernecker-Welle and Werner Hermann[1]

Introduction

Addiction self-help is a very important aspect of help for addicted people, and low-threshold offers of emergency help in particular offer a helping hand to people who often find themselves in a desperate life situation. Self-help has long since emerged in the health-care system as a component of social and health-related support systems, which were essentially conceived as accompanying support to medical treatments and, with regard to the problem of addiction, as support systems for maintaining abstinence and surviving thet long-term negative effects of substance use disorders.

In Germany, the self-organisation of drug users took place with substantial support from the German AIDS Help (Deutsche AIDS-Hilfe DAH) organisation, a nationwide network of groups primarily from the gay community that advocate for HIV prevention and against the discrimination of people with HIV and AIDS. This public health approach also received government support because the substantial importance of self-help for health prevention and treatment success, especially among marginalised groups, is widely recognised in the professional world, in accordance with the World Health Organisation (WHO) principles on the role of self-help in the health sector (Kickbusch 1983).

1 Both had been members of self-help groups of drug users, both on methadone treatment, and both died from AIDS (Cecilia Bernecker-Welle1957-1993; Werner Hermann 1942–1997). Werner Hermann was coordinator of JES self-organisation under the umbrella of Deutsche AIDS-Hilfe (DAH); Cecilia Bernecker-Well worked with the Munich AIDS service organisation.

The History of Non-Governmental support for prevention and treatment of drug use disorders

The history of the role of non-governmental organisations in the prevention and treatment of substance-related problems (especially those related to alcohol and opioids) in Germany is closely linked to the development of HIV infections among drug-using people in the mid-1980s. Because the government was facing a rapid increase of HIV infections, the decision was made to financially support the self-help of those affected by the epidemic and to include them in state programmes. This had already been the case before, but now there was a clear understanding that the state could only gain access to this group and prevent the spread of HIV/AIDS to the general population by involving those affected and their representatives in preventive activities. The example of the commitment of the gay community, which has grown stronger in Germany with the support of scientists and well-known artists and political representatives, also led to this insight. The role of civil society and NGOs plays a central role in a democratic social structure not only in Germany but throughout Europe. This is expressed not least in the EU Parliament resolution of 2008.

In April 2008, the European Parliament passed a resolution on the Green Paper on the role of civil society in drugs policy in the European Union (European Parliament 2009). In this resolution, the European Parliament "acknowledges the fundamental role of civil society in supporting the development, definition, implementation, evaluation and monitoring of drugs policies, in terms of information exchange and best practice, scientifically tested and documented in the actual application of drugs policies. […] insists on a strengthening of the role played by civil society in developing a drugs policy embodying a European approach and stresses the importance of setting up the Civil Society Forum on Drugs as a first step towards the more practical and constructive involvement of European civil society associations in EU activities relating to policies to prevent drug use and combat drugs."

The EU Commission has set up a drug policy advisory board, the so-called "horizontal drugs group", with monthly meetings of government representatives from the areas of home affairs and health

to develop drug policy guidelines. The EU Parliament has also set up a "Civil Society Forum on Drugs" which includes representatives from addiction and drug-specific non-governmental organisations. The European Parliament is of the opinion that the Civil Society Forum on Drugs should be inclusive rather than exclusive, representing a wide spectrum and variety of views, not to create an assembly intended to voice various ideologies but rather to engage in a dialogue on European drug policy, holding of an annual conference and cooperates with the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA). It calls on the Member States, where possible, to extend provisions concerning state funding to services provided by civil professional organisations and stresses how important it is for society to set aside funding to support voluntary organisations and parents' associations committed "to combating drug abuse, particularly among young people".

This resolution is an important step for the involvement of civil society organisations in the decision-making process surrounding the implementation of European drug policy.

A wide range of civil society organisations (CSOs) such as drug-user groups, non-governmental/third sector organisations, and networks of existing organisations, seek to shape the development of drugs policy at both national and international levels. However, their capacity to do so is shaped by the contexts in which they operate nationally and internationally. Civil society involvement (CSI) in policy decision-making and implementation is acknowledged as an important aspect of representative democracy (O'Gorman/Schatz 2020).

In the field of drug policy, a diverse range of civil society stakeholders bring a variety of experience, knowledge, and perspectives to the drug policy debate based on peer, professional, and public policy expertise (see also: Council of Europe 2009; O'Gorman et al. 2014; Greer et al. 2017).

