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**Vulnerability assessment of people living with HIV (PLHIV) in
Turkey**

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**United Nations Development Programme in
Eastern Europe and the CIS project**

Vulnerability assessment of people living with HIV (PLHIV) in Turkey*

United Nations Development Programme



Sociological Association, Ankara

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* Bu araştırma projesi, Sosyoloji Derneği adına Prof. Dr. Aytül Kasapoğlu başkanlığında, Prof. Dr. Nilay Çabuk Kaya, Doçent Doktor Feryal Turan ve Doçent Doktor Elif Kuş Saillard tarafından gerçekleştirilmiş ve raporlaştırılmıştır.

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Authors

The research was conducted and the report was written by sociologists (*Prof. Dr. Aytül Kasapođlu, Associate Professor Dr. Nilay abuk Kaya, Assistant Professor Dr. Feryal Turan, Research Assistant Dr. Elif Kuş*) from the Sociological Association, which was subcontracted to conduct the study in Turkey.

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The research team was also in contact with a number of experts from the Ministry of Health, who are responsible for the implementation of the National Action Plan in order to ensure that a realistic and balanced picture of the HIV and AIDS situation in Turkey is presented.

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Acronyms

ART	Antiretroviral therapy
FPAT	The Family Planning Association of Turkey
IDU	Injection drug use
IEC	Information, education and communication
MOH	Turkish Ministry of Health
MSM	Men who have sex with men
NAC	National AIDS Commission
PLHIV	People living with HIV
SP	Service provider
STD	Sexually transmitted disease
SW	Sex worker

Executive summary

This report aims to explain the social vulnerabilities associated with HIV and AIDS in Turkey. The research will identify specific recommendations and strategies for reducing the stigma towards and vulnerability of people living with HIV (PLHIV).

The HIV epidemic is spreading all over the world, and the number of people living with HIV in Turkey has been increasing. The first AIDS case in Turkey was officially reported in 1985. According to data from the Turkish Ministry of Health (MOH), the total number of reported HIV and AIDS cases in the period between 1985 and 2006 is 2,544. However, the actual number of HIV and AIDS cases remains unclear. It is likely to be higher than the official number of reported cases, due to limitations in HIV surveillance and monitoring, inadequate rates of testing, and a long asymptomatic period whereby HIV infection can remain undetected.

Most of the people with living HIV and AIDS in Turkey are male (69%) and the percentage of females is relatively low (31%). According to Ministry of Health data, the main mode of transmission is heterosexual sexual intercourse (1343 recorded infections), followed by men having sex with men (MSM; 207 infections) and injection drug use (IDU; 120 infections). However, the mode of transmission in many reported cases is unknown (599) suggesting that these figures are somewhat unreliable.

HIV is not yet seen as an important health problem in Turkey due to the low number of people living with the disease. However, there are several risk factors related to the increasing spread of HIV in Turkey that should be taken into consideration. Commercial sex work is considered to be the major driver of the epidemic in Turkey, which is reasonable given the epidemiological stage of HIV/AIDS in Turkey and the low prevalence of drug use. It is also important to note that sex workers from Eastern European and the former Soviet Union come to Turkey on tourist visas and work as commercial sex workers.

Although the first AIDS case was reported in 1985, HIV and AIDS have not been regarded as priorities in national policy. Three commissions for HIV/AIDS-related issues have been established: the High AIDS Commission in 1987, the AIDS Counsel Commission in 1993, and the National

AIDS Commission in 1996, The National AIDS Commission has organized annual meetings since its inception. It is the only defined decision mechanism for Turkey, but its membership is diverse and members do not always attend meetings. Hence the Commission's effectiveness and responsiveness remains limited. It is obvious that limited budget allocation for health is the main constraint preventing improvements in the quality and the range of health services for both the general public and PLHIV.

Since 1987 serologic tests have been compulsory for blood and organ donors and registered sex workers, and since 2002 HIV testing has been required for couples before getting married. All health centres that perform HIV tests report their test results to the MOH. In 1994 HIV/AIDS was included in the coding system of communicable diseases.

In the Constitution of Turkey, there is no clear reference to allow PLHIV to make full use of their fundamental rights and freedoms. As seen in most countries during the initial stage of the epidemic, stigmatization and discrimination are now widespread in Turkey, making vulnerable groups hard to reach and targeted prevention activities difficult to implement. There are no specific legal arrangements addressing the educational rights of children living with HIV, but these children can benefit from general Constitutional rights. The lack of legal arrangements for children living with HIV and AIDS in education is a significant gap in Turkish law.

