Dare to start again – standing and striving for self-determination, solidarity and emancipation

We want to end AIDS in Germany by 2020!

Four years ago at our annual General Meeting in Kamen, as an organization we agreed to a joint strategy up until the year 2020. Strategies are subject to change processes, which is why in the coming years it will be important to have a close dialogue within our organization about what has already been achieved and to see what further tasks still need to be done.

In this sense, the Deutsche AIDS-Hilfe Reloaded has the broader goal of ending AIDS in Germany by 2020.

We want to achieve social change. We let ourselves be guided by the realities of living with HIV today, which therefore also means the realities of the groups particularly at risk and affected by HIV. In Germany, this mainly means gay men, drug users, sex workers, and migrants from countries with a high prevalence of HIV. Overall these groups do not have the same chances as the general population for health or social and economic conditions.

The basis of our work is the concept of structural prevention, which has to always be filled with new life and applied to our respective circumstances. In its unity of primary, secondary and tertiary prevention as well as of behavioral and conditional prevention, this concept is still viable.

In this paper we:

- first describe what living with HIV means today (I)
- list the successes of structural prevention as well as what still needs to be done (II)
- define medium-term goals (III)
- outline how we want to achieve these goals (IV).

We set out our goals under the headings:

- Fighting against the exclusion and discrimination of people living with HIV
- Protecting the human rights of the groups at risk and affected by HIV
- Expanding patient-centered care
- Promoting self-determination
- Creating a political framework.

I. Living with HIV today

Living with HIV in Germany has significantly changed several times in the past few decades. When the Deutsche AIDS-Hilfe (DAH) was founded in 1983, there was not even a test for the virus that causes AIDS, which was yet to be named HIV. Like society as a whole, the communities and scenes affected reacted with panic and fear. AIDS deaths became a part of life for gay and bisexual men, as well as for drug users.

Thanks to several factors – the foundation of local AIDS service organizations (Aidshilfen), the notion of curtailing the transmission of the virus through “safer sex” (mainly through the use of condoms) and “safer use”, a new commitment to the acceptance and equality of different lifestyles (“alliance of street urchins”), and resistance to the marginalization and isolation of the infected – the view took hold that AIDS could be conquered without sacrificing the freedoms of an open society. That laid the foundations of a success story – fear and panic have not disappeared, but have been pushed to society’s margins.

In the mid-1990s, the introduction of antiretroviral combination drug therapy dramatically changed the lives of those with HIV. These treatments saved, and still save, the lives of the infected and sick – a terminal illness became a chronic disease. The medication also reduced the risk of HIV transmission so decisively that people with HIV who are taking a functioning therapy not only have an almost normal life expectancy, but are also no longer infectious – an enormous relief for them and their partners. Today, even the prospect of a cure – long considered unrealistic or even impossible – is seriously being discussed.

Because of all this we speak of the “normalization” of HIV infection. What we did not see was that the discrimination and stigma associated with the virus would stay. As part of the international Stigma Index, the project “positive voices” (Positive Stimmen) has recently made this clear once again: people with HIV are shut out by their families and friends, are subject to abuse and even physical attacks (also within their communities and scenes), are turned away by doctors and dentists, and their right to well-informed self-determination is violated. Feelings of shame and guilt after an infection are just as prevalent today as they were at the start of the AIDS crisis. Internalized stigmatization often means that people with HIV do not enter sexual relationships, and those who test positive must think carefully about who they confide in. Even partners, family members, and friends of those with HIV are often subjected to marginalization and discrimination. Another example: although an estimated two-thirds of HIV-positive people in Germany work for a living, an HIV infection can still lead to bullying and even dismissal. Anti-discrimination laws offer no protection to those with HIV or other chronic diseases.