Non-state political actors are increasingly forced to engage in discourse now more clear. under predetermined premises. "The actions of NGOs (and thus also of movement organizations) is supported by legitimacy charging of "dialogical procedures" and "formal organization" is framed and co-determined. NGOs are both producers and product of the generation of these new hegemonic conceptions legitimate forms of practice and protest" (Stickler 2005, p. 376). Non-

governmental organisations are involved in dialogic processes that make spontaneous and emotionally driven action difficult.

The inclusion of NGOs in political decision-making processes legitimises political action, especially in the area of development cooperation, which is based on the constitutional foundations of a humane society that should also be available to people in non-democratic structures. Friedrich Kitschelt (former State Secretary in the German Federal Ministry for Economic Cooperation and Development)[2] formulated the principles of German development cooperation fundamentally through the constitution: "This is the idea of Article 1 of our Basic Law: "Human dignity is inviolable." Everyone has the right to a life in dignity – whether they were born in Germany or somewhere else in the world. Everyone counts, no one should simply be left behind. Secondly, this is linked to the idea of subsidiarity, i.e. the belief in the responsibility and abilities of each individual or, for example, the family. For development policy, this means creating space for private initiative. […] This results in an indispensable role for civil society, business and churches in the development process of our partners. This does not mean that the state and state development cooperation can or want to shirk responsibility. Rather, it means "helping people to help themselves." Thirdly, subsidiarity is complemented by solidarity, i.e. human cohesion. […] Since its founding, the Federal Ministry for Economic Cooperation and Development has worked with development non-governmental organizations (NGOs). […] On the other hand, NGOs are also critical […]. They observe and comment on state policy and economic activity, draw attention to deficits, bring into play the needs of socially and politically disadvantaged groups, advocate for the interests of society as a whole and future-oriented ("advocacy") and formulate alternative policy proposals" (Kitschelt 2017).

These principles also apply to health and drug policy in Germany, especially against the background of the UNGASS resolution from 2016. It is always the form of contemplation that makes a glass appear half-full or half-empty. For the one, the UNGASS

2 The Ministry is actually financing the DAAD project SOLID (social work on the prevention and treatment of drug addiction, with the main focus on the role of NGOs) as part of the implementation of the Sustainable Development Goals (SDGs). See: www.solid-exceed.org

(UNITED NATIONS GENERAL ASSEMBLY SPECIAL SESSION ON THE WORLD DRUG PROBLEM) General Assembly from 19th to 21st April 2016 in New York was a bitter disappointment, whilst for others it was a big step forward. UNGASS launched a final declaration, which had already been negotiated at the UN Commission on Narcotic Drugs (CND) in Vienna: "We reaffirm our commitment to promote the health, well-being of the individual and the well-being of all people, families, communities and society as a whole, and to facilitate a healthy lifestyle through effective, comprehensive demand-reduction research based on scientific knowledge." "Drug dependency must be seen as a complex, multifactorial health disorder characterized by a chronic and recurrent nature with social causes and consequences that can be prevented and treated, including through effective medical treatment based on scientific evidence, aftercare, treatment and rehabilitation programs, including community-based programs" (UNGASS). It is new that a "drug treatment" of this kind, which in this instance refers to opioid substitution treatment, is part of a document supported by all Member States, but with the restriction that this should be "in accordance with national legislation", which leaves the back door open, not to implement this effective measure.

In many statements, mainly from countries in Latin America, such as Columbia and Uruguay, but also from Canada, some European countries such as the Czech Republic, Greece, the Netherlands, and Portugal, or statements by Kofi Anan, Secretary General of the UN, the end of the "war on drugs" has been called for. The focus of drug policy must be on prevention and treatment, not on prosecution (which is meant by "war on drugs"). What are the future challenges for international drug policy and what is the German perspective in this regard?

Germany and its European partners have been content with the UNGASS outcome document, although it does not meet all expectations especially from civil society. That said, it has a guiding character that can be used in the years to come to help facilitate progress in international drug policy. Germany particularly supports the chapter on alternative development and related socio-economic issues. Incorporating a comprehensive and free-standing chapter on the broad range of development interventions in the framework of drug policies has been a priority for both Germany and the EU. The

principles of shared responsibility and a balanced approach require a sound set of development policies in order to address the root causes underlying the global drug problem in a sustainable fashion (Michels 2016).