Turkish law does not currently address discrimination against PLHIV in the workplace. According to The Labour Act of Turkey (Law No. 4857: date 22.05.2003 - Article 5.) discrimination based on language, race, sex, political opinion, philosophical belief, religion and sex or similar reasons is prohibited in an employment relationship. Discrimination against people living with HIV introduces a significant additional consideration in the national framework concerning anti-discrimination and workers' rights. Employers often justify the termination of known PLHIV by giving unrelated reasons, even when there is no legitimate ground for ending employment.

All aspects of treatment and health care of PLWHA are covered by various health insurance systems (i.e., Emekli Sandığı, Sosyal Sigortalar and BAĞ-KUR) in Turkey. PLHIV are guaranteed HIV and

AIDS-related medical treatment including antiretroviral therapy (ART), which is provided free by the state.

Non-governmental organizations (NGOs) are the most active and devoted national stakeholders in the process of addressing HIV and AIDS in Turkey. The scope of their activities is limited, however. Most engage in advocacy and information, education and communication (IEC) activities, such as publishing educational materials or conducting training programs for adolescents, students, the general public, and specific vulnerable groups. Besides these NGOs that address prevention, NGOs founded by PLHIV have recently started to provide support services to PLHIV.

Although PLHIV are represented in almost all urban areas, most are from Istanbul, Izmir, Ankara and Antalya. It is also possible to say that HIV and AIDS cases have been identified in all provinces but most PLHIV are registered in Istanbul, a city of more than 15 million people. This may be due to the anonymity problem. In the small provinces or towns the social pressure is much more than big cities and people who have AIDS/HIV cannot explain their illness in these places. In addition to this problem, patients living in rural areas have to travel long distances to receive treatment in bigger cities.

In order to understand the conditions of PLHIV in Turkey, this study used three different data collection techniques. These included: (1) Literature review of the epidemiological and policy research on HIV and AIDS in Turkey, with a specific focus on the social context of PLHIV; (2) In-depth interviews with PLHIV; and (3) Focus group discussions with representatives of institutions (i.e., education, health and employment)

The research team carried out 20 interviews: 16 of them were with PLHIV; three were with parents of HIV-positive children (one father and two mothers); and one was with the wife of an HIV-positive individual.

The study adopted purposive sampling to achieve a sample that approximated the distribution of the PLHIV population in Turkey. Sixteen of the individuals were recruited through the Positive Living Association NGO, three were recruited through HATAM (Hacettepe University Treatment and Research Center/Ankara), and one was recruited through the Numune Hospital in Ankara. The team

carried out interviews in Ankara and Istanbul by using face-to-face or telephone interviewing. While the sample has strong representation from Istanbul because that is where most PLHIV live in Turkey, the study was also able to access some HIV-positive residents of Ankara and other cities, including Malatya, Konya and Iğdır. The team was successful in recruiting an equal number of participants from several target risk groups identified by the UNDP: sex workers (SWs) and men who have sex with men (MSM). It was impossible to interview an injection drug user for this study.

The main objective of focus group discussions was to understand society's general ideas and attitudes toward PLHIV. The research team carried out focus groups with representatives of school institutions, the business sector and health-related institutions. Following a suggestion from the Positive Living Association, an additional fourth focus group was carried out with representatives of the health sector. The focus groups were carried out in Ankara (2) and Istanbul (2).

The key findings of the study demonstrate shortages in three sectors; health, education and employment.

- The individual interviews revealed that PLHIV perceive high levels of stigma directed toward them.
- The focus groups confirmed this finding, as most the professionals from the three sectors reported stigmatizing attitudes towards PLHIV. The professionals themselves openly stated this fact and explained the main reason as their lack of knowledge about the issue. Health professionals dealing with PLHIV also stated some institutional insufficiencies that contribute to fears of contagion among medical personnel.
- All HIV treatment costs are covered by social security, but psychological treatment and support is not provided to PLHIV. Psychological consultations are given voluntarily by some physicians, but there is a lack of systematic psychological support to PLHIV. Therefore, health professionals highlighted the need for financial support of this service.