The fact that someone under a functioning antiretroviral therapy is not infectious has not yet been understood by most people in our society – even by many people who are HIV-positive and their partners. This fact is only gradually being considered in lawsuits determining criminal liability in cases of HIV infection or exposure. Courts generally still put the sole responsibility for protection against HIV onto the HIV-positive partner. This message is as outrageous as it was at the beginning of the epidemic – and one of the situations that we must overcome to beat AIDS. This means that we must convey our position once again and even more forcefully to the public: both partners in a consensual sexual encounter carry the same responsibility; and making it criminally punishable is counterproductive to HIV prevention.

II. Successes of structural prevention and what still needs to be done – some examples

Thanks to the division of responsibility between the government’s Federal Centre for Health Education (Bundeszentrale für gesundheitliche Aufklärung) and the NGO

Deutsche AIDS-Hilfe, Germany has one of the lowest HIV infection rates in the world, and is seen as a model internationally. But even we still have a lot to do, and there are many areas that need work.

Gay, bisexual and other men who have sex with men/LGBTI

One part of our success, apart from defending the sexual rights of gay men (for example by preventing a blanket ban on gay saunas or darkrooms), is seeking progress in the legal equality of gays and lesbians (for example the abolition of Criminal Code Paragraph 175, the introduction of the Civil Partnership law).

But we are a long way from complete equality (for example in income tax law and adoption rights). The discrimination of lesbians, gays, bi, trans* and intersexuals* is still pervasive – not just in countries like Russia and Uganda, but here too. Psychological disorders, experiences of sexual violence, and drug consumption are disproportionately prevalent among gay men. Workers on the ground have observed a tendency towards more dangerous drug-consumption methods, such as intramuscular and intravenous injection. Moreover, gay men and other men who have sex with men are still at greater risk of HIV and other STIs.

Drug users

Needle exchanges, the distribution of sterile needles, and drug substitution treatments have become well established, and there are now drug consumption rooms in most German states. The German Parliament's decision to allow diamorphine-supported treatment was a milestone in drug policy. The proportion of new HIV infections among drug users sank from 15% in the mid-1980s to three percent in recent years.

But on closer examination we see large gaps in rural areas and flaws in the quality of services offered, such as substitution programs, and drug consumption rooms are often prevented from being established because of protests by local residents. For most drug users, hepatitis is a bigger problem than HIV – an estimated 50–60% of them have suffered from hepatitis B, while three to five percent have chronic hepatitis B, and so form a reservoir for virus transmission. The situation is similar with hepatitis C: while there is a national prevalence of 0.4% among adults, between 60–80% of drug users are infected.

People in prison

In many German prisons, inmates have access to drug substitution treatment. The state of Baden-Wurttemberg even allows diamorphine treatment. Vaccinations against hepatitis B are often also available, while in North-Rhine Westphalia condoms must be made available anonymously.

Many prisons work on the assumption that there are simply no drugs within their walls, and therefore disregard the principle of equivalency – that inmates should have access to the same medical care that they would have outside of prison. Needle exchange programs, the cheapest and most effective prophylactic against infection, have been

stopped – with one exception. Substitution treatment is often denied, data protection rights are ignored, and HIV tests are carried out without consent or counseling. In short, German prisons systematically and openly violate human rights.

Sex workers

Self-confident sex workers deal with the health risks of their work in a well-informed and self-determined way. Germany's prostitution laws have set the course for the acceptance of sex work as a recognized profession, even though the opportunities that the law provides (like health insurance) remain out of reach for many.

On the other hand, there is poverty prostitution, drug-related prostitution, and forced prostitution, as well as an increasing tendency towards repression (also internationally). Here too, protests from local residents often lead to the closure of street prostitution areas or the establishment of restricted zones. Under these circumstances, sex workers – particularly women, many of them migrant workers – are nearly beyond the reach of HIV/STI prevention offers. At the same time the risk of being exposed to violence increases.

Migrants

Migrants have organized themselves, they engage in their communities through HIV prevention projects like PaKoMi and MuMM, and represent their own interests at the DAH. In 2011, an HIV-positive woman with Turkish roots was courageous enough to show her face on posters for the national World AIDS Day campaign.