The AIDS Crisis in Germany as a Catalyst for the Development of the Self-organisation of Drug-User Groups

The birth of the self-help network JES (Junkies, Formers, Substitute users) in 1989—as well as the development of the philosophy of harm reduction (Michels/Stöver 2012)—was due to the fact that in the mid-1980s, the number of HIV infections among injecting heroin users in Germany increased substantially. The AIDS crisis created threat scenarios, as sexuality and drugs are always dealt with within the framework of non-rational discourse. Sexuality and drug use are often denounced as uncontrollable that lead to careless behavior that causes infections with sexually transmitted diseases. Instead of focusing on education and harm-reducing measures such as the distribution of condoms and sterile syringes, drug use is also often viewed as an instinct-driven behaviour that increases the risk of infection.By the end of the 1980, it was clear that this crisis could only be overcome if the main groups affected in Germany—gay men and drug users—were not included in prevention measures. This meant that socially marginalised lifestyles shall be taken into account and not simply sexuality or drug use behavior, so that this mihght be the basis of successful prevention strategies.

Mobilising Self-Help Resources

In 1986, three years after the founding of the network German AIDS Help (DAH), the drug and penal system department of DAH was also set up, at a time when the self-help aspect of interventions in drug scenes had been thought of but not yet implemented. In those years, there were structural and ideological obstacles to successful prevention (which is still the case today). Since the spread of this life-threatening infection in this group could not be contained with-

out the distribution of sterile injection equipment, political action had to be taken. However, the legalisation of the administration of injections was only achieved with the change in the Narcotics Act in September 1992. In 1989, the DAH began to specifically promote the process of self-organisation among people who use drugs. Meetings and seminars were primarily used to mobilise self-help resources, one of which, held in Hamburg in 1989, led to the founding of JES. In 1990, Werner Hermann was hired by the DAH. He was an expert in the area of drug self-help who knew from first-hand experience (he was a drug user himself, now in Methadone treatment) about injecting drug use, as well as about the everyday threat posed by HIV and AIDS.

The Model of AIDS Self-Help

When it comes to healthcare, self-help has long been part of the social and health-related help system in Germany, but it was essentially seen as support for medical treatment or—in the area of addiction—to maintain abstinence. However, the self-help of affected drug users in the context of HIV/AIDS was understood differently. The role model here was the commitment of gay men in the context of assistance for people living with HIV (PLWH). This was not just about participation in the tasks of established health services, but above all about leading a self-determined life with HIV and AIDS, by promoting subcultural social structures, the acceptance of all lifestyles, avoidance of moralising messages in prevention work (especially with regard to safe sex in view of sexual wishes and desires), psychosocial and everyday practical support for infected and sick people to preserve autonomy and human dignity, and support for a humane dying process. In Germany, this policy also helped with the development of the hospice movement.

AIDS self-help always saw and continues to see itself as emancipatory and, in this sense, also exerted an influence on the healthcare system—it reduced the reliance on medicine and the dominance of medicial approaches and helped in the development of innovative approaches to counselling, support, and care, passing it on to actors in other healthcare fields. Nevertheless, due to public funding, self-help has always been integrated into bureaucratic structures and

processes. However, the AIDS help movement opposed the instrumentalisation by state control bodies and did not allow them to intervene into the areas of gay lifestyle and gay identity.

In 1989, the social scientist Horst Bossong identified five types of drug self-help:

1. ritualised, less risky forms of drug use (ritualised drug use includes phases of reflection on pleasure-oriented consumption, rather than simply seeking to prevent withdrawal symptoms);
2. limiting your own drug consumption with self-initiated forms of quitting consumption (self-initiated reduced consumption, rather than merely unsuccessfully attempting to simply stop consumption due to pressure to abstain);
3. self-managing housing projects of the release groups (self help groups named "realease") as counterproposals to the institutionalised therapeutic facilities; (in therapeutic communities, dependency relationships can be extended, which can make it difficult for individuals to act independently and stand on one's own feet again);
4. self-help programmes to stabilise abstinence (e.g. Narcotics Anonymous) as a supplement to the professional help system (in which self-desired abstinence is supported in groups);
5. mancipatory and autonomous self-organisation (such as Synanon, which is the major residential self-help organization (SHO) for drug dependent individuals in Germany) or identity-forming self-organisation (e.g. the drug user associations in the Netherlands, which called themselves "Junkiebond" or later JES in Germany), also with commitment to addiction- and drug policy.

As Bossong worked as the drug policy commissioner of the city of Hamburg, he had influence on the development of the drug help system in this city. It was decided that professional institutions had to better document their activities and systematise the training of their employees. The organisations of those affected were also given a greater voice in the development of political and professional decisions. However, this claim cannot always be implemented as originally propagated, either because the political will for a comprehensive reform of drug policy is not sufficient to defuse the fundamental criminalisation of the consumption of psychoactive substances

that have been declared illegal (such as opiates or stimulants) or because financial resources have become increasingly limited in recent years. The United Nations' policy of prohibiting these substances has largely continued, although the demand for respect for human rights for people who use drugs is increasing and a number of countries have taken steps towards decriminalisation, such as Portugal (Rego et al. 2021).