- The most important employment-related problem is the bureaucratic procedures of pension funds and social security.
- Their main source of support for PLHIV is their families. They also receive support from service providers (especially infectionists) and NGOs (such as the Positive Living Association). PLHIV who contributed to the work of NGOs reported increases in their self-esteem.
- The problems most commonly mentioned by both the professionals and PLHIV were the invisibility of PLHIV in the country and problems such as unawareness and ignorance.

CHAPTER 1: INTRODUCTION

This report aims to explain the social vulnerabilities associated with HIV and AIDS in Turkey. The research will identify specific recommendations and strategies for reducing stigma towards and vulnerability among people living with HIV (PLHIV).

Turkey has a population of 73,875 million.¹ The population of Turkey is expected to reach 76 million in the year 2010 and 88 million in 2025.² Turkey is located between Europe and Asia, inhabiting a region that represents one of the most rapidly expanding HIV epidemics in the world. Furthermore, Turkey is located along the major drug transit route, which originates in South and Central Asia and radiates outward toward Europe. Due to its geographic proximity to other national epidemics (e.g., in Ukraine, Russia), Turkey risks having a significant HIV epidemic.

The risk of the rapid spread of HIV is high. Commercial sex work is considered to be the major driver of the epidemic in Turkey,³ given the epidemiological stage of HIV/AIDS in Turkey and the low prevalence of drug use. It is also important to note that sex workers from Eastern European and the former Soviet Union come to Turkey by tourist visas and work as commercial sex workers.⁴ The high prevalence rate in Eastern Europe may have an important impact on Turkey. It is reasonable to assume that trading activities and tourism increase the risk of HIV/AIDS in Turkey.⁵

The Turkish society encountered its first AIDS case in 1985. Twenty years later, studies show that the level of information about HIV and AIDS in Turkish society remains insufficient.⁶ Studies have examined levels of HIV knowledge within high-risk groups, including samples of adolescents,

¹ SIS projection for 2006

² Population Reference Bureau, 1999

³ P.Altan, UNGASS Indicators Country Report: Reporting Period January 2003-December 2005. Ankara:MOH; (2006); P Ay and S.Karabey, "Is There A Hidden HIV/AIDS Epidemic in Turkey: The GAP Between the Numbers and The Facts", Marmara Medical Journal, 19 (2):.90-97. 2006

⁴ Ay and Karabey, 2006

⁵ Ay and Karabey, 2006.

⁶ U. Ertuğrul, .). HIV/AIDS: Current Status in Turkey and Policies of the Ministry of Health. *AIDS Savasım Bulletin*, 38:14-16. (2001); M. Kontas. HIV/AIDS in the World and Turkey. In S. A. Simsek (Ed.), *6th Turkey AIDS congress book* (pp. 13-19). Istanbul: Markon Press. 2003;

healthcare professionals, sex workers and workers in the tourism industry.⁷ Other studies have examined attitudes towards HIV and AIDS in general community samples, including workers at beauty salons⁸ and university and high school students.⁹ The main findings of these research studies highlight the need for improved education about HIV prevention and modes of transmission.

Campbell has stated that women are at high risk of HIV transmission through gender-defined roles and gender stratification.¹⁰ The gender roles peculiar to the Turkish society also make women more vulnerable and therefore put them at risk of HIV infection.

it is possible to say that the behavior of men and women is differentiated in all cultures, and there is strong social pressure to maintain these distinctions. Since the beginning of the 1980s, changes in Turkey's social and economic structure have had considerable impact on the traditional roles of men and women in the society. Although the traditional social pressure related gender is still dominant in most parts of the country, particularly in rural parts, the impact of the changes in the demographic,

⁷ V.Duyan et.al., Surgeons' attitudes toward HIV/AIDS in Turkey, *AIDS Care*, 13:243-250.; 2001; S Köksal, et.al., The Knowledge Levels of the People Working in the Tourism Sector on AIDS. In E. T. Çetin (Ed.), *2nd Turkey AIDS Congress book* (pp. 59-60). Istanbul: AIDS Combat Society Press. 1995.; S.Savaşer., Knowledge and Attitudes of High School Students About AIDS: A Turkish Perspective. *Public Health Nursing*, 20: 71-79. 2003.; A.Unsal et.al., Level of knowledge of Nurses About AIDS in Several Health Services of Eskisehir. *General Medical Journal*, 9: 53-58,1999.; Yıldırım, 2003; cited in N. Acaroğlu., Knowledge and Attitudes of Mariners About AIDS in Turkey. *Journal of the Association of Nurses in AIDS Care*, 18 (1):48-55. 2007.

