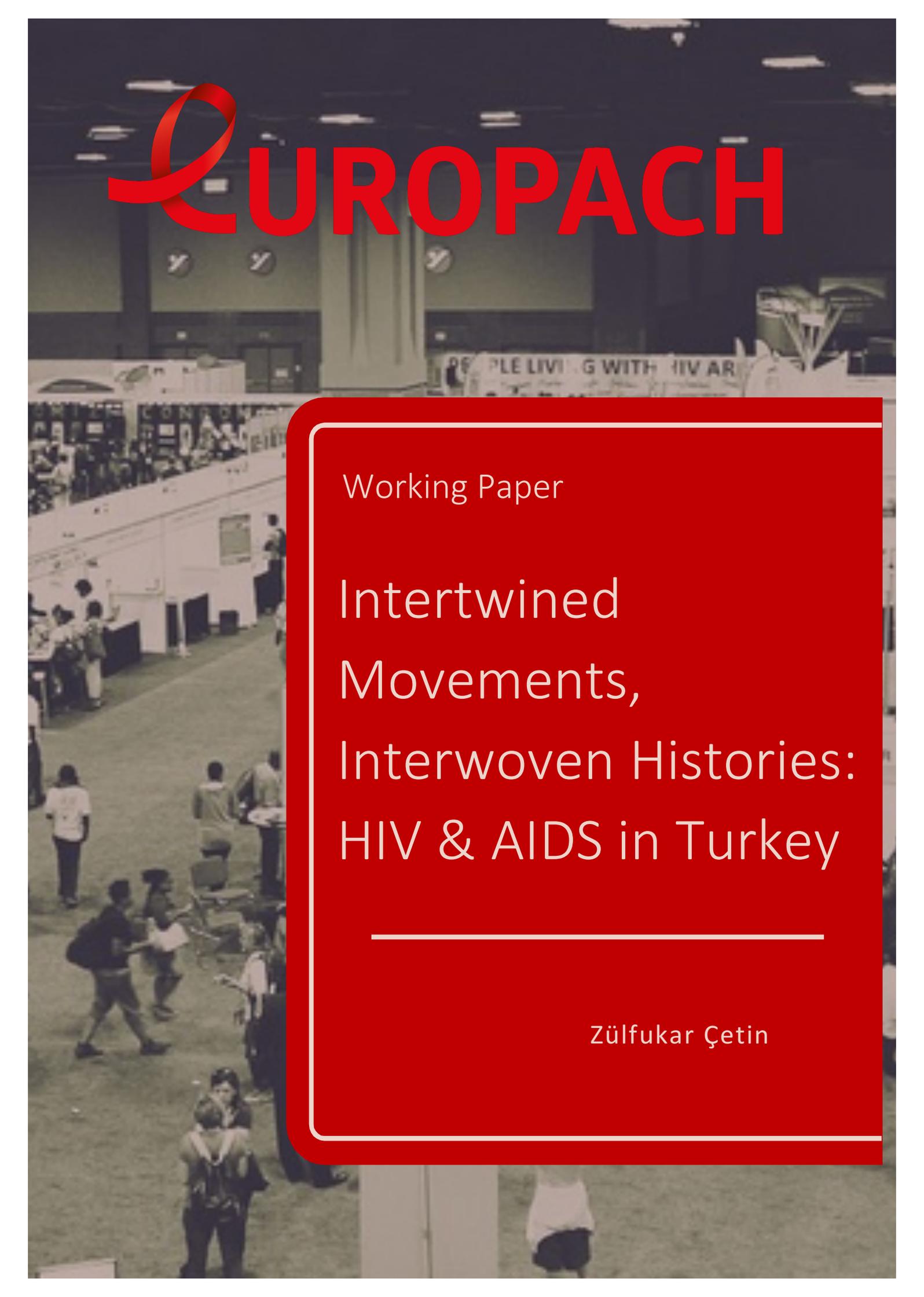




# EUROPACH



Working Paper

## Intertwined Movements, Interwoven Histories: HIV & AIDS in Turkey

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The “Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health” (EUROPACH) research team is made up of scholars based at four European universities – Humboldt-Universität zu Berlin (Institute for European Ethnology), Goldsmiths, University of London (Department of Sociology), University of Basel (Department of History) and Jagiellonian University (Institute of Sociology) – and works with another researcher who is based at a fifth academic institution, the Free University of Berlin (Friedrich-Meineke Instiut, Didactics of History). It also works in close collaboration with a number of non-academic partner organizations including AIDS Action EUROPE, European AIDS Treatment Group (EATG), Hydra (Germany), İnsan Kaynağını Geliştirme Vakfı (İKGV) (Turkey), Kaos GL (Turkey), the International Committee on the Rights of Sex Workers in Europe (ICRSE), National AIDS Trust (UK), SIEĆ PLUS (Poland), the ACT UP Oral History Project, the European Network of People Who Use Drugs (EuroNPUD), Deutsche AIDS-Hilfe (Germany), Justri (UK), Pembe Hayat LGBTT Dayanışma Derneği (Pink Life LGBTT Solidarity Association) (Turkey), Social ADIS Committee (Poland), and the Social Policy Foundation “Prekursor” (Poland). For more information, visit our website at: europach.eu



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## HIV AND AIDS<sup>1</sup> IN TURKEY

HIV and AIDS did not become a mainstream discourse in the health policy field in Turkey until the early 2000s. Rather, like syphilis, chlamydia, gonorrhea, or genital herpes, HIV and AIDS would be listed under the umbrella term "sexually transmitted infections" without receiving any particular attention by state health policy. For this, several social and health policy reasons can be mentioned:

First: In contrast to some major countries in the West, registered cases of HIV and AIDS in Turkey were comparatively less widespread (Tümer, 2016). Due to the low or unknown numbers of HIV and AIDS cases, the topic was either ignored or the country was considered unaffected by AIDS and HIV infection. For example, between 1985 and 2000 there were about 200 people registered with HIV (ibid.).

Second: The political situation in Turkey was/is characterized by the existence of different political and social movements, and has been since the founding of the Turkish Republic. At the beginning of the 1980s, for instance, Turkey was dealing with a successful military coup and responding to the new social movements that arose in reaction to it. The queer movement, the women's movements, and the Kurdish movement are just a few of the many (new) social movements that arose after the 1980 coup.

Third: Even if society and state in Turkey were dealing with other political issues in the 1980s and 1990s, there were a few groups of trans\* persons, sex workers, pacifists, and socially-conscious medical workers who were already aware of HIV and AIDS and tried to raise the issue, but due to the repressive political situation after the military coup could not build any strong lobby for people with HIV and AIDS.

This article focuses on the different phases of HIV and AIDS history in Turkey and shows the interwovenness of different social movements that can be described as resistant and emancipatory responses to the continuity of a generally repressive policy after the military coup. For instance, trans people defended themselves collectively because police action directly threatened their livelihoods and put them at risk of losing their jobs and homes. Protests that emerged in response to this situation led to the organizing of trans, lesbian and gay people, who sought out support from feminist and left-wing groups as well as human

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<sup>1</sup> In contrast to the transnationally and locally prevalent term "HIV / AIDS", I will not mention HIV and AIDS together with a slash, but with the conjunction "and" separately from each other. In my opinion, the spelling "HIV / AIDS" often leads to misleading mental homogenization of HIV and AIDS as if the two phenomena were synonymous with a particular type of "fatal" disease.

rights organizations. They assembled in public space, organized demonstrations against the police, staged protests outside the employment office to demand jobs for trans people and collected signatures for a petition calling for the legalization of sex reassignment surgeries (Çetin, 2015).

Furthermore, in 1987 police raids led to a collective protest, which was supported by the “Radikal Demokratik Yeşil Parti, RDYP (Radical Democratic Green Party)” and carried out mainly by trans sex workers and some lesbians and gay men. On April 29, 1987, 37 trans, lesbian and gay people launched a hunger strike in Gezi Park to protest against the repression. Neighbouring citizens as well as a number of artists and intellectuals lent their support to the protesters. This ten-day hunger strike is viewed as a watershed event by today’s queer movement (ibid.).

The history of the HIV and AIDS movement is presented here against the backdrop of the political situation in Turkey since 1980 and is therefore periodised by turning points in domestic politics as well as related to the histories of other new social movements. This type of HIV and AIDS history aims to understand AIDS policy and the AIDS movement as parts of a series of new social movements in the wake of the 1980 military coup and to reconstruct their dynamics along political events.

### **THE HEALTH SYSTEM IN TURKEY**

In order to be able to understand the current health policy in general and in particular how it deals with HIV and AIDS in Turkey, a historical review of the country’s health system is necessary.

The foundation of the Turkish Republic was aimed firstly at the dissolution of the Ottoman multi-ethnic state, and secondly at the formation of a nation-state following the European model, which sought to establish a rigid concept of nation. According to this European model, a nation was based on a common language, common culture, shared history, common religion, common soil and, in the most extreme case (like in Nazi Germany), common blood. In the founding years of the republic, neither the traditions and customs of the “new nation”, which should be defined as Sunni Muslim and Turkish, should be neglected, nor should the modernization of the economy and other social structures be missed. Thus, large and important parts of the country’s legal, economic, political and socio-cultural institutions were either renewed or wholly adapted following the standards of different European countries. Since at the time Europe had no homogeneous state and social structures either, the founders of Turkey adopted different laws from different European countries, which were to be applied

in the new republic. For example, the Italian penal code and the Swiss civil code were adopted, with some changes, into the then Turkish society. These two legislative examples show that Turkey in its founding period did not import everything from a homogeneous Europe, but also made sure that the new Turkish nation should remain as original as possible, without, however, having to be categorized as in contradiction to an “enlightened” Europe. On the contrary, since its founding in 1923, the Turkish Republic has claimed recognition as a Western or European country worldwide. The newly founded Republic and its institutions were absorbed with the overriding goal of Europeanizing society, with the goal of establishing a “modern”, secular, Turkish national society with an ideological basis not in religion, but in Enlightenment ideals. The guidelines were the principles of Mustafa Kemal Atatürk, namely populism, nationalism, secularism, statism, revolutionarity, and republicanism.