Against this backdrop, AIDS-specific self-help represents the culmination of a development in which awareness of the disease has been increasingly linked to the commitment to improve health policy. Werner Hermann[3] summarised this as follows: *"Despite all the difficulties associated with the AIDS crisis among intravenous drug users, despite all the suffering, despite illness and death – what is the central consequence for health policy? I think that it is the opening of health services to self-help and to the recognition of the skills of those affected to a degree that is unprecedented in the history of medicine. And that is why this opens up incredible possibilities for a reorientation of the somatically oriented medical system towards a holistic health policy …"*.

Werner Hermann was convinced that the drug- and AIDS self-help network would lead to a paradigm shift in the professional drug-help system and enable it to perceive a drug-free life as equal to a life with drugs and acceptance-oriented healthcare and to create appropriate offers for drug users who did not want to submit to the abstinence requirement.. The drug self-organisation JES (for junkies, ex-users, and substitute users), which did not exclude people who were still using drugs) and was then supported by many drug services and AIDS help organisations.

3 Werner Hermann was the first drug self-help organisation coordinator employed by the German AIDS Help organisation; he was a former Heroin user and was later in a methadone program and he was therefore no longer prosecuted because he did no longer use Heroin from the black market but the opioid Methadone in a medical treatment. However, he did not advocate abstinence for people who consumed illegal drugs.

JES Guiding Principles

HIV prevention alone, through the distribution of sterile injection equipment, the establishment of drug consumption rooms, substitution treatment, and diamorphine-supported treatment is not enough. It must instead be linked to a commitment against exclusion and marginalisation of people using illegal psychoactive substances and to the advocacy of the rights and dignity of people who use drugs., of which the acquisition and possession of which is not permitted.. The founding document of "Junkies, Ex-Users and Substitutes" expresses the philosophy of drug self-help in the following words (JES 1989):

> *For a decent life with drugs …*
>
> *… is our guiding principle: We want to create social conditions under which people can live humanely, even with drugs: without the threat of criminal prosecution, without exclusion and permanent disadvantage.*
>
> *… is the lowest common denominator, binding for all groups in the JES network and the basis of our joint work.*
>
> *… should not be misunderstood as an invitation to consume drugs. We know full well that living with drugs under current social conditions is often associated with illegality, discrimination and health risks. We also respect the right of every individual to choose whether or not to use drugs. We are therefore far from idealizing and propagating drug use.*
>
> *… however, for us, it means supporting drug users by working towards appropriate framework conditions, by imparting knowledge and encouraging them to develop skills and competencies in order to avoid self-destructive drug use (safer use). In this sense, our work is always work on the development, stabilization and transmission of a drug culture that is oriented towards use with self-imposed rules. Such rules are intended to enable a lifestyle that does not harm anyone, but rather enables independence, self-respect and joy in life* (Barsch 2018).

The Contagious Nature of Self-Help

Today, JES is a stable network. There are JES activists who meet with like-minded people There had been also international meetings with drug user groups from England, the Netherlands, Australia, and Eastern Europe, supported by the Deutsche AIDS Hilfe. Drug self-help is contagious: all over the world, whether in Iran, India,

Ukraine, China, Indonesia, Thailand, or Malaysia, such approaches are emerging in the epicentres of HIV disease and intravenous drug use. At international conferences on the topic of harm reduction, spaces are provided for self-help meetings and activists have been invited to be speakers and discussion partners. The importance of self-help is being recognised. Overall, civil society and non-governmental organisations and representatives of self-organisations of drug users are playing a greater role in defining the objectives of drug policy in Europe, even if their influence is still small. The slogan "No decision about us without us", which plays an important role at conferences on the HIV/AIDS problem in particular, is still relatively unknown outside of this sphere but should be included in the into international drug policy in which those involved should be heard.

Conclusions

The support of an active self-help movement of (active and substituted) drug users by professional AIDS and drug assistance facilities and their committed employees was an important activity for the inclusion of people affected by HIV/AIDS, not only to improve their (survival) situation but also to point out the socio-political situation of these people who have been and continue to be criminalised and discriminated against and to change the current legal obstructive laws and measures. This policy was adopted by the gay community, especially in Germany and other European countries. Help was largely provided by social workers, who define their work not only in the professional counselling setting, but also as a drugs- and socio-political task.

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