⁸ Kişioğlu, et al., Isparta'daki Kuaför ve Güzellik Salonlarında HIV/AIDS Konusunda Bilgi ve Durum Değerlendirmesi (Evaluation of Situation and Knowledge about HIV/AIDS at Hair Dressers and Beauty Saloons of Isparta). *HIV/AIDS*, 6 (2),2003.

⁹ L. Dönmez. Akdeniz Üniversitesi Turizm Yüksek Okulu ve Beden Eğitimi ve Spor Yüksek Okulu Öğrencilerinin Cinsel Tutum ve Davranışları (Akdeniz University Tourism and Sport Academy Students' Sexual Attitudes and Behavior) *HIV/AIDS*, 4 (2):147-151. 1999; Deniz, et al., Cinsel Yolla Bulaşan Enfeksiyonlar Konusunda Üniversite Öğrencilerinin Görüşleri(University Students' Views About Sexually Transmitted Diseases) *HIV/AIDS*, 7 (2). 2004; N. Güler, et al., Lise Öğrencilerinin HIV/AIDS Konusundaki Bilgi Düzeylerinin Belirlenmesi(Determination of Knowledge Level of High School Students about HIV/AIDS) *HIV/AIDS*, 6 (1). 2003;.

B. Demirtaş, Bir Üniversitenin Eczacılık Fakültesi Birinci Sınıf Öğrencilerinin Cinsel Yolla Bulaşan Hastalıklara İlişkin Bilgileri.(Junior Pharmacy Students' Knowledge Towards Sexually Transmitted Diseases) *HIV/AIDS*. 2005; G. Ekuklu, et al Trakya Üniversitesi Tıp Fakültesi Öğrencilerinin HIV/AIDS Konusundaki Bilgi Tutumları ve 1996'dan Buyana Değişimi.(Trakya University School of Medicine Students' Knowledge and Attitudes on HIV/AIDS and Their Change since 1996) *HIV/AIDS*, 8 (1). 2005.

Ş. Aras, et. al., Lise Öğrencilerinin Tutum ve Davranış Özellikleri, *Sağlık ve Toplum*, 14:78-87, 2004

S. Bulduk, et al. Adölesanların HIV/AIDS Bilgi Düzeyleri ve Hastalığa Karşı Sosyal Önyargıları (Adolescents' Level of Information about HIV/AIDS and Their Social Prejudices about the Disease). *Sted*, 15(8). 2006 ; İnce et al., İstanbul İli Silivri İlçesi Adölesan Dönem gençliğinin AIDS ve Stigma Konusunda Çeşitli Eğitim Yöntemlerinin Etkinliği. (Effectiveness of Various Educational Methods for AIDS and Stigmatization on Adolescents Youth of İstanbul/Silivri). *İstanbul Tıp Fakültesi Dergisi*, 69 (3):63-69,2006.

¹⁰ C. A. Campbell, Women, Families, and HIV/AIDS: A Sociological Perspective on the Epidemic in America. Cambridge: Cambridge University Pres. 1999.

legal, and economic situation has been felt especially in the big cities. Some women has not benefited education and health services. As stated in the UNAIDS Turkey Situation Analysis¹¹, the reproductive health status of women in Turkey is low compared to developed countries.

Overview of the HIV epidemic in Turkey

Since the first reported AIDS case in 1985, the total number of reported HIV and AIDS cases in Turkey in the period between 1985 and 2006 has reached 2,544. As shown in Table 1, there were only two patients in 1985, but the total numbers of new HIV diagnoses increased each year, reaching 33 new cases in 1990, 158 new cases in 2000, and 290 new cases in 2006. This increase might be the result of increased testing (e.g., through the projects run by the Global Fund programme).

Table1.Reported HIV/AIDS Cases by Year

Year	Case	HIV (+)	Total
1985	1	1	2
1986	2	3	5
1987	7	27	34
1988	9	26	35
1989	11	20	31
1990	14	19	33
1991	17	21	38
1992	28	36	64
1993	29	45	74
1994	34	52	86
1995	34	57	91
1996	37	82	119
1997	38	105	143
1998	29	80	109
1999	28	91	119
2000	46	112	158
2001	40	144	184
2002	48	142	190
2003	52	145	197
2004	47	163	210
2005	37	295	332
2006	35	255	290

¹¹ UNAIDS Turkey Situation Analysis 2006.