At the same time, migrants are disproportionately affected by HIV: while just 19% of the German population has an immigrant background, the proportion of migrants among new HIV diagnoses in 2010 was significantly higher at 27.8%. Meanwhile, the Asylum Seekers' Benefits Act (Asylbewerberleistungsgesetz) does not allow a humane standard of living, even after benefits were recently raised. Refugees experience humiliating asylum procedures, sometimes resulting in new trauma. They are not allowed to work, and residency restrictions deter them from self-help and social participation. The situation is even more difficult for those without papers who live constantly under threat of deportation: when they need medical care, they are dependent on doctors motivated by humanity rather than legal requirements or financial compensation.

Older people in our communities

Particularly in urban areas there is a wide range of counseling and care projects for older people with HIV, older gay people, drug users, migrants or older people who fall through other social safety nets. These projects, whose priority is the acceptance of different ways of life, include outpatient care at home, shared flats for gay men with dementia and communal living projects for older drug users.

But outside metropolitan areas, these people are often only left with the option of retirement homes or nursing homes, which are generally ill-equipped to deal with their ways of life or with HIV or hepatitis infections.

III. Our medium-term goals (Horizon: 2020)

Our goal is that each individual and society as a whole should be well-informed, self-determined and responsible enough to deal with the risks of HIV/AIDS, hepatitis and other infections that can be transmitted sexually and through drug use (Deutsche AIDS-Hilfe mission statement).

In addition, we have a very concrete goal: by 2020 no one in Germany should have to die from AIDS. We already have everything we need for this: antiretroviral drug therapies, a network of good test offerings and a tight support network for people with HIV. It is not a utopian idea, but a realistic possibility: We can end AIDS!

This requires the political will and determined action at all levels from national stakeholders to medical doctors, AIDS service organizations (Aidshilfen) and self-help networks. Existing resources must be brought together.

Why is there still AIDS in Germany? The main reason is the discrimination against people with HIV. Exclusion causes fear of HIV testing and thus often prevents a timely start of therapy. Outdated images of HIV as a quick and fatal disease do the rest, and it can become a self-fulfilling prophecy.

The ambitious goal of ending AIDS in Germany by 2020 is a commitment to protecting as many people as possible – for all of those who are able and make a decision to protect themselves – against the avoidable consequences of an HIV infection.

In order to achieve this goal, we need our full commitment against discrimination and the exclusion of people with HIV, the respectful promotion of test and therapy, and the expansion of low-threshold services, also outside of metropolitan areas.

We cannot and do not want to leave anyone behind! We make our goal of ending AIDS by 2020 public in appropriate ways and point out key factors in a suitable form.

At the same time, we are focusing on the following priorities:

Fighting against the exclusion and discrimination of people living with HIV

1. The decriminalization of HIV exposure and transmission through consensual sexual acts.
2. Free access to HIV treatment as well as counseling and healthcare services for all people with HIV.
3. The freedom for everyone to decide for or against an HIV test. It is essential that counseling is free and anonymous if needed.
4. The freedom not to be forced to take HIV antiretroviral drug therapy.
5. The equal and anonymous access to healthcare and medical treatment for people without papers.

6. The end of discrimination against HIV-positive people within the gay community and other subcultures.

Protecting the human rights of groups at high risk of HIV

7. The complete legal acceptance of prostitution as a profession and the lifting of all repressive measures against sex workers.
8. The reversal of the Asylum Seekers' Benefits Act (Asylbewerberleistungsgesetz), residency restrictions, and the work ban for refugees; greater consideration of the needs and aims of migrants within AIDS service organizations (Aidshilfen).
9. The decriminalization of drug use.
10. The complete legal equality of lesbians, gays, and bisexuals, and the legal and social recognition of trans* and intersexuals is long overdue. We must make this clear.
11. The complete integration of the EU's anti-discrimination directive into German law, including the protection against HIV-related discrimination.