In the new society, the nuclear family was to play a central role. The emancipation of women and their participation in economics, science, technology, and other areas of society were both required and supported. The Republic thus placed great value on a gender politics that was supposed to lead to equality between men and women. For example, women had the right to vote and to run for office by 1934. The progressive nature of this politics becomes clear if we keep in mind that such reforms were still quite unimaginable in many European societies in the 1930s. Then as well as in former times, homosexual acts among adults were legal in Turkey. This may have been due either to the adopted Italian penal code or to the earlier Ottoman-era laws that were still in force and did not impose a penalty for homosexual acts. Deviations from the heterosexual binary gender system took a back seat to the ambitious new gender politics and were largely ignored. Therefore, in contrast to many other European countries at the time, the Republic of Turkey simply ignored lesbian, gay, bisexual, and trans\*persons altogether until the 1960s (ibid.).

The Europeanization of Turkey is also an important basis for dealing with the history of health policy in general and with the development of HIV and AIDS policies in particular. When the Republic of Turkey was founded in 1923, all areas of society were reformed, including education, justice, labour, civilian life, etc. Health care was also one of the areas to be newly configured. The Ministry for Health and Public Welfare (Sağlık Sosyal ve Yardımlaşma Bakanlığı) was founded in Turkey at the time. At a European level this was a relatively major step, since at the time such a ministry only existed in very few European countries (Akin & Ersoy, 2012). The new ministry, however, was responsible above all for treating those wounded in war and for developing new legislature. Regulating general health services and public health were not yet provided for when the ministry was founded (Türkiye

Cumhuriyeti Sağlık Bakanlığı, 2015). In 1930, the first Public Health Law (Umumi Hıfzıssıhha Kanunu) was passed in Turkey (Akin & Ersoy, 2012). This first law, which is still in force today, regulates the tasks, duties, and scope of the state in the area of public health. In the first years of the republic, due to the losses incurred in several wars, the state was following a pro-natalist population policy, that is, a policy of encouraging population growth (ibid.). Since 1965 Turkey has been following an anti-natalist population policy in order better to control population growth and public health (ibid.). As part of this new population policy the state has targeted a horizontal health policy, which is to say that the state aimed at establishing health services not only in urban but also in rural areas as well as guaranteeing access to health for all groups of the population regardless of their economic status, place of residence, or other characteristics. Protective and preventive measures have formed the main pillars of the new health politics. In order to improve health services in rural regions and the general health of the population, the “The Socialization of Health Services” (Sosyal Hizmetler Kanunu) was passed in 1961 (Kurt & Şaşmaz, 2012). With the then new constitution, which became effective in 1961 by a referendum after the first military coup in Turkey, the “social state” was redefined and its duties towards the citizens were determined. Accordingly, the Social State is obliged to accept its responsibility for the citizens, to recognize their right to public health as a fundamental one, and to make public health services available to the public. The new constitution and the law about “The Socialization of Health Services” (also from 1961) aimed at stabilizing the health of the population, developing a social and economic public health system, promoting protective health services and decentralizing health care services by establishing a nationwide system of family doctors. The further intention of the law “The Socialization of Health Services” was equal rights and equal access to health services. The main guiding principles of this law were (ibid.):

- Welfarism: Health services are among the main tasks of the state and are offered according to the principle of “well-being of the population.”
- Equal treatment: Every person can use the health services on equal terms.
- Continuity: Health services are organized in the individuals’ vicinity, no matter where they live, are available for them whenever necessary and can always be accessed without barriers.
- Incremental treatment model (triage): Any individual wishing to use healthcare services must first turn to the cottage hospitals (sağlık ocakları) or local dispensaries (sağlıkevi), except in emergencies. Depending on the severity of the complaints, they will be referred to larger health facilities.

- Integrative services (protection and treatment): Cottage hospitals and local dispensaries<sup>2</sup> offer all kinds of medical protective treatments within their capacities. The aim is to offer patients from sparsely populated places comprehensive treatment (horizontal approach).
- Participatory treatment services: In all cottage hospitals, local dispensaries, health centres and hospitals as well as in all other health facilities in the cities, health advisory councils are set up to ensure good relations with the population. Free services: The examination and treatment of patients as well as the receipt of medicines are provided free of charge, if they correspond to referral guidelines.
- Treatment services appropriate to the population: In each of the regions with 5-10 thousand inhabitants, a cottage hospital (sağlık ocakları) will be set up. Each of these health facilities is autonomous to act independently of regional guidelines on healthcare services.

In spite of the good intentions of the two laws, equal access to health services could not be realized nor could the protective health services be further developed as had been provided for by the laws. The inequality of development between the country's eastern and western parts as well as between rural and urban areas remained unchanged. The mortality rates among mothers and children could barely be reduced, nor could the casualties due to (sexually) transmissible diseases (ibid.). Turkey's health policy deteriorated especially after the 1980 military coup, which also negatively affected the entire political climate in Turkey, which I will discuss in more detail below. The constitution of 1961 was changed again after the putsch in 1980 and a new constitution entered into force in 1982. The principle of the Social State was abolished informally and a new politically repressive regime was enforced in almost all sectors of society. At the same time, the urge to adapt to the global liberalization of the economy and other areas also prevailed in Turkey. In the course of these developments, an attempt was made to reform or, rather, to liberalize (that is, to privatize) general health services. The "Socialization of Health Services" program was effectively terminated, inequality in health care services became stronger, public health subsidies were shortened, hospitals were privatized and the gaps between rich and poor, and urban and rural, grew. "The

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<sup>2</sup> Depending on the size and density of the population, different polyclinics have been set up in each region: sağlık ocakları (cottage hospitals), sağlık evleri (local dispensaries), sağlık merkezleri (health centers), hastane (hospital) etc. In each residential area and in each village primarily the cottage hospitals (the smallest health center) were set up, where people could be treated for their health problems. Depending on the degree of the complaints, the patients were referred to a larger health center or hospital. (Kurt & Şaşmaz, 2012)

Socialization of Health Services” law, which aimed at “health for all”, failed during this time due to a repressive policy of a military regime that also sought economic liberalization. The new government run by the Anavatan Partisi (Motherland Party), elected in 1984, did not abolish “The Socialization of Health Services”, but continued to fully liberalize the health system, obliging the health care institutions to finance themselves. These attempts at liberalization were continued in the following years by different governments, but they failed to achieve success in improving the health system. After Turkey was officially recognized as a candidate for the European Union at the EU Summit in Helsinki in 1999, international expectations rose with regard to reforms aimed at improving due process and the conditions for minorities and for civil society in general. Ankara reacted by passing a series of so-called “harmonization packages” between 2002 and 2003. The proposed legal and constitutional changes included above all those concerning freedom of thought and expression, the prevention of torture, the freedom and security of the individual, the right to privacy, the inviolability of the home, the freedom of communication, the freedom of residence and movement, and the freedom of association and gender equality. At the level of civil society, changes were to be instituted in the areas of gender equality, protection of children and the infirm, as well as freedom of assembly (Çetin, 2016). With the accession to power of the Justice and Development Party (Adalet ve Kalkınma Partisi - AKP) in 2002, the health system and policies were also subjected to this ongoing reform process. In the course of the EU-Accession negotiations and through the support of the IMF (International Monetary Fund) and the World Bank as well as other international organizations such as World Health Organisation (WHO), the government initiated the campaign “Health for All” (Herkese Sağlık) as part of an Emergency Action Plan (Acil Eylem Planı). With this plan, the government declared the priority objectives of the new health policy and launched the “Health Conversion Program” (Sağlıkta Dönüşüm Programı - SDP) in the following year. The objectives of this program were, for example, facilitating access to health; quality assurance of the health system; the development of a health service friendly to patients and centred around their needs; performance-oriented, productive, affordable and competitive healthcare services and a new Ministry of Health based on the flexibility of staffing policy and a horizontal, non-bureaucratic and non-hierarchical structure (ibid.). In light of global economic developments since the early 1980s, it can also be noted for Turkey that the health system has been subjected to a liberalization process by a conservative party like the AKP. Regardless of implementation and success, this program is considered one of the most comprehensive health reforms in Turkey. Although this new health program adopted the guiding principles of the

old law (The Socialization of Health Services), it cannot be argued that the principle of the Social State has been fully achieved. The dilemma between liberalization on the one hand and the welfare state on the other might explain why. While the state aimed at “health for all” by state support, it privatized at the same time; there were now care facilities, which offered better quality health care services, aiming only at specific sections of the population. Neither has the problem of access to healthcare based on the social status of people (for example, poor/rich) been solved completely, although some attempts have been made by the introduction of the Green Card system. In order to improve this situation, the health system, again under the AKP government, was restructured in 2011.