Total	623	1921	2544
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Source: www.unaids.org-Türkiye'de HIV/AIDS verileri.

However, the actual number of HIV and AIDS cases remains unclear. As discussed by several researchers,¹² the actual numbers of HIV and AIDS cases are likely to be significantly higher than the reported number of cases. The main reason for underreporting may be systemic: there is no comprehensive surveillance system for HIV and AIDS cases in Turkey, making it impossible to estimate the reliability of the data. The long asymptomatic period of the HIV disease also undermines reliable estimates of HIV incidence. Societal factors, including ignorance and stigmatization of HIV, also limit accurate surveillance and monitoring; these factors challenge efforts to improve rates of testing in the general population.

Factors contributing to the rise in HIV infections in Turkey are as follows¹³:

- Increasing numbers of sex workers, especially unregistered sex workers
- Developed tourism sector
- Population movements
- A large number of people working abroad (for example, Europe)
- Increasing prevalence of injection drug use in recent years

Although traditional values and customs still have an important impact, industrialization, urbanization and education have resulted in social and cultural changes in Turkey. As a result of these changes, young people in some parts of Turkey have greater sexual freedom than previous generations, and they are also at greater risk of sexually transmitted infections (STIs), including HIV. In this context, the attitude of young people and their behaviour in terms of sexual and reproductive health should be evaluated properly by experts and health professionals.¹⁴ The spread of STIs is influenced not only by rates of sexual intercourse, but also by the habit of using condoms.

¹² V.Duyan and G. Yıldırım “A Brief Picture of HIV/AIDS in Turkey”, AIDS Patient Care and STDs, 17(8):373-375, 2003; A.Tümer, “HIV/AIDS and other Diseases Infected by Sexual Relations” in Manual for Centers of Testing and Voluntary Counseling .Ankara :General Directorate of Primary Health Care of MOH, 2006.

¹³ Tümer, 2006. p.31

¹⁴ Aras et al., (2004).

As a result of these social and cultural changes, reproductive health education for youth is necessary.¹⁵

Most people with HIV and AIDS in Turkey are male (69%) and the percentage of females is relatively low (31%)¹⁶ (see Table 2). Among all reported cases, the male-female ratio is 2:1.¹⁷ The number of women living with HIV is low, but it should be noted that women are an increasingly vulnerable group.

Table 2. Distribution of cases by gender and age.

Age-groups	Male	Female	Total
0	13	4	17
1-4	6	12	18
5-9	3	8	11
10-12	3	2	5
13-14	1	1	2
15-19	23	37	61
20-24	150	166	316
25-29	241	139	380
30-34	304	108	412
35-39	276	58	334
40-49	300	68	369
50-59	158	63	221
60 and +	76	26	102
Unknown	200	96	296
TOTAL	1755	789	2544

Ministry of Health (2006) www.saglik.gov.tr

Risk factors for HIV infection in Turkey

“The epidemiological pattern of the HIV epidemic in Turkey is very similar to the one in Africa, where heterosexual transmission represents the main mode of transmission.”¹⁸ According to the statistics of the Ministry of Health, the main mode of transmission is heterosexual sexual intercourse (1343 infections), followed by men having sex with men (MSM; 207 infections) and injection drug use (IDU; 120 infections) (see Annex 7). It should be noted that the mode of transmission for 599

¹⁵ (Dönmez, 1999; Deniz, et al., 2004; Güler, et al., 2003; Demirtaş, 2005; Ekuklu, et al., 2005, Aras, et al., 2004, Bulduk, et al., 2006, İnce et al., 2006.

¹⁶ Tümer,2006.

¹⁷ Ay and Karabey,:p:92, 2006

¹⁸ Ay and Karabey, p:92, 2006.

cases is unknown; these are all among men, and many may be attributed to injection drug use or sex between men. There are no reliable data on the number of sex workers (SWs), MSM, or IDU in Turkey. A recent surveillance study shows that the risk is higher in MSM and IDU.¹⁹

HIV/AIDS in Turkey is not generally regarded as an important health problem due to the small number of people living with the disease. According to Duyan and Yıldırım²⁰, a young population and inadequate knowledge about sexually transmitted diseases are the main factors increasing the number of HIV cases in Turkey. There is an urgent need to improve scientific research, to ensure that HIV and AIDS become a priority among policies, projects and actions, and to organize educational programs to inform people about how to protect themselves.

Socio-economic picture of PLHIV in Turkey

Although reliable data on HIV and AIDS are limited, various sources of information have addressed the social context and cultural environment of PLHIV in Turkey. These include governmental reports (especially reports of Ministry of Health) and non-governmental reports.

Several studies have confirmed the MOH's findings regarding the gender distribution of PLHIV in Turkey. For example, a study carried out by Numune Hospital in Ankara reported on 67 PLHIV, of whom 76.2% were male. The average age of individuals in this study was 39.8 years.²¹ Another study was conducted in the clinics of both Hacettepe and Numune Hospitals. This study reported on 76 PLHIV, of whom 67.6% were male. This study also confirmed the MOH's findings on mode of transmission. The highest percentage of stated transmission from partner is "having a sexual relationship abroad" (37%). Most PLHIV in the study were married (55.5%).

¹⁹ ICON-INSTITUT Public Sector GmbH (D), Hacettepe University (TR), Price Leopold Institute of Tropical Medicine(B). Reproductive Health Programme in Turkey: Operations Research on Key Sexually Transmitted Infections (STIs) and Human Immunodeficiency Virus (HIV) in Turkey., Nisan –Özet Rapor 2007, EuropeAid/121388/C/SV/TR

²⁰ Duyan and Yıldırım, 2003.

²¹ Eren et al., HIV/AIDS Olgularında Ölüm Nedenleri(Causes of Deaths in HIV/AIDS Cases). *Türk HIV/AIDS Tıp Dergisi*, 6, 4. 2003

Another study involved 36 HIV-positive individuals from Istanbul, Ankara and Izmir, and it provides some information about the socioeconomic status of PLHIV. Two-thirds of these individuals were male, 33.3% were aged 25-36 years, and 58.3% reported having been infected via a sexual relationship. Fifty percent were married, and 36.1% had graduated from high school. One quarter of the individuals had a Green Card, 55.6% did not have a job that provided a regular income, and 47.1% had no regular job. However, 78.8% reported receiving social support from their families.²²

According to the UNGASS Country Report,²³ socio-economic and socio-cultural features as well as demographic characteristics of the population are leading factors contributing to the rapid spread of sexually transmitted infections (STIs), including HIV. However, this report does not provide any information about employment status, income, education, marital status, social security, or other factors.

Policy responses to HIV and AIDS in Turkey

Twenty years after Turkey experienced its first AIDS diagnosis, HIV still has not been regarded as a priority for national policy. Major policy milestones are described here.

Several national commissions to address HIV and AIDS in Turkey have been established, including the High AIDS Commission in 1987, the AIDS Counsel Commission in 1993, and the National AIDS Commission in 1996.²⁴ The overarching aim of the National AIDS Commission (NAC) is to scale up the national response to HIV and AIDS. It is chaired by the Ministry of Health (MOH). A national NGO, the Family Planning Association of Turkey (FPAT), functions as the secretariat of the NAC. FPAT organizes NAC activities under the supervision of the MOH. With the contribution of 30 national counterparts from public institutions, academies and NGOs, the NAC identified national targets and strategies in 1996, and prepared a plan of action composed of the following

²² Akıncı & Öz, HIV/AIDS'li Hastaların Tedaviye Uyumunu Etkileyen Psikososyal Faktörler (Psychosocial Factors Affect PLWHA Patients' Adaptation to Treatment). *Türk HIV/AIDS Tıp Dergisi*, 6, 4. 2003.

²³ UNGASS Country Report Turkey, Ministry of Health, 2006,

²⁴ A.Namal,. AIDS'li Dünyamız ve Ülkemiz (Our Country and World with AIDS). DATE of ACSESS: 10.03.2007 http://www.tr.net/saglik/genel_saglik_aids_dunya_ulkemiz.shtml, 2007

components: prevention; diagnosis, treatment and social support; legislation; and information dissemination and research (TCR). Although the NAC was established in 1996, it does not function at full efficiency. It is the only defined decision mechanism for Turkey, but its membership is diverse and some members do not participate regularly in meetings. Hence the Commