

A Model for Nationwide Coordination and Partnership



The National German AIDS Organization



Deutsche AIDS-Hilfe e.V.,

©

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Deutsche AIDS-Hilfe (DAH)

The Deutsche AIDS-Hilfe (DAH) was founded in the early eighties (1983) as a result of the AIDS-Hilfe movement in Germany, in response to the growing epidemic. The DAH combines self-help and service functions under one roof, including prevention and education initiatives. The theoretical basis for the work of the DAH is the health promotion strategy of the WHO (Ottawa Charter 1986). Health and illness are no longer seen as being problems only of the body, but as psychosocial problems, as well.

In Germany the AIDS prevention campaign is implemented by the Federal Center for Health Education (BZgA) and the DAH. In this sharing of responsibility between the private and public sectors, the Federal Center provides information for the general public; whereas, the DAH focuses its efforts on producing materials specifically for groups most affected by the epidemic (gay men, drug users, and women who are marginalized in society).

AIDS work in Germany is financed at all levels (national, regional, and local) primarily by public funding.

The DAH, located in Berlin, is the umbrella organization for some 130 AIDS-Hilfe groups in Germany. With approximately 6000 volunteers and 500 paid staff, these groups constitute a comprehensive, non-governmental network. Under a division of labor between the local and national levels,

The following tasks are performed by the DAH:

- Planning for prevention and education initiatives
- Initiating and supporting the organizing of people with HIV/AIDS
- Developing strategies for medical and psychosocial services
- Developing, producing, and distributing educational materials
- Providing in-service training and continuing education for volunteer and professional staff of the local groups.
- Performing public relations work
- Providing advocacy and representation for local groups
- Representing political interests at the national level

The tasks of the local AIDS-Hilfe groups include:

- Setting up self-help and discussion groups for people with HIV/AIDS and their significant others, including safer sex discussion groups
- Distributing educational materials
- Providing education and counseling for gay men and drug users in places frequented by these groups
- Caring for people with HIV/AIDS at home, in hospitals, in prisons, and in drug rehabilitation centers
- In-person and telephone counseling for various populations
- Prevention and education sessions for various groups
- Local public relations work

Mission Statement of the Deutsche AIDS-Hilfe (Board of Directors)

Guiding Principles

The following principles are guidelines for the national office and for the member organizations of the DAH, regardless of the various differences found within the membership. These principles are to be operationalized through the planning and implementation of appropriate programs and campaigns.

The Foundation for the Work of the DAH: „Structural Prevention“

In accordance with the WHO Ottawa Charter of 1986, health and health promoting behaviors are not only the result of individual decision-making, but are the product of political, social, and cultural factors. Prevention strategies which concentrate solely on the illness itself, thereby ignoring these other factors, are destined to fail. Preventing risk behaviors cannot be separated from strategies to

The Deutsche AIDS-Hilfe...

...safeguards the interests of people with HIV and AIDS and of the main groups affected

address the larger context in which these behaviors occur (in German: Verhaltens- und Verhältnisprävention). Therefore a focus on the person and the realities of his/her daily life is imperative.

Central to prevention work is empowerment of the individual and his/her community or subculture. This is accomplished by promoting:

- Unity over isolation
- Information over ignorance
- An active instead of a passive role on the part of those affected
- The development of uniqueness and diversity instead of conformity
- The articulation of one's own needs instead of the intervention of others

The DAH is a Political Organization

The DAH represents the interests of people with HIV/AIDS and of those at risk for infection. Given the current social and political structures, the DAH must define itself in terms of the needs of the most powerless segments of its constituency; namely, those experiencing discrimination and legal persecution. Therefore, the groups most central to the work of the DAH are gay men, drug users, and women who are marginalized in society.

As a political organization the DAH:

- Promotes human dignity
- Fights against discrimination, marginalization,

- and exclusion
- Protects against elements of society which promote extremism or threaten community
- Maintains a fundamentally oppositional stance which is both socially and politically critical of the current order

The DAH is a Self-Help Organization

All services and activities are structured to give all people with HIV/AIDS the strength they need to live openly, to act in their own interest, and to assert their needs. The establishing of networks and other structures by and for people with HIV/AIDS must be supported ideologically, financially, and with adequate human resources. In building these networks and other structures, the existing social support systems must be taken into account.

The Deutsche AIDS-Hilfe...

**...fights for the protection of human dignity ,
for cultural variety and for social policy
which aims at human living conditions**

The DAH sees as its task:

- The building of community and solidarity within society
- The protection, promotion and stabilization of existing social support systems

The DAH is a Professional Organization

As a professional organization the DAH develops standards to assure quality at all levels of service (prevention self-help and care for those affected). This is done on the basis of research findings and practical experience. In this way, professional competencies are combined with the expertise of those affected.