As an example, in 2011 the New Public Health in Turkey was reformed by a “Decree Law” (Kanun Hükmünde Kararname). This Decree Law defines the organization and tasks of the Ministry of Health and the institutions subordinated to the Ministry, or those that cooperate with it. This Decree Law also set up the Public Health Agency of Turkey (Türkiye Halk Sağlığı Kurumu), which, according to the policies and goals of the ministry, was meant to take over and implement basic health services. In this Decree Law the tasks and responsibilities of the new agency were formulated. Some of the most important resolutions with regard to the areas of responsibility and goals of the Public Health Agency of Turkey can be summarized in general as follows:

- a) Protecting and developing public health and combating risk factors for health;
- b) Implementing basic health services and passing provisions to this end; and
- c) Observing, analysing, and examining transmissible and non-transmissible illnesses as well as cancer among risk groups, such as mothers, children, adolescents, the elderly, and people with chronic conditions or disabilities.

In this context, the Ministry is also charged with monitoring and collecting data with regard to these conditions and “risk groups,” preparing appropriate (health) plans and programs, implementing, checking, evaluating, preventing, and making recommendations for health policy (Türkiye Halk Sağlığı Kurumu, 2013). The Public Health Agency focuses on a “protective health policy through the prevention, promotion, quality assurance and the balancing out of disadvantages of marginalized and/or vulnerable groups within the framework of the Strategic Plan 2014-2017” (ibid.). With the new office, the state aimed at a new decentralized health policy, which was meant to work more effectively at the local and regional level. Not only in the urban areas, but also in rural areas, several health authorities were founded, which were subordinated to the Public Health Agency, but still had some

autonomy with regard to prevention and protection strategies in their regions. For example, some of the many health authorities were able to set up anonymous and free testing centres for sex workers and LGBTI\* people, which is still not available in Turkey as a whole.

### **ACCESS TO HEALTH CARE FOR PEOPLE WITH HIV**

According to a report from the WHO in 2009, Turkey is one of the 21 countries in the world in which people with HIV have easier access to counselling, free testing, and treatment. Also according to this report, until 2009 there were a total of 1,362 health institutions in Turkey where HIV testing and counselling were offered.<sup>3</sup>

The costs of medical care for people with HIV were absorbed by the national insurance until 2012. This insurance is available to all those who either work as civil servants, are employed, or are self-employed. The medical expenses of those not in this national insurance system and of unemployed, low-income and poor people were covered by the Green Card (Yeşil Kart) until October 2012, that is, by state support. The Green Card was introduced for the first time in Turkey in 1992. The goal of the Green Card was to provide access to health and medical treatment for socially and economically disadvantaged people who were not in any insurance system or who could not benefit from any insurance services. The Green Card holders were able to receive comprehensive medical care free of charge or at very low cost. The number of Green Card holders in 1995 was 1.7 million in total. By 2010 this number has risen to over 10 million. According to statements from the Ministry of Health it had been difficult to verify the economic situation of citizens who had applied for the Green Card. Furthermore, there are supposed to have been a large number of Green Card users who took advantage of the system (Deldal, 2015). For this reason, the Green Card system was abolished by the then Ministry of Health on October 1, 2012 and replaced with the General Health Insurance (Genel Sağlık Sigortası). With the new General Health Insurance, the state aimed to guarantee health insurance for all citizens. The previous Green Card holders were also integrated into this system so that they could continue to have access to comprehensive or almost unrestricted health services and treatment. For example, unemployed, low-income or poor people with HIV can receive both their medicines and their medical treatment through this General Health Insurance for free. In order to use the General Health Insurance all citizens must register a declaration and verification of their income with their local social welfare office. This made it easier for the state to verify who had how much income and who was able to benefit (and to what degree) from state support. The premiums could thus be graded according to levels of

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<sup>3</sup> See: Positive Living Association (without date) <http://www.pozitifyasam.org/a-m-3579>

income. This new process was meant to strike a balance between those with high earnings and the poor. The unemployed also have a right to General Health Insurance according to this system. According to the Social Security and General Health Insurance Law (Sosyal Sigortalar ve Genel Sağlık Sigortası Kanunu) the health insurance system encompasses not only Turkish citizens, but also migrants and refugees who fulfil certain requirements (Ekin, 2012). So the stateless, refugees, and other migrants who have residency permits in Turkey or who have no insurance in their countries of origin can benefit from the General Health Insurance, as well as those who have been resident in Turkey for more than one year.<sup>4</sup> People with HIV or other sexually transmitted diseases can also benefit from this new health system.

### **THE DYNAMICS OF THE HISTORY AND POLITICS OF HIV AND AIDS IN TURKEY**

This section presents the history of HIV and AIDS policies in three phases. The first phase centres mostly on the media reactions to the first known HIV and AIDS case in Turkey, that of Murtaza E., and the state's handling of HIV and AIDS at this early stage. The AIDS illness of Murtaza E. became known in 1985 and is considered the beginning of the history of HIV and AIDS in Turkey. Murtaza died in 1992. His death also received special attention in the media and in civil society, making this event a milestone in the history of HIV and AIDS in Turkey. The second phase, taking place between 1992 and 2002, can be considered one of intense preoccupation at the civil, activist and state levels. This phase is characterized not only by the establishment of new social movements but also by the institutionalization of HIV and AIDS policies. The rise to power of the conservative AKP in 2002 marks the beginning of a new phase not only in regard to HIV and AIDS policies. Rather, the new government intended a significant restructuring of the country and its institutions, including the health system as well as HIV and AIDS policies. Even though the AKP is still in power in the moment of submitting the working paper at hand, this third phase ends in the year 2015, at the same time marking the beginning of a new chapter in the history of HIV and AIDS policies in Turkey. This is because in 2015 the huge increase in HIV-positive persons in Turkey prompted the WHO to issue a warning to the country and call for new preventive measures and action plans.

#### The first phase and the case of Murtaza E.: 1985-1992

Between 1985 and 1992, there were 71 registered people in Turkey with HIV and AIDS (Hatam, 2016). The Turkish public became aware of HIV and AIDS in the fall of 1985

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<sup>4</sup> İçişleri Bakanlığı Göç İdaresi Genel Müdürlüğü. Ankara. Available at: [http://www.goc.gov.tr/files/files/SGK\\_KITAPCIK\\_tr-1.pdf](http://www.goc.gov.tr/files/files/SGK_KITAPCIK_tr-1.pdf) [Accessed 29 Jan. 2018].

through newspaper reports on the first known case, Murtaza E. He was known at the time for his friendships and relationships with singers popular all over Turkey. His prominence continued to increase due to stigmatizing reports in the nationwide dailies about his personal encounter with AIDS as “someone infected”. Before the case of Murtaza E. AIDS was not considered a “serious” problem in Turkey by the public, the media or the state (the Ministry of Health). One had heard of AIDS as a deadly disease in the US and Western Europe, that is, as something that was very far away from Turkey. Only with Murtaza E. did people start talking about what AIDS was really all about and how it reached Turkey.

At the time the reporting in the different daily newspapers and the public reactions to this first case were more or less homogeneous. While the newspapers labelled AIDS as a deadly disease, Murtaza E.’s friends and acquaintances (including famous ones) abandoned him. He was regarded as a bearer of disease, a body that brought death to the population, or someone who was no longer to be touched. Because of this kind of reporting and public reactions, even the Ministry of Health intervened and subjected Murtaza E. to various examinations. In this first phase of HIV and AIDS, he tried to fight and show that he was not impacted in the ways that people portrayed. It was known at that time in Turkey that Germany had earlier experiences with HIV and AIDS, and it was believed that therefore treatments and prevention strategies might have been developed there. So Murtaza E. even went to Germany to get treatment, and returned with “HIV negative” results. He died in 1992. Because of the fear of AIDS, his body was washed with bleach and buried in a galvanized coffin. Only a few people attended his funeral because many were afraid of Murtaza’s “AIDS body”.

Even though the public response to this first case was marked by stigma and moral panic, it is helpful at this point to take a look at the subsequent proceedings of state and civil society during this first phase. Beyond the stigmatizing mass media representations of AIDS, the Ministry of Health adopted precautionary measures against HIV and AIDS relatively early and took the first steps in this direction. Hence, institutional prevention and control measures are characteristic of the first phase, which will be discussed in more detail below. At that time, HIV and AIDS were not approached forcefully, whether by civil society, science or activism. This is due, on the one hand, to low infection rates and, on the other, to certain socio-political conditions in Turkey, which were at that point still under the impact of the 1980 military coup. In its aftermath, the activities of numerous associations and unions were restricted and all political parties were banned. The leaders of the three largest parties were constrained with a political ban. The parliament was dissolved and only convened again after the elections in 1983. The army installed a cabinet of technocrats. Freedom of assembly, association, press

and speech were each drastically restricted. Furthermore, arbitrary arrests, mass usage of torture and denaturalization were the order of the day. As many as 517 death sentences were imposed and 50 of these were executed. Schools and universities were subject to massive militarization (Çetin, 2016). When the Kurdish Workers Party (Partiya Karkerên Kurdîstan – PKK) took up their “armed struggle for the liberation of Kurdistan” in 1984, this process was further intensified. The attempts by then Prime Minister and later President Turgut Özal (1983-1993) to deescalate the Kurdish conflict did little to alleviate the repression. The military regime primarily targeted left-wing and right-wing political organizations that had led armed struggles before the coup and that were responsible in the 1970s for numerous politically motivated assassinations. Sustained police, legal and military repression led to numerous activists fleeing to Europe and the USA, where they joined anti-military, environmental and feminist movements, which provided them with insights into these new social movements. This was also the case for many members of the queer movements. The experiences of these temporary exiles would later become significant for the new social movements in Turkey. The military coup largely annihilated the radical left, temporarily debilitated the radical right, and thus unwittingly opened up public and political space for new social movements, including the queer movement and later also the anti-AIDS movement (ibid.).

At first, though, the military coup and its impact prevented both a movement against AIDS and the emergence of an AIDS discourse. At that time, which was dominated by the military, the state assumed all responsibility for public services, including health services. Thus, the first phase of HIV and AIDS history in Turkey was characterized by the repression of all political and social movements on the one hand and, on the other, by state intervention in all structures of (civil) society. For instance, concerning health politics, Turkey was one of the first countries in the world to include HIV and AIDS in the list of transmissible diseases as early as 1985, when the first case, Murtaza E., became known. In addition to Turkey, this obligation to report was also implemented in countries such as Germany, France, Greece, Israel, Austria, Norway and Sweden (Başer, 1998). In order to prevent HIV and AIDS, Turkey rapidly expanded its preventative policy in the following years, which was mainly based on control. The following measures were to be taken against HIV and AIDS and other transmissible infections:

- since 1986: HIV testing of all blood and blood products
- since 1987: the use of single-injection in hospitals and polyclinics

- prevention by controlling barbers in order to avert the multiple use of razor blades for different clients and by controlling circumcisers in order to avert possible transitions through blood
- HIV tests for people visiting the health care facilities; due to scarce resources (lack of staff and inadequate infrastructure) the measure was not implemented, instead patients were committed to HIV testing in large operations and in surgical settings (Çokar et al., 2008).

In addition to these legally prescribed preventive measures, the first HIV testing centres were opened in 1987 and the “High Advisory Board on AIDS” (AIDS Yüksek Kurulu) was constituted. The advisory board consisted of members of scientific institutions and representatives of the Ministry of Health. The tasks of this advisory board consisted of collecting information on HIV and AIDS, training the health care staff and developing further measures against the spread of the infection (Çetin, 2016). Because of the low number of known people with HIV on the one hand, and on the other hand because of the suppression of civil society by the military regime, no self-organization among people living with HIV came about at this phase. Instead, the state (the Ministry of Health) acted as the only body against “AIDS” and determined the health policy for sexually transmittable infections. In the first years, Turkey also turned to the experience of other countries with HIV and AIDS policies, notably cooperating, on the international level, with the World Health Organization (WHO). In 1987, the WHO launched the Global Program on AIDS in order to strengthen social awareness for HIV and AIDS, develop fact-based policies, provide technical and financial support to countries, conduct research, mobilize non-governmental organizations and promote the rights of people with HIV (AVERT, without date). In line with the recommendations of the WHO, the Turkish Ministry of Health prompted further steps in the fight against HIV and AIDS in those years. In 1987, it tightened the preventive measures, prohibiting the use of untested blood and blood products, introducing validation tests in order to detect infections with HIV and starting to control sex workers routinely. Furthermore, single-injection was to be used more consistently and disposed of appropriately. Condoms were only to be distributed through health care facilities and circumcisions could only be carried out by qualified persons. In 1988, the Turkish General Staff introduced HIV testing for those who had to join the army due to compulsory military service (Başer, 1998).

In this phase of the history of HIV and AIDS, where the political and social movements were largely ousted, the only non-governmental organization to address the issue of AIDS was the

“Family Health and Planning Foundation” (TAPV), which was founded in 1985. Already in 1986, this foundation began to deal specifically with the issue of HIV and AIDS and to collaborate with the Ministry of Health. The foundation mainly targeted students, informing them, in their capacity as multipliers, about HIV and AIDS. TAPV is not considered a part of a movement of socially marginalized or discriminated groups like people with HIV; the approach of non-governmental organizations to HIV and AIDS is discussed in more detail below.

Murtaza E. died on June 14, 1992, following his illnesses related to AIDS. His death was reported in an alarmist manner by the nationwide dailies, which previously had made his AIDS-related illness public, although his was not the first death due to AIDS in 1992.

### The second phase: institutionalization and self-organization: 1992-2002

In the second phase of the HIV and AIDS policy in Turkey, there was still the war between the Turkish state and the PKK going on, leading to fundamental demographic and economic changes in Turkey: the destruction of agriculture in Kurdish areas, forced migration from Kurdistan to western Turkey, irregular urbanization and suburbanization of the western regions, increasing unemployment, rising inflation and the impoverishment of the entire population were only a few consequences of the Kurdish emancipation movement and/or the conflict between the Turkish state and the PKK, which was also, more or less, influencing or even mobilizing other social movements in Turkey. On the other hand, this phase is characterized by the aftermath of the political climate in the wake of the military coup. In the 1990s, human rights violations and political repression reached its peak. Nevertheless, this phase is characterized by resistance movements, self-organization of social groups marginalized in different ways and increased human rights activism. However, the HIV and AIDS policy of the 1990s cannot be seen as detached from the prevailing political atmosphere, since AIDS activism is also one of the socio-political movements that have been, and still are, intertwined.

#### *HIV and AIDS interventions at the non-governmental level*

While the left and right movements were weakened in the wake of the military coup, the new social movements began to develop slowly but steadily. At the same time, Turkey was at the peak of its war with the PKK. The political agenda was therefore determined by this war and its socio-economic consequences. However, the early 1990s were also marked by an attempt at a new neoliberal policy by the ruling Motherland Party (Anavatan Partisi - ANAP), which

aimed at rapid urbanization and industrialization as well as the privatization of certain state institutions and a re-internationalization of the Turkish economy. At the same time, there was increased internal migration from the east to the west of Turkey.

During this time, the Motherland Party could neither eliminate nor reduce the influence of the military. Political persecution, arrests, torture, murder of intellectuals and journalists, restrictions on the freedom of the press and the freedom of speech, repression against (especially) Kurdish politicians and others continued during the conflict with the PKK. Due to the prevailing riots and the associated socio-economic instability, the 1990s are characterized throughout by political instability. Even though during these years Turkey experienced a total of seven parliamentary elections and ten changes of government with different political demands, each newly elected government pursued the same repressive policy under the influence of the military (Mater, 2008). This political climate, which considerably affected civil society, was, however, an important driver for the emergence of resistance and socio-political movements, which no longer defined themselves as left or right. Rather, they understood themselves as human rights organizations, initiatives, and/or groups that wanted to represent the human rights of different social groups and to implement them through activism. The 1990s are a symbol of “civil disobedience” due to and despite this repressive policy (ibid.). The queer movement, the women’s movement, environmental activism, political art, the liberation struggle of the Kurds, student self-organizations, the workers’ movement, antimilitarist associations, and struggles and resistances in other areas of social life became more visible and effective in this decade. For example, the Human Rights Association (İnsan Hakları Derneği), founded in 1986 (Human Rights Association Turkey, 2014), intensified its work in the 1990s and supported all forms of social movements organizing against human rights violations. The relation of civil society to western countries increasingly took on greater significance. With the support of European queer organizations queer groups were able for the first time to found lasting associations. A queer group was founded under the name Rainbow ‘92 (Gökkuşluğu ‘92). The relations between Turkish and German or European queers go back to the early 1980s. As shown above, there were also queer activists who fled to Europe and Germany after the military coup, possibly making contact with gay and lesbian groups there. After their return to Turkey, in 1987 some lesbians and gay men attempted to form a party with other activists, the Radical Democratic Green Party (Radikal Demokratik Yeşil Parti, RDYP), which was explicitly meant to campaign for the rights and issues of LGBTI people.<sup>5</sup> The German initiative Schwule Internationale initiated a collaboration with other queer

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<sup>5</sup> For more on this see (Çetin, 2016).

groups in Istanbul to organize a lesbian-gay parade in 1993 on the occasion of Gay Pride Day (ibid.). In those years, the anti-AIDS movement also increasingly managed to enter into civil society. While the fight against HIV and AIDS in the first phase was characterized by state intervention, the first self-organizations were emerging in the early 1990s, even if these initiatives were still not started by people with HIV, but by socially-conscious doctors, lawyers, and intellectuals. The first organizations explicitly devoted to fighting HIV and AIDS were founded in 1991 in Izmir AIDS ile Mücadele Derneği (Association for Combating AIDS) and in 1992 in Istanbul AIDS Savaşım Derneği (The Association for the Battle against AIDS). Muhtar Çokar, general secretary of IKGV (İnsan Kaynağını Geliştirme Vakfı – Foundation for the Development of Human Resources), stated that the founders of the two organizations were strong personalities, working closely with the Ministry of Health on the basis of their medical professional expertise, and that they were also able to acquire state subsidies and mobilize other institutions (Çokar, 2006a). For example, the founders, professors Dr. Enver Tali Çetin of AIDS Savaşım Derneği (The Association for the Battle against AIDS) and Dr. Melehat Okuyan of AIDS ile Mücadele Derneği (Association for Combating AIDS), were at various times employed by the Ministry of Health and also served on advisory councils of the Ministry. Through their positive relations with the Ministry, they were able to initiate cooperation between their associations and the state (ibid.). These associations viewed HIV and AIDS primarily from epidemiological and medical perspectives. The social dimensions of the epidemic became of great relevance in the associations' work only in later years, when their active doctors would also be confronted with the experiences of discrimination of their HIV and AIDS patients and therefore recognized a need for action in the social sphere.

Both these organizations had several goals, such as educating society, further education of personnel in the health system, organizing conferences and similar events, informational events for target groups, legal support for people with HIV, guaranteeing HIV treatment and medical care according to global standards, etc. For example, the “Association for Combating AIDS” has been collaborating since its foundation with the Ministry of Education to train teachers in this area. Unlike in European countries and the USA, this first organization in Turkey was not founded by people with HIV or AIDS, nor by activists, but by doctors from various medical areas. These areas included: pediatrics, gynaecology, public health, dentistry, and microbiology. Over the last few years, this association has opened other locations in Ankara and Istanbul. Both in the central office and in the group's other locations one

could/can take part in training workshops, anonymously and free of charge, receive counselling, and get tested.

Another goal of this association was education and awareness training in prisons. For instance, prisoners are informed about HIV and AIDS and are encouraged to get tested. This association's projects were largely funded through the Turkish Ministry of Health and international organizations like the European Union, the WHO, the Global Fund, the World Bank, the IMF, the UNPDF, etc.

At the same time, a large number of members of "The Association for the Battle against AIDS" worked as medical doctors in either the medical faculties of the state universities or in hospitals and therefore had direct contact with patients or with the first registered people with HIV. Out of political conviction, they did not just aim at a medicalized response to HIV and AIDS, but would also oppose the social discrimination and stigmatization of people living with HIV. Thus, for example, they were able to persuade the Ministry of Health to provide the first state infrastructural support – in the form of space, staff, and salary.

"The Association for the Battle against AIDS" dissolved in 2016 for financial and infrastructural reasons (lacking staff, for instance). This association opened a total of 22 locations throughout Turkey. The association was very well connected, both nationally and internationally, and addressed several groups regardless of HIV status. Their work included, for instance, holding informational events for and by persons with HIV, empowerment, self-help, education, legal and medical support, and networking people with HIV.

Other organizations, such as IKGV and TAPD (Family Planning Association in Turkey – Türkiye Aile Planlama Derneği), which were primarily concerned with population policy, reproductive health, the right to reproduction, and family policies, also devoted themselves to HIV and AIDS policies and managed to cooperate with the state relatively successfully. The reason for the "successful" cooperation with the state can be seen in the fact that these two organizations did not directly regard themselves as representatives of marginalized groups, which is why they were not considered in obvious opposition to the state's health policy.

In addition, the TAPD was set up as an organization of civil society due to demographic development in Turkey, and at that time pursued state demographic policies based on control and regulation of population growth. In this respect, this organization also took over several tasks of the state, especially with regard to access to the population.

The Family Planning Association (TAPD) was from the start a member of the International Federation for Family Planning (IPPF). TAPD had already begun to deal specifically with the topic of HIV and AIDS in 1986. The main target group of the association was students, and the goal was to inform and educate them about HIV and AIDS. TAPD was sponsored by funds from the European Union between 1994 and 1997. During this period, the target groups were extended to include parliamentarians, bureaucrats, and journalists and other people working in the media. TAPD was able to mobilize parliamentarians, bureaucrats, and the media landscape with its project “AIDS, intervention of top political and decision-making bodies” and make an important contribution to the normalization of AIDS as a topic. Within the framework of this EU-funded project, TAPD focused on the prevention of HIV and other sexually transmittable diseases and developed national programs and strategies. While the politicians and the government were mobilized, the media were sensitized to HIV and AIDS and made aware of ethical standards in reporting. The education of society was also one of the core objectives of TAPD. To achieve these goals, the TPAD focused on intersectorality, i.e. on cooperation between several sectors such as health, education, the media, and pharmacy, and could form advisory and working groups made up of representatives from universities, trade unions, non-governmental organizations, and institutions of public service (CEDAW, 1993). The founding of the National AIDS Commission (Ulusal AIDS Komisyonu – UAK) in 1996 was one of the most important initiatives of the association. In this committee, TPAD brought together different players from different sectors and played a major role in the formation of this national network against AIDS in Turkey (Başer, 1998). One of the other important organizations in the field of HIV and AIDS was IKGV (The Human Resources Development Foundation – İnsan Kaynağını Geliştirme Vakfı), which was founded in Istanbul in 1988. In the beginning, it carried out projects to improve reproductive health care, mother-child health, and family planning. Since 1994, following an “international conference on Population and Development (ICPD)” in Cairo,<sup>6</sup> the organization has also been committed to a human rights-based HIV and AIDS policy and is conducting various projects, campaigns, and research in this area. AIDS prevention, the sexual health of young people, the prevention of sexualized violence, the fight against human trafficking, and child labour are among the other priorities of the organization, which in the early 2000s also started dealing with

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<sup>6</sup> The ICPD took place through the initiative of the United Nations Population Fund in 1994 with the participation of 179 countries. At this conference, a new global population policy was adopted with a declaration. With this text, the governments involved committed themselves to implementing a jointly adopted action plan in their own countries. Some of the key issues of this action plan are combating HIV and AIDS and working against discrimination in the field of health and health services. (For more on this topic see: UNPF, 2014).

migration and flight in Turkey and supporting refugees there (Human Resource Development Foundation, without date).

### *HIV and AIDS interventions at the state level*

It was a success in the fight against HIV and AIDS that TPAD initiated the first action plan against HIV and AIDS in 1994 and was able to win state and non-state institutions over to it. From the point of view of movement history, this action plan can be considered a first attempt at lobbying within the AIDS movement. Within the context of this project, the goal was to develop a “national policy to combat AIDS” and to found a commission to do so. In 1996, the National AIDS Commission (Ulusal AIDS Komisyonu – UAK) was founded under the direction of the prime minister. The coordination office of the commission was placed under the Ministry of Health, and the “Family Planning Association in Turkey” took over the task as secretariat of this body. The commission consisted of civil society, 10 ministries, TRT (state television), and various professional branches that have a direct connection to HIV and AIDS. The National AIDS Commission had four working groups:

- social education,
- social counselling and support,
- academic work, and
- legislation

At the time of its founding the UAK was intended to observe the official strategies for managing HIV and AIDS, to evaluate them, and to plan effective prevention measures, as well as to support the implementation of these measures. In addition, this commission was supposed to meet twice a year and react as quickly as possible to any exceptional circumstances. For example, at the request of WHO, the commission was recalled in 2015 to develop and implement new prevention strategies and action plans because of the huge increase in HIV infections. The UAK was furthermore authorized to invite institutions outside the member organizations to its meetings, and if necessary to seek counsel from them. Since its founding the UAK has carried out several national plans of strategy and action and achieved its work through smaller working groups. The work of the UAK is based on the general principles of human rights. In relation to responding to HIV and AIDS in Turkey and protecting the human rights of people with HIV, the following working principles of the commission are significant:

UAK Principle 4 – Every individual, every group, state or non-state institution has the responsibility to protect itself from HIV and AIDS and to recognize and advocate for the human rights of people with HIV. AIDS can be combated in a climate in which equal rights and duties rule. Individuals voluntarily take part in this by believing in the future and on the basis of their own interests.

UAK Principle 12 – HIV and AIDS related policies and socio-pedagogical measures (education) are to be shaped and carried out with the active participation of people with HIV and AIDS.

UAK Principle 22 – State institutions, laws, and practices should not foster any discrimination against people with the HIV virus (sic). They should serve to protect them.

UAK Principle 23 – State institutions take advice from international organizations in order to conceive national policies for prevention, treatment, and social support and to make use of international support.

UAK Principle 25 – State institutions are responsible for the protection of public health. These institutions bear the responsibility for creating the policies and strategies to protect against HIV and AIDS and to facilitate access to health care for all citizens.

The commission has no legal entity, so its resolutions, recommendations, and goals are not legally binding. It functions as a kind of advisory group for the state and civil society. The members of the UAK are either employed in state agencies or they are representatives of non-governmental organizations. The working groups and their members work on a voluntary basis. The members meet exclusively in meetings that have become fairly irregular over the years. Participation in the meetings is also voluntary and regular participation is not expected. For these reasons, there are constant difficulties in maintaining cooperation. Even if the National AIDS Commission is an important step in the fights against HIV and AIDS, it is not very influential in political decision-making processes because structurally it neither has legal entity nor is it an institution of the state or a similarly functioning organization. There is therefore very little material sponsorship for the work of the UAK, which is why the proposed goals of observation, evaluation, and planning cannot be effectively followed.

Even if the UAK has not yet been able to do any effective work, its founding idea is an important political sign for the legal improvement of the health care system, for the protection of people with HIV from discrimination and stigma, and for human rights-based prevention strategies.

Today there are several non-governmental organizations that are calling on the state to support the UAK structurally and to formalize its existence. The commission met relatively regularly from 1996 until 2007. Due to the enormous increase in HIV cases in Turkey, the commission was called up again and in 2015 the members met once more (which means that between 2007 and 2015 there was no meeting at all). The 2015 meeting not only included participation by representatives from the various ministries, but also from science and civil society. Martin Donoghue from the WHO Regional Office for Europe was also invited to this meeting. In his lecture, Donoghue gave a report on the rate of increase of HIV infections at a European level. According to his report, this increase was 467% in Turkey in the period between 2004 and 2013. At a wider European level this figure was 81% (Pozitif Yaşam Derneği, 2015).

### The third phase: The AKP's New Turkey and the new public health policy: 2002-2015

#### *Self-organizations for and by HIV-positive people*

After Turkey was officially recognized as a candidate for joining the European Union at the EU Summit in Helsinki in 1999, international expectations rose with regard to reforms aimed at improving due process and the conditions for minorities and for civil society in general. Turkey reacted by passing a series of so-called “harmonization packages”. The legal and constitutional changes proposed included above all those concerning the expansion of freedom of thought and expression, the prevention of torture, the freedom and security of the individual, the right to privacy, the inviolability of the home, the freedom of communication, the freedom of residence and movement, the freedom of association, and gender equality. At the level of civil society, changes were to be instituted in the areas of gender equality, protection of children and the infirm, as well as freedom of assembly (Çetin, 2016). These EU-induced developments in Turkey had an immediate effect on the new social movements and contributed to the process of their institutionalization in the form of associations and/or by receiving the status of legal persons, which began in the second half of the 1980s and won stability with the reformation of the Turkish Associations Law.

The parliamentary elections in autumn 2002 led to the Justice and Development Party (AKP) taking power for the first time. Due to the heavy fragmentation in the party system and an extreme majority voting system, the AKP was able to win an absolute majority in parliament with only 34.2% of votes, which was to fundamentally alter the political and economic situation of the country in the long term. The AKP, which presented itself – despite its

Islamist roots – as a conservative-democratic party, declared the fulfilment of the political criteria from Copenhagen as part of its program. In its election platform in 2002 it called for a comprehensive reform of the constitution, meant to guarantee rights to all sections of the population regardless of their “differences” (ibid.). The platform in 2007 also cited the goal to reform the constitution, which was meant to be achieved by the 100th anniversary of the republic (2023). The one-party government of the AKP brought political stability and led to an economic boom. In a rapid reform process a series of harmonization packages were passed as part of the EU accession process, which influenced the next elections in July 2007 in favour of the AKP. The AKP was given credit for the path they were taking by large parts of the society. Along with the leading oppositional party, the Republican People’s Party (CHP), business leaders, academia, civil society, and the majority of the population endorsed joining the EU. This phase was of great importance for representatives of different social movements in order to gain visibility. For example, in November 2004, as part of the EU negotiations, the Turkish Associations Law was reformed. Now interest groups could found associations with significantly less bureaucratic efforts. The (old) Associations Law, adopted in 1983, not only had codified restrictions, but also maintained strict control of the associations and all of their activities. It forbade associations to do any political work, lobbying, and representation. “Limitations on the establishment of associations on the basis of race, ethnicity, religion, sect, region, or any other minority group are removed with the new law. Although constitutional prohibitions which could be used to restrict the establishment of certain kinds of association are invoked in the new law, recent practice suggests that associations are increasingly permitted to open, even when established on the basis of currently prohibited categories” (Commission of the European Communities, 2004). The new act was limited to setting the framework for founding associations and only contains 40 articles, whereas the old Associations Law consisted of 97. It lifted a number of restrictions that were introduced after the military coup in 1980, thus alleviating the difficulties of organizing associations, platforms, and foundations in civil society (Çetin, 2016).

With the strengthening of the AKP government under the reign of Recep Tayyip Erdoğan and the adoption of the new Associations Law, one can speak of the beginning of a new phase of HIV and AIDS policy in that the new Associations Law encouraged queer-feminist, anti-racist, and system-critical activists, including those who fight discrimination against people with HIV and stand up for equal treatment for all people in the health system.

*The phase of Positive Living*

One of the important organizations for combating HIV and AIDS currently was founded in Istanbul in 2005, one year after the passing of the new Associations Law, with the name “Positive Living Association” (Pozitif Yaşam Derneği). This association brings together people with HIV and AIDS, their families, activists, and experts. The group’s main goal is free and accessible medical care, as well as psychological support for people with HIV and AIDS.

According to their self-presentation, the initiative “Positive Living” was formed in 2003 by a few people with HIV in order to support each other. In the course of the first few years, the support of some activists, medical doctors, and people working with UNAIDS could be won by the group. The first activities of the association were organized through an electronic mailing list titled “HIV POZITIF”, also serving to network HIV-positive people. This was especially important for those who did not live in Istanbul and therefore were unable to obtain vital information on the ground. The mailing list also served as a kind of safer space where HIV-positive people could empower themselves. In this mailing list, the participants exchanged their experiences as people living with HIV and therefore exposed to different forms of discrimination and stigma. Through this exchange of experiences, one can assume that they supported each other and built a collective awareness of emancipatory self-organization. In 2004, some participants in this list decided to set up an association for and by HIV-positive people. Since that year, it was possible for almost all groups in the population to establish their own associations or to gain institutional status in the form of self-organization. So the Pozitif Yaşam Derneği association was founded in Istanbul in June 2005. Because people with HIV were among the initiators of Pozitif Yaşam Derneği, the association is also considered by doctors, lawyers, and people with HIV to be the first self-organization in the history of HIV and AIDS policy in Turkey. Since 2006, the association has received funding from the Global Fund and the Ministry of Health in Turkey. Since its inception, the association has also been recognized by the Ministry as a representative of people living with HIV and is invited to attend meetings of the UAK because of its expertise.

Pozitif Yaşam Derneği has been offering free peer counselling for HIV-positive persons and their relatives, psychosocial support, psychotherapy, nutritional counselling, legal support and the establishment of contact with attorneys-at-law, assistance with access to free medicines and treatment, and free HIV testing. In addition to these offers aimed specifically at the target group, the association organizes workshops as well as further education and awareness-raising

seminars for people from different sectors of work. Pozitif Yaşam Derneği has been trying to create a lobby for people with HIV since its inception. To this end, human rights violations against HIV-positive people are monitored, documented, and published, questions are posed to members of parliament on a regular basis, legislation to enhance the rights of HIV-positive people in different areas (constitution, labour and civil law as well as criminal law) is proposed, and international cooperation with other organizations is sought.

Another organization founded in 2006 in the period of the AKP and the new Associations Law is the Association of the Positive (Pozitifler Derneği – PODER). This association is considered the second organization by and for HIV-positive people in Turkey. PODER works directly with and for people with HIV and tries to provide HIV-positive people with access to health care services and to support them in their positive living in the domestic or everyday life area. PODER saw itself neither as an activist association nor as a representative of people with HIV. The association limited itself to supporting HIV-positive people in need of domestic care and other forms of aid in their everyday lives through care, support, and counselling (Çokar et al., 2008). This association no longer exists today and neither in literature nor in the internet is there any detailed information to be found about its work and projects.

### *HIV/AIDS NGO platform*

Even though several organizations, groups and initiatives have been formed in Turkey, and have participated in different socio-political arenas, e.g. in health policy, their effectiveness is either very limited or temporary in nature due to domestic political reasons. Muhtar Çokar attributes this situation, among other factors, to the structural conditions imposed by state institutions (Çokar, 2006b). In detail, he outlines the situation as follows:

- HIV and AIDS prevention is not one of the priority areas on the health policy agenda of the state and the public services. Non-governmental organizations therefore do not receive social-political support for their activities.
- Even though the UAK consists of a large number of governmental and non-governmental organizations and institutions, its power of action is limited because it lacks status as a legal person, or rather dependent on the general health policy of the governing party, whose agenda has different priorities. Non-governmental organizations are particularly affected by this situation, which means that their role in the design and implementation of national HIV and AIDS policies remains marginal.

- Until the mid-2000s there was no continuous program in Turkey for monitoring and evaluating the spread of HIV infections. This has resulted in the failure of the planning, design, and implementation of HIV and AIDS policies in Turkey and uncertainty about the future prevention and anti-discrimination activities of non-governmental organizations.
- Under these social and health policy conditions, there was either inequality in the distribution of financial resources or they were used otherwise and therefore could not fulfil their purpose in terms of prevention and anti-discrimination.

Because of this marginalization of non-governmental organizations, which are mainly representative of certain groups, a new association was launched in 2007 with the name “HIV/AIDS STK Platformu” (HIV/AIDS Civil Society Platform). Ten non-governmental organizations, including KAOS GL, Pembe Hayat LGBTT Dayanisma Derneği, Pozitifler Derneği, Pozitif Yaşam Derneği, and IKGV, participated in this platform (ibid.). The platform aimed at tackling the global, regional, and local causes of HIV and sensitizing society to the issue. Prevention, social support for people with HIV, and the development of human rights-based monitoring, counselling and treatment concepts, lobbying, and public relations are further objectives of the platform.

In the third phase of the history of HIV and AIDS, self-organizations as well as others dealing with sexually transmittable infections and reproductive health are focusing on the legal situation of people with HIV as well as HIV and AIDS legal regulations and basic conditions. Although in the early years the topic of HIV and AIDS was discussed in the media as well as on the level of health policy, there were no legal regulations to protect people with HIV against discrimination and stigma in institutional and social areas of public life. With the rise in HIV infections since the 2000s, the labor and civil law issues that have increasingly affected HIV-positive people became more visible, and new legislation is needed to improve the situation of people living with HIV (Çokar, 2008). As part of a cooperation between the Ministry of Health and the Global Fund, a new program “HIV/AIDS Prevention and Support Program for Turkey” (Türkiye HIV/AIDS Önleme ve Destek Programı) was launched in 2005 (ibid.). Within the framework of this program all areas of the law affecting people with HIV are to be reviewed and evaluated; then proposals to the government are to be formulated, aiming to improve their legal situation. The platform renders its work visible in the form of questions posed to political parties and the parliament.

*HIV/AIDS Prevention and Support Program for Turkey*

Due to the increase in HIV infections in this phase, international health organizations such as the WHO and the Global Fund are increasingly interfering in Turkey's health policy on the one hand, while on the other initiating concrete cooperation on HIV and AIDS prevention and anti-discrimination work. For instance, the "HIV/AIDS Prevention and Support Program for Turkey" (Türkiye HIV/AIDS Önleme ve Destek Programı) is a good example of an intersectoral and nationwide project involving not only the state institutions, but also various organizations from the field of reproductive health, as well as self-organizations of people with HIV, such as the Association of Positive Living. This project, funded by the Global Fund between 2005-2007, enabled a more or less successful cooperation between the state and civil society; on the other hand, it aimed at HIV and AIDS work that fully takes into account the needs and problems of people living with HIV as well as sensitizing society as a whole, the media, and the public and private health institutions to the issue. A total of eleven projects have been carried out in five large cities, a number of voluntary consulting and anonymous test centres opened, and a wide range of brochures and leaflets with information for different target groups (police, media, NGOs, and certain key groups such as sex workers, men who have sex with men, prisoners, drug users, etc.) appeared. In addition to the publications and the opening of the consulting and testing centres, numerous further educational courses as well as workshops were implemented. As part of a project, the Positive Living association also took on the evaluation of existing laws (for example, employment, civil, and criminal law) and the drafting of new legislation to protect people from discrimination based on a possible HIV status (KLİMİK, 2015; Çokar et al., 2008).

While in the 2000s there was a decline in HIV infections in western countries, there has been a rapid rise in Turkey for reasons that have not yet been sufficiently investigated (NTV, 2015). There are a variety of explanations for the increase in HIV-positive people in Turkey. First, some scientists assume that there are more and more people in Turkey who are informed and sensitized about HIV and other sexually transmitted infections and can therefore be tested, which ultimately leads to an increase in the number of registered HIV-positive data. So the more people get tested, the higher the statistics would be year after year. On the other hand, there are other scientists who observe certain changes in people's safe/unsafe sexual behavior. These assume that people would be prone to unsafe forms of sexual behavior due to improved treatment options and assured access to different medications, which would ultimately contribute to the spread of the infection. Another assumption is that, as a result of improved health services, fewer and fewer people are dying of HIV and AIDS, but new

infections are constantly being added so that the number of people living with HIV does not remain constant, but it continues to increase due to the new registered cases.

### **EXCURSE: HIV AND AIDS AND INTERNATIONAL COLLABORATION**

According to the research done so far, there are several international projects on the topic of HIV/AIDS that have included participation by agents from Turkey. The organizations usually finance their projects by means of international funds (usually EU funds) and the Turkish Ministry of Health. The following are three of the most important international organizations and networks supporting projects in Turkey:

#### World Health Organisation (WHO)

Turkey belongs to the founding states of the WHO and has been a member since June 9, 1949. Since becoming a member, Turkey has also accepted the Constitution of the World Health Organization. Geographically, the WHO places Turkey in the European realm. There is a WHO country office in Turkey. Turkey receives regular material support for local projects from the WHO. The Ministry of Health in Turkey has a positive view of the relationship between the WHO and Turkey. At the end of the 1980s Turkey introduced the first National AIDS Control Program on the basis of WHO recommendations. The WHO observes and documents the spread of HIV infection and publishes these with recommendations for health policy. The Ministry of Health follows the recommendations and goals of the WHO and attempts to implement them. Some examples of the recommendations formulated by the WHO are: a) verifying political and economic structures in order to facilitate access to health care for everyone in order to prevent HIV/AIDS, b) integrating approaches like harm reduction with HIV/AIDS, tuberculosis, mother-child health, and drug users, c) support and fortification of the health care system in order to develop and expand public health, d) protecting key populations through new measures against legal and structural barriers (Pozitif Yaşam Derneği, 2010).

#### UNFPA–United Nations Population Fund<sup>7</sup>

UNFPA started working in 1969 and began working with the Government of Turkey in 1971. UNFPA Turkey activities were initially carried out on a project-by-project basis. Since the beginning of this cooperation the UNPFA has supported Turkey in the areas listed below:<sup>8</sup>

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<sup>7</sup> This section is taken from the website of the UNFPA and includes minor changes.

- Promoting mother and child health,
- Improving reproductive health and rights,
- Empowering young people to fulfil their potential
- Promoting gender equality,
- Combating violence against women,
- Enhancing the collection, use, and dissemination of development data.

### UNDP (The United Nations Development Program) and UNAIDS

UNDP Turkey plays an active role in the UN Country Team's Thematic Group on HIV/AIDS to integrate HIV/AIDS issues and concerns into UNDP's programs and strategies. In partnership with other UN agencies in Turkey, UNDP contributes to the objectives of strengthening the national response to HIV/AIDS, supporting advocacy and coalition-building among national stakeholders, and supporting education, training, and awareness-raising. In particular, UNDP's programmes focusing on young people and street children in south-eastern Anatolia (the GAP region) will enable awareness-raising and training on HIV/AIDS related issues. These in turn help to strengthen national efforts at awareness and prevention among at-risk and vulnerable populations.

### UNAIDS: A joint response to HIV/AIDS

The joint United Nations Programme on HIV/AIDS, UNAIDS, is the main advocate for global action on the epidemic. It leads, strengthens, and supports an expanded response aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS, and alleviating the impact of the epidemic.

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<sup>8</sup> UNFPA. Available at: <http://turkey.unfpa.org/tr/node/9295> [Accessed 29 Jan. 2018].

## CONCLUSION

The history of HIV and AIDS policy in Turkey can be subsumed from four perspectives:

- HIV and AIDS policy from an institutional or governmental perspective,
- HIV and AIDS policy from the perspective of NGOs,
- HIV and AIDS policy from the perspective of self-representation (advocacy) and finally,
- HIV and AIDS policy from the intersectoral perspective

HIV and AIDS policy from the institutional or governmental perspective primarily means state intervention and strategies since the early stages of HIV and AIDS in Turkey. On the basis of the history described in this article, it can be said that the Turkish Ministry of Health reacted relatively quickly to the spreading of HIV infections and made the first steps in prevention and health education. For example, the High Advisory Board on AIDS was established in 1987, the National AIDS Committee was established in 1993, and the National AIDS Commission was established in 1996 by state and non-state initiatives. Since the first phase, blood and organ donors and registered sex workers have been tested for HIV. Since 2002, future married couples have to be tested before the wedding in order to determine whether or not the prospective spouses are HIV-positive. However, HIV-positive test results do not bar people from marrying (Çokar et al., 2008). In addition, all health care facilities offering the HIV test are required to transfer the number of clients and the results to the Ministry of Health. Even though Turkey is always guided by the recommendations and guidelines of the WHO in the area of sexually transmittable infections, it can be seen at the institutional level that the state-sponsored prevention work was initially based on an overall control policy. However, the discussion in this article has equally shown that the protection of people living with HIV has also attracted increasing attention at the institutional level and that more and more anti-discrimination and sensitizing projects such as free and anonymous counselling and test centres are being promoted, the number of which increases every year.

HIV and AIDS policy from the NGO's point of view describes the HIV and AIDS work of non-governmental organizations, emphasizing reproductive health, family planning, women and health, and mother-child health. In the initial phase of the HIV and AIDS work, these organizations had the leading role and focused on the level of civil society. The Family Planning Association in Turkey (TAPD), the Family Planning and Health Foundation (TAPV), and the Human Resources Development Foundation (IKGV) have been providing preventive and later anti-discrimination work since the mid-1980s and are still active in this

area. These organizations initiated the first cooperation with the state and at the same time with the international health organizations and contributed to the improvement of sexual and reproductive health. Without claiming to represent them, they also worked for and with the vulnerable groups which have greater potential for HIV infection due to their precarious socio-economic living conditions.

HIV and AIDS policy from the perspective of self-representation here means the work of certain self-organizations who were and are working for and with people with HIV. In the earlier stages of the second phase, organizations with a focus on HIV and AIDS, among others, were established under the umbrella term “sexually transmittable diseases” and reproductive health. Their goal was to create a lobby for people with HIV and to represent them on different levels of society. However, they were not founded by people with HIV, but by some medical doctors and members of other social movements. They represented people with HIV both in the public health and anti-discrimination policies as well as in the general public. This claim of representing people with HIV by doctors has been legitimized by the successes of the anti-AIDS work at the local, regional, and global levels, although in later phases different conflicts of interest and financial problems arose and the first interest organizations like AIDS Savaşım Derneği and AIDS ile Mücadele Derneği had to close. With the new Associations Law described above, new organizations or associations were founded after 2004 based on the argument of the necessity of self-representation. Thus the organizations Positive Living Association (Pozitif Yaşam Derneği), in 2005, and Association of the Positive (Pozitifler Derneği), in 2006, were founded by and for people with HIV, among others. These new associations proved not only able to continue the successful work of the older AIDS organizations on the non-governmental level, but also to expand it on behalf of the target groups to the level of representation.

HIV and AIDS policy from the intersectoral perspective means the close collaboration of different non-governmental organizations from different sectors or fields of work and their interventions in the state’s HIV and AIDS policy since the beginning of the history of HIV and AIDS. While Turkey has experienced a political upheaval with the AKP in power since 2002, a new awareness of self-organization has emerged in all areas of society. The new Associations Law, adopted within the framework of the harmonization packages resulting from the country’s intended accession to the EU, and facilitating the establishment of a legal entity, also contributed to a boom in the founding of new associations which had emerged from the earlier new social movements and/or activism and were now, through the status of legal entity, able to work in a more professional way. The HIV/AIDS STK Platformu

(HIV/AIDS NGO Platform), the founding history and objectives of which have been discussed above, can be regarded as a prime example for intersectoral HIV and AIDS work. This platform has achieved national and international co-operation with different organizations and (health) scientific institutions, with the aim of expanding the number of member organizations nationwide. It has adopted concrete tasks under headings such as Communication/PR, Information/Education, Resource Development, Representation of Interest, Observation of Human Rights Violations, and Research. This HIV and AIDS NGO platform has been able to reach national and international NGOs, private and governmental institutions from different sectors. Taking into account the history recounted here so far, HIV and AIDS policy at the intersectoral level can be viewed as a gain for different actors.

With the intersectoral HIV and AIDS policy approach, many sectors and areas have been sensitized to the issue; in addition to the prevention work a more or less functioning anti-discrimination policy could be developed; HIV and AIDS are no longer defined by so-called risk groups; an understanding of self-organization and self-representation has prevailed, and in this context, the state has been constantly called upon following a human rights-based HIV and AIDS policy. Although these developments seem positive at first sight, both the self-organizations, such as Pozitif Yaşam Derneği, as well as other actors from different socio-political areas, seek to maximize the improvements and criticize the failure of the state's human rights policy also with regard to people with HIV.

### **LOOKING FORWARD**

Within the framework of this working paper, an attempt was made to provide an overview of the historical development of HIV and AIDS politics in Turkey from the interrelated perspectives of activism, civil society, health policy, and media along three phases. The goal of this working paper was not to present how these histories are interrelated with other histories of social movements, but to trace them in their complexity and interdependencies. While working on the EUROPACH project and in exchange with other researchers from Poland, the UK, Switzerland, and Germany, several new research questions on the history of HIV and AIDS in Turkey were proposed, which either had to remain open in this working paper or at the very most answered cursorily.

One example of the central questions that remain open is “how and whether we can consider the HIV and AIDS movement in Turkey a new social movement,” in light of the fact that “old” social movements, which were understood as either left-wing or right-wing, had been destroyed during the 1980s by the military regime. A large number of intellectuals as well as

left-wing and right-wing activists from the old social movements fled to European countries or the USA after the military coup, where they came into contact with the new social movements in the respective western, post-industrialist countries. After returning to Turkey in the second half of the 1980s, during which the political bans established by the coup had been lifted, the former exiles attempted to import the new social movements, which had existed in the western countries since at least the 1960s, to Turkey. One example of this is the queer movement in Turkey, although the emergence of this movement cannot be restricted to the influence of the western movements.<sup>9</sup> The fact that trans sex workers engaged in a hunger strike in 1987, not only as a struggle for recognition of their identity, but also for basic human rights, or that LGBTI groups had collectively protested against police violence in Istanbul's queer streets in 1996, are reminiscent for many queer activists in Turkey today of the Stonewall Riots in the US. In order to address the question above on a better understanding and consideration of the HIV and AIDS movement, I referred in this paper to the concept of new social movements taken from Donatella della Porta and Mario Diani (della Porta & Diani, 1999). According to them, a new social movement is characterized by collective organizing in post-industrial countries, by the demand to restructure the concept of equal citizenship, and by the call for establishment of new individual rights. For della Porta und Diani the agents of the new social movements demand close cooperation between the state and those citizens and their representatives that are marked as "others" and thus remain marginal as unequal/outsider citizens in political discussions. This means that new social movements insist on publicness, or in transparent discussions of political topics that had previously been treated without the participation of the affected groups by the ruling politicians and the political parties present in the parliament. The goal of the new social movements is for the agents of the movements to be recognized as equal citizens in the policy world, for them to be allowed to have a voice in political affairs. It is against this backdrop that they question the ordinary concept of citizenship and seek to redefine it (Topal Demiroğlu, 2014).

Since the social structure in Turkey is markedly heterogeneous due to the particularities of its geography, economy, politics, and specific population groups, the concepts of new social movements established in the west cannot be directly transferred over, and certainly not always for the entire country. Because the differences in Turkey between eastern and western, urban and rural, rich and poor, Sunni and Alevi, as well as Turkish and non-Turkish are so clearly and historically anchored, the social movements that arise there must be examined

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<sup>9</sup> For more on this see (Çetin, 2016).

against the backdrop of these specific political and social histories. In this context, a further question was raised as to the causal connection between the Kurdish movement and the HIV-AIDS movement, which again requires a particular analysis. In order to address this, however, a subsequent question should be asked, namely whether or not the Kurdish movement can be viewed as a new social movement. Even if the activists and militants in the Kurdish movement can generally be described as leftist, and their struggle is based on Frantz Fanon's theory of legitimate anti-colonial violence (Fanon, 1961), it is difficult to classify it as a new or old social movement. And it is not only this theoretical basis of the Kurdish movement that make such a classification impossible, but also the political circumstances under which this struggle was, and still is, being carried out. Aside from this problematic, it is clear that both the Kurdish and the HIV and AID movements arose during the same period under the similar political circumstances of a military regime. While Kurds struggled for recognition of their basic rights, such as the right to their language, their land, the freedom to practice their religious and cultural traditions, for education, health, and housing, the war between Turkey and the PKK destroyed areas inhabited by the Kurdish population on all social levels. Neither the Turkish state nor the warring PKK party bore the brunt from this war. Because of this war Kurdish citizens were forced either to abandon their towns and villages and to migrate to western Turkey, or if they remained they had to lead their lives in a destroyed Kurdistan, for instance without access to education and health care. In this respect, the early activists in the HIV and AIDS movement were also aware that there were also people in Kurdistan who, while they were indeed Turkish citizens, were nonetheless not capable or not allowed to take advantage of their rights as citizens. Early HIV and AIDS activists, for example in Antep and Diyarbakir—two large cities in Kurdistan—took up a variety of prevention and medical care measures, working in solidarity with Kurds affected by war. This kind of solidarity is typical for the new social movements, because a collective was formed time and again in opposition to existing state power in order to be able to struggle together, not only for human rights as they pertained to specific groups, but also in general, and to compel the state to engage in these debates on human rights in public, with and for those affected.

Another question from the research groups was “how the focus on human rights became central to the Turkish social movements.” Turkey is a country that still does not belong to the European Union for a variety of reasons, and that by now, due to the conservative government, no longer will/wants to become a member of that union. Nonetheless, since the end of the Second World War Turkey has participated in the constitution of several international and supranational organizations, institutions, and commissions, either as a co-

founder or as a signatory. In 1949, for instance, long before the creation of the EU, Turkey joined the Council of Europe, in which debates about human rights were held, and human rights conventions and anti-discrimination guidelines were negotiated and adopted. Turkey has also been a founding member of the World Health Organization since 1946, and ratified the Universal Declaration of Human Rights (UDHR) on April 6, 1949. These examples indicate that the topic of human rights has not only been relevant within the new social movements, but has long been an essential component of a country that has, ever since it was founded, been between a (colonial) political Europe and a homogenous Muslim Near and Middle East defined as foreign. Due to its geographical position, an important geopolitical role has been ascribed to Turkey time and again, or Turkey has been made responsible for the security of Europe, for instance when a “refugee deal” was struck in 2016 to house refugees from Syria, Iraq, or Afghanistan in order to block their way to “liberal” Europe. Alongside this border regime, which is based in arguments about international security, economically influenced military interventions by the Global North have usually been justified with reference to some sort of human rights violations in the Near and Middle East (women’s rights and gay rights) (Yılmaz-Günay, 2014). The question of human rights “there” has thus been turned into an instrument of global power relations “here.”

The understanding of human rights, like in many places in the world, is above all based on equal treatment or non-discrimination of persons, independently of any racist, heteronormative, colonial-capitalist qualities attributed to them. This means that the struggles against colonial-racist, cultural-dominant, nationalist, heteronormative, and class-based power relations can be found everywhere, since wherever there are movements for human rights, there are also practices of human rights abuses. The question of how the topic of human rights has taken on a central role in Turkish social movements can be worked out through further research in Turkey, on site, and with the agents of the movements, and above all mediated from their perspectives. Working with the histories and politics of HIV and AIDS in Turkey has shown that these histories and politics are interwoven, and cannot be viewed separately from one another. From the perspectives of these agents, HIV and AIDS prevention and anti-discrimination work in Turkey cannot be limited to a marginalized population group, such as LGBTI, (trans) sex workers, or prisoners. Because the first generation of HIV and AIDS movements recognized the social dimensions of the epidemic relatively early on, they have worked against discrimination alongside securing social health policies. Different agents in Turkey constantly emphasize the necessity of working on human rights from the perspectives of the state, the civil society, activism, and those affected. The founding of a (not always

effective) National AIDS Commission was an attempt to establish human rights-based HIV and AIDS politics in collaboration with international and supranational organizations.

One final question posed by EUROPACH researchers should be addressed here: “What has changed through all these developments and interventions. Is there something like a normalization? Or an institutionalization? Or professionalization?” One purpose of this paper was to trace the political and social transformations in Turkey without necessarily making a complete claim to represent these social movements, political and social developments. It was clear that on the one hand HIV and AIDS have generated discriminatory politics and practices on various levels of society. At the same time, however, anti-discrimination movements have been organized that are not only dedicated only to protecting HIV positive people, but also seek to contribute to social awareness. Since the beginning these movements have defined those affected by HIV and AIDS not by means of any identity marker (defined from outside). They have viewed HIV and AIDS as a problem for society as a whole, which should be approached horizontally. For example, the term “risk groups,” which was imported from the west, was criticized relatively early on, and a new understanding of “risk behaviour” was developed instead. According to this critical perspective all people, regardless of their age, sex/gender, sexual orientation, profession, ethnic/racialized affiliation, nationality, social status, etc., can belong to risk groups. That is why critical actors in the field prefer to speak about risky behaviour rather than risk groups. As mentioned above, it is primarily the intensive collaboration between a variety of state and non-state actors, as well as national and international organizations, that has led to this understanding. Aygen Tümer, who works at Hacettepe University HIV/AIDS Treatment and Research Centre (HATAM), also confirms the assumption that the term is no longer being used in recent years. Instead they speak of people who show/practice risk behaviour. “Risk behaviour” is thus no longer reduced to sexual behaviour and sexual practices, but expanded to include other behavioural patterns that can lead to infection with HIV. This exemplary development can be viewed as an indication of normalization and professionalization, at least in the field of HIV and AIDS politics in Turkey. The most current situation under a conservative-repressive government has not been explicitly addressed in this paper. Such a reflection has been opened up in the framework of the EUROPACH project, as well as in the form of oral histories and interviews with experts and other actors in the field of HIV and AIDS online, as well as in the form of books and further publications.

\*Translated from German by Salih Alexander Wolter and Daniel Hendrickson

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