Expanding patient-centered care

12. The expansion of lifestyle accepting, needs-based, and quality-assured care services for all people affected or at risk of HIV. These services are indispensable.
13. Prevention and care for HIV, STIs and hepatitis that is closely integrated into communities – in particular for gay men and drug users.
14. Nationwide availability of low-threshold harm reduction programs for drug users – including drug checking –, including in detention and psychiatric centers.

Promoting self-determination

15. The ability for people to assess their risk of contracting HIV through sexual encounters or drug use.
16. The ability for people to deal with a positive test result in a well-informed, confident manner, and with no fear of discrimination and marginalization.

Creating a political framework

17. We demand a national hepatitis strategy, which will do justice to the lifestyles of the various groups that are particularly affected by the disease, and we will work with our action plan towards this goal (in close cooperation with other organizations involved).
18. We publicly call on Germany to live up to its responsibility in the international fight against HIV/AIDS.

19. We support a federal Prevention Law.
20. We want to develop as an organization so that we are in a position to achieve the above goals – structurally, financially, and at a personnel level.

IV. Important steps towards achieving our goals

The Deutsche AIDS-Hilfe – as a center of expertise for structural prevention, as the representative of interests, as a provider of social services, and as a learning, society-changing organization – is sustainable if it strengthens, develops, and confidently markets its unique qualities. It is okay to celebrate past success, but we must continually re-engage with our goals: with determination, solidarity and emancipatory ambition.

But all change begins at home. For that reason, we will keep comparing our work against our goals and our mission statement and will ask ourselves critical questions, for example: Why have so many AIDS service organizations (Aidshilfen) withdrawn form prison work? Why do some gay prevention projects fail to engage with the gay scene? With what approach, with what aim, and how do we go about our work in schools? Are our member organizations, regional associations, and the national organization truly open to the participation of people with HIV and people from our communities? Indeed, do they even foster these communities – and how does that become apparent?

Provoking and fostering self-help at all levels of our organization and structurally guaranteeing their participation

At the Deutsche AIDS-Hilfe we accept people as they are (“the norm-breaker's association”), and we accept their decisions. The special qualities and strengths that distinguish us from other organizations is this: those with the most at stake in AIDS prevention – people with HIV and people of the social groups most affected by HIV – are part of our organization at all levels. The Deutsche AIDS-Hilfe needs their contributions in the development and implementation of ideas, in discussions and decisions. To that end, we will maintain or create the necessary space, and get the message across loud and clear at all levels of the organization: participate, get involved! The Deutsche AIDS-Hilfe needs those living with HIV, needs gay men, drug users, and migrants, both as volunteers and employees, as part of self-help who takes responsibility, makes decisions, and shapes our organizations.

Forming cooperations and coalitions

Many associations, organizations, and people share our aims. It is part of our work to reach these partners and develop strategies with them to realize our common goals. This way we also communicate our positions and approaches to society at large. Therefore, we will reinforce our cooperation with other organizations for the chronically sick and disabled within our umbrella organizations “German Working Partnership Self-Help” (BAG-Selbsthilfe) and “Paritätischer”, and with other partners, in order to anchor HIV and other chronic diseases in Paragraph 1 of the General Equal Treatment Act (Allgemeines Gleichbehandlungsgesetz, AGG). Similarly, we will campaign for a national hepatitis strategy alongside representatives from science, politics, specialist

organizations, and the national liver association (Leberhilfe). And it is only together with refugee, migrant, and human rights organizations, as well as politicians, that we will be able to reverse the Asylum Seekers' Benefits Act (Asylbewerberleistungsgesetz), residency restrictions, and the work ban for asylum seekers.

Expanding community-based HIV testing services; securing informed consent for both test and treatment

There is growing pressure on people with a higher risk of HIV infection to take an HIV test and to undergo treatment immediately if the result is positive. We will vehemently resist this pressure at both a national and international level, and campaign for our objective, that every individual can make an informed and self-determined decision free from pressure, as to whether and when they will take a test or begin their treatment – first and most importantly for their own individual benefit. The aim of stopping new infections should not lead to missing this goal. We will critically assess new testing possibilities, such as home testing, and new prevention methods such as PrEP, and include them in our work only if they serve this goal. Furthermore, we will reinforce and develop counseling as a “structured learning situation” to facilitate the reflection on risk management in different ways and in different spheres of communication, and at the same time communicate a realistic image of life with HIV today. And last but not least, we will campaign for the expansion of testing opportunities in AIDS service organizations and help to establish and guarantee community-based, low-threshold counseling and testing.

Working together on integrated HIV, STI and hepatitis prevention and healthcare which accepts different ways of life

Sexually active people can hardly avoid the risk of sexually transmitted infections, but can at most reduce the risk. That’s why early diagnosis and treatment is decisive. Important tools are community-based and low-threshold counseling, testing, inoculation, and treatment opportunities, which we will campaign to expand and get financing for. We will also expand our cooperation with doctors and public health officials in order to establish integrated prevention and healthcare that accepts different ways of life and respects self-determination.

Working against discrimination and stigmatization

As a further part of our anti-discrimination work, we will do more to recruit people with HIV and support them to live publicly with HIV (for example in campaigns) and so not only to work towards emancipation, but to show society, our communities, and other people with HIV the many different aspects of life with HIV today. We encourage and support the fight against discrimination and exclusion. Through documentation and annual publications, we create a social awareness of discrimination and its consequences. And last but not least, we will help doctors and medical personnel treat patients without discrimination, and expand our project “Communication in the doctor's practice” (Kommunikation in der Arztpraxis) with the appropriate modules.

Accepting and demanding international responsibility

As a large NGO in one of the richest countries in the world, we have a duty to share our knowledge and experiences if partners from projects, organizations or even state institutions have an interest in them and want to cooperate to develop approaches for their particular needs. Whenever possible, we will provide support where people need help to organize themselves. We will remind our own government of its international obligations and human rights as a basic principle. If the international community wants to end AIDS by 2030, it also needs material resources. We will increase our efforts at all levels of our organization to campaign and participate wherever our help is needed or requested.

Learning from each other and furthering the development of standards and quality to make all levels of our organization sustainable for the future

We will foster the exchange of experience between local AIDS service organizations (Aidshilfen) as well as the various organization levels, in order to strengthen our case to public grant providers as well as to find new financing paths, and so secure the financial foundations of the umbrella organization, the regional associations, and the member organizations. Moreover, we will set up our work in preparation for the Prevention Law that we have been calling for. That is why we will discuss the certification of certain fields of our activities in order to strengthen our brand and be able to profit from common standard and quality development when dealing with future grant providers.

Developing, implementing and securing healthcare that accepts different ways of life

We want to strengthen and expand the Deutsche AIDS-Hilfe as a provider of alternative healthcare structures wherever they can be financed. But we cannot make all services available everywhere, and where it proves impossible, we will seek out cooperation with institutions that are already established, contribute our expertise, and make sure that people are accepted without prejudice and receive optimal care. The Deutsche AIDS-Hilfe will participate in the development of standards and accompany transitional phases, so that a self-determined life becomes possible in old age, so that sexuality and drug use will no longer be taboo, and spaces are created for other ways of life in old age.

Fighting for an alternative asylum policy and for access to healthcare for people without papers

In order to make sure that people without papers get access to medical care, we will campaign together with other organizations for the introduction of an anonymous health insurance card or another similar solution. We will continue to support migrant, refugee, and human rights organizations as well as politicians who lobby for a change in asylum policy, and we will participate in campaigns for the reversal of the Asylum Seekers' Benefits Act (Asylbewerberleistungsgesetz), residency restrictions, and the work ban.