Through the national office the DAH offers printed material and continuing education for those working in the field of AIDS, providing a foundation for the successful work of the local AIDS service organizations.

The Relationship of the DAH as Umbrella Organization with its Member Organizations

Firstly, it is important to recognize that the members of the DAH are autonomous, independently incorporated organizations. Each member has a unique history and reflects a particular regional situation, resulting in a broad diversity within the membership. Central to the discussion is the question: Do the member AIDS service organizations need to be active at all levels of service (prevention, selfhelp, and care) and for which populations?

In reality, the member organizations do not provide the full spectrum of services, nor must they. In many cases the work has been focused on particular areas, with certain aspects of AIDS work being carried out by other organizations with whom partnerships have been formed. But although certain tasks can be „delegated“ to others in the field, the responsibility remains that of the member organizations to assure that all levels of service are provided locally. A member organization cannot and must not assume that a certain need regarding HIV/AIDS is being covered by some other body or organization until they have determined that the need is, in fact, being adequately addressed.

Member organizations make themselves available to all segments of the population. Exactly who is served is influenced largely by circumstances particular to a given region or locality. However, the original target groups of the AIDS service movement may not in any way be neglected. These groups are gay men, drug users, and women who are marginalized in society.

At the national level the Deutsche AIDS-Hilfe acts as a political interest group and professional organization, representing the needs of the original target groups within the context of the general population. The national office is active on every level of service, although, at any given time, there may be a focus on particular areas of need.

The above understanding of the relationship between the national and local levels is based on „structural prevention“,

which does not allow us to separate the individual from the societal situation, nor prevention activities from other levels of service. This understanding is also the result of the political nature of our organization. Above all else the Deutsche AIDS-Hilfe sees as its role the provision of prevention and other services to the primarily affected groups in Germany. Should the DAH lose its image as an organization for „the undesirables“ of society, it would lose the creative fire which has resulted in its success to date. It would become a meaningless structure, no longer being able to act in a political capacity for those most in need.

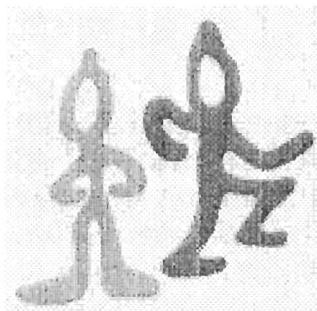
At the same time we clearly recognize that even within the primarily affected groups there are subgroups which need to be taken into account: Gay men do not constitute a homogenous group. And we cannot limit our work with drug users to those who use intravenous drugs.

The Deutsche AIDS-Hilfe...

...provides training for the staff to guarantee professional councelling, care and nursing, care according to lifestyles and habits

The Networks

In the following we describe the three networks in Germany, which were founded in the last years:



The HIV+ Network

This is a network by and for people with HIV/AIDS in Germany, representing their needs within the AIDS service movement and in society as a whole. It was founded in May 1996. This network is self-sustaining and functions independently of all other organizations and bodies working within the field of AIDS.

Das Bundesweite Netzwerk von
Menschen mit HIV und AIDS
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J E S

Drug-users - like all other men and women - are entitled to a life of human dignity. This right is unconditional, regardless of whether or not the person is abstinent from drugs or whether or not he or she complies with expected norms of behaviour.

Not until the beginning of the AIDS epidemic were the prevailing moralistic drug policies in Germany called into question. In 1989 the self-help group JES was founded (Junkies, Ex-Junkies, Substituerte). Now with fifty member groups nationwide, JES is involved in various activities to organize junkies nationally. Workshops are held on HIV prevention, health education, and organizational issues. Although people using drugs are still often considered to be out of control, criminally involved, and antisocial, JES has been able to gain recognition because of the competence of the staff and volunteers working for the organization. The Speakers Council, which functions as a board of directors, manages the organizational structures and political activities of JES, participating actively in public debate at both the national and local level.

JES is, however, not yet generally recognized as an important partner in developing HIV prevention strategies and drug policy. Instead, it is more often seen by the authorities as a disruptive group which needs to be kept

under control. For example, the Federal Central for Health Education, dependent on the Ministry of Health for funding, took action in 1992 against the „Safer Use“ information being distributed.

Major activities of JES take place in connection with HIV prevention and living with AIDS. Sixty thousand copies of the brochure „Safer Use“, produced by JES, have been distributed to IDUs by JES groups and other organizations. Except for the workshops which are run in collaboration with the Deutsche AIDS-Hilfe, there is no funding by the Ministry of Health or any other central organization. Regional and local authorities are more likely than the federal government to contract with JES member groups to run drop-in centers, needle exchanges, and information services, and to consult JES regarding drug substitution programs. JES has recently taken on more creative tasks such as all-night needle exchanges, needle and syringe recycling, and a successful program for codeine substitution in Berlin and several other cities.

The JES network in Germany is a unique achievement!

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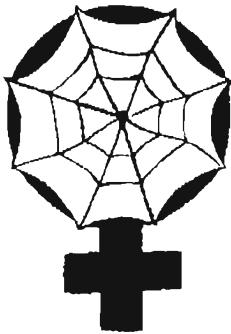
HIV/AIDS- KEY DATA AND TRENDS

Epidemiological Summary Information from the AIDS Center of the Robert Koch Institute

First Quarter, 1998

A synoptic overview and extrapolation of the available data as of the end of March 1998 regarding the epidemiology of HIV and AIDS in Germany:

HIV Infection	AIDS Cases
Estimated total number of infections since the beginning of epidemic: 50,000-60,000	Percentage of all AIDS cases actually reported: >85% Total number of reported cases since 1982: 17,283 Number of deaths among reported cases: 11,099
Distribution by Gender: Men: ~ 80% Women: ~ 20%	Distribution by Gender: Men: 89% Women: 11%
Children under 13 years old: ~ 500 cases (1% of total)	Children under 13 years old: 114 (0,7%)
Number of new infection per year: 2,000-2,500	Number of new AIDS cases per year: ~ 1,000
The currently most important means of transmission: homosexual contact between men: ~ 55% IVDU: ~ 15% heterosexual contact: ~ 13% persons from Pattern II countries: ~ 17% vertical transmission (mother to child): < 1%	Means of transmission (for cases diagnosed over the last year) homosexual contact between men: 52% IVDU: 12% heterosexual contact: 10% persons from Pattern II countries: 7% Hemophiliccas: 1% blood transfusions and blood products: 0% vertical transmission (mother to child): 1% no response: 17%
Regional Distribution: 53% of all HIV infected persons live in the major metropolitan areas of Frankfurt am Main, Munich, Berlin (West), Düsseldorf, Cologne and Hamburg. 45% of all HIV infected persons live outside of the above cities and within the former West Germany. In the former East Germany there have been 1,200 HIV infections diagnosed (2% of total cases).	Regional Distribution: 53% of persons with AIDS live in the major metropolitan areas of Frankfurt am Main, Munich, Berlin (West), Düsseldorf, Cologne and Hamburg. 45% of all cases are outside of the above cities and within the former West Germany. In the former East Germany there have been 322 AIDS cases diagnosed (2% of total cases).
Trends: As has been case throughout the epidemic the largest number of new infections continues to occur by way of homosexual contact between men. The rate of new infections among IVDUs is stabilising. The number of infections due to heterosexual contact continues to rise slowly. Heterosexual transmission is largely the result of sexual contact with members of the primary risk groups. Transmission among groups of heterosexuals independent of contact with the primary risk groups has been infrequently reported up to this point. In the former East Germany the number of HIV infections is at a very low level, but is rising slowly. In the former West Germany the regional distribution of new infections remains stable, reflecting the distribution of the groups engaging in high risk behavior.	Trends: Due to the recently considerably improved therapeutic possibilities, the span between HIV-infection and the onset of AIDS-defining diseases has significantly increased. Thereby the number of newly diagnosed AIDS-events decreases also significantly - at least transient- (1997 to approx. 1.000 prospectively). The number of patients to be taken care of with progressed immune-deficiency will be increasing through prolonged survival-times and constant numbers of new infections. Also a further increase of survival-times as well as changes within the spectrum of immune-deficiency-primary-manifestations are to be expected.



Women and AIDS Network

Although the rate of HIV infection for women in Germany is steadily rising, women are still not given the attention they deserve and services are often inadequate. Women with HIV/AIDS come from very diverse segments of the German population; they do not belong to one homogenous group. The Women & AIDS Network is a nationwide joint operation by and for women with HIV/AIDS and for women who work in the field. The Network is also a political action group for women with HIV/AIDS.

The Network was founded in 1992 by a small group of active women. Today there are more than 100 women from all over Germany connected to each other. The Organization strives to create a network of local centers and a lobby for HIV-infected women. It is open to all interested people and serves to collect and distribute information, create projects, and exchange experiences on the topic Women and AIDS. The network produces a newsletter, DHIVA. It also runs seminars and work groups on various topics (public relations, drugs, lesbians, law, medicine, prevention), as well as

developing policies and politics around women, HIV/AIDS. It puts on workshops and conferences.

The organization's work includes the creation and expansion of an information pool on women and HIV; the promotion of various approaches to prevention; counselling and self-help specifically for women; support of medical research and psychological care geared to meet the specific needs of women; and the formation of a political forum.

During 1997 the Network's major efforts have included research into Femidoms - the 'female condom'. At this stage of its development we do not recommend the use of Femidoms due its user unfriendliness, its cost and material composition. However, we continue to collect information and scientific findings on it. We have also focussed on socio-political questions. For instance, if women use Femidoms, are they yet again solely responsible for the prevention of AIDS, STDs and pregnancies?

The Network attempts to confront the German 'Women's Movement' with the subject of women, HIV/AIDS. We try to create a conversation with feminist groups and unions and are involved in celebrations and actions around International Women and Lesbian Pride Day on March 8th. We always want to incorporate discussions about the quality of life for women living with HIV/AIDS into our work.

Women with HIV/AIDS have become more and more public in Germany and now do a lot of intensive media work. Interviews in the newspapers or magazines, participation in TV talk shows, all tell the public about positive women's living situations and about their wishes and expectations.

Recently, the AIDS movement in Germany has started a debate about whether or not it should be participating in the 'disability movement'. The network is still discussing what it's point of view is and if participation is useful, what would it look like in practice. Our work is wide ranging, continuing and necessary.



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The Departments

Department for Coordination to Member Organizations, Fundraising, Press and Public Relations, and International Relations

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This department is responsible for all requests of the member organizations of the Deutsche AIDS-Hilfe.

It's also responsible for fundraising, it seeks to augment the public funding received by the DAH with financial support from non-governmental sources.

Another task is the responsibility for working with the press and other communications media to promote the work of the DAH. This includes lobbying and advocacy at the national and local levels.

This department establishes and maintains contact between the Deutsche AIDS-Hilfe and other non- 21

governmental AIDS organizations in europe. This includes representing the DAH at the national and international level and organizing the exchange of expertise between our members and their colleagues abroad.

Department Women and AIDS

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This department was created in 1992. Women in Germany are affected by HIV/AIDS in various ways: as people living with the disease; as mothers, partners, and family members of people with HIV/AIDS; and as workers (for example, within the helping professions). We recognize that women lead a variety of lifestyles and that roles and priorities can change over time. In this department we acknowledge the various situations in which women live and we seek to provide appropriate information and support to women affected by HIV/AIDS. Most important are services provided to women living with HIV/AIDS themselves, including printed materials, workshops, and training. Women living with HIV/AIDS are included to the fullest extent possible in the design and planning of all our activities. International contacts and the sharing of information are essential components of our work.

Department for Drug Users and People in Prison

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The diverse responsibilities of this department include political work within national and international commissions, providing education and information, and advocating for the needs of drug users and people in prison. The latter is done in close collaboration with the national association by and for drug users and former drug users (JES). In addition to the production of printed materials (posters, brochures about safer sex, safer use, and prison life), we offer comprehensive training programs. We bring together professional and volunteer workers from the drug treatment drug user, and AIDS service movements as well as people from the target groups themselves with their significant others.

Department for Gay, Bisexual Men, and Hustlers

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This department is responsible for the production of prevention materials which are distributed nationally to reach the target groups of gay and bisexual men as well male sex workers and their clients. Among gay men there are several subgroups to be reached: men who are coming out, men in relationships, the leather and S/M communities, gay immigrants, etc. The materials produced range from indepth information to pamphlets, posters, and giveaway items (coasters, pens, matches, etc.). The subject and design for the specific materials produced are based on national and international research findings, successful prevention campaigns in other countries, and the experience of our members. We organize workshops for

the target groups to promote personal development (e.g., coming out workshops) as well as courses for counselors and others working with the target groups (e.g., outreach workers, peer counselors). In addition, meetings are organized to promote joint action and the sharing of ideas (e.g., meetings for bisexuals, older gay men, gay immigrants) in accordance with the concept of „structural prevention“ which is the basis of the work of the Deutsche AIDS-Hilfe (see Mission Statement).

Department for People Living with HIV/AIDS

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This department focuses on the needs of people living with HIV/AIDS. Various printed materials, workshops, and training opportunities are offered, providing information and support relevant to improving the quality of life for those living with the disease. In addition, we collaborate with the other departments of the DAH to ensure that the policy and products of the organization reflect the needs of those most directly affected by HIV/AIDS. We also are involved in political organizing and policy work at the national level to give people with HIV/AIDS a voice within decision-making

structures and to build unity and solidarity among all Germans living with the disease. An important service of this department is organizing the annual National Conference of People Living with HIV/AIDS, which serves as a focal point for HIV activism in Germany.

Department for Medicine and Health Politics

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This department is responsible for the biomedical information released by the Deutsche AIDS-Hilfe. We therefore focus on providing information services as well as educating individuals involved in AIDS work. Information is provided predominantly in the form of brochures, leaflets, and periodicals (e.g., a German language version of „AIDS Treatment News“ and a publication called „Therapien bei AIDS“). The opportunities for training consist of general courses on biomedical issues and workshops regarding more specialized topics (e.g., alternative medicine, nutrition). In addition, the department is available to respond to members' individual concerns, answering questions about new developments in the treatment of HIV

and how the virus is spread. Finally, we represent the Deutsche AIDS-Hilfe regarding medical and health policy issues, including the practices of pharmaceutical companies and the design of clinical studies.

Department for Nursing and Healthcare

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Languages Spoken: German, English

The focus of our work is improving the quality of life for people with HIV/AIDS in need of nursing care and to provide support to their significant others. Caring for someone with HIV/AIDS means, most importantly, seeing the person as a whole and allowing that person to speak for him/herself. We believe in a needs-oriented approach to providing care, thereby promoting people with HIV/AIDS to assert themselves within the health care system. We understand caring for the sick as being a professional service provided to people living with sickness, disability, and the process of dying. Here at the national office we service the local and regional nursing agencies and ASOs by offering technical

support and consultation. We advocate for the needs of AIDS patients and their significant others in society, particularly among professionals in the fields of homecare and nursing.

The goals and objectives of our work are: Expanding and supporting the appropriate infrastructure to address the psychosocial and nursing care needs of people with HIV/AIDS.

We seek to do this by: supporting patient-centered, innovative models for care; promoting need-based models, as developed by the DAH, at the national and international levels; promoting collaboration between providers in the field of AIDS care and other organizations and political bodies so as to improve the current infrastructure and to promote a political discussion of carerelated issues (longterm care insurance, national healthcare regulations, quality assurance, etc.).

Department for Psychosocial Issues and Continuing Education

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This department organizes continuing education on various topics for the 130 regional AIDS service organizations who are members of the DAH. Through more than 60 workshops and trainings per year, the personnel of the local groups are prepared for the typical problems and tasks encountered in their daily work. The course offerings are published twice yearly and cover a broad spectrum: from orientation for beginners to specialized certificate-training programs. Management courses focusing on nonprofit structures, personnel, and volunteers ensure the long-term development of our member organizations. Given the unique problems encountered in training AIDS staff and working in ASOs, a special train-the-trainers curriculum has also been developed.

In fulfilling the role of the DAH as a professional organization, this department also produces books in collaboration with academic publishing houses. Through these publications we seek to influence the discussion concerning various AIDS-related topics.

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In close collaboration with the other departments of the DAH

Deutsche AIDS-Hilfe, we design printed materials and develop messages for primary prevention. The focus and content of prevention messages for specific target groups are primarily the responsibility of the appropriate department; however a portion of the materials produced by the Deutsche AIDS-Hilfe are our direct responsibility. These include the brochures regarding the basic facts about HIV/AIDS (Heutiger Wissensstand), World AIDS Day, and prevention through safer sex (Vorbeugen - Safer Sex). These materials are designed to reach not only the target groups, but also a large general audience. They deal with broad themes which are of general concern. The goal of these publications is to provide the basic knowledge necessary for effective prevention and to present a positive and understanding view of the lifestyles of people from the primarily affected groups. In this way, we seek to promote acceptance, lack of prejudice, and support of various kinds for these groups within society. Our materials form a link between the individual, target group, social, and political components of the WHO concept of health promotion, which is the basis for the work of the Deutsche AIDS-Hilfe.

DE AHA Company of the Deutsche AIDS-Hilfe

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Languages Spoken: German, English

The DE AHA is an income-generating venture of the DAH, raising money through the retail sales of condoms (Hot

Rubber), lubricant and novelties. Many of the products are designed to promote support for people with HIV/AIDS; for example, by using the red ribbon and rainbow flag designs. This in-house business is financially independent from the DAH, supported solely by the sales generated. All proceeds go toward the non-profit activities of the various departments. In addition to the financial benefits, the marketing of the DE AHA merchandise contributes to raising awareness about HIV/AIDS in Germany.

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Health promotion is the aim. That means ...

- avoiding HIV-infections
- improving the infected people's chance of survival
- securing for people with HIV/AIDS the highest possible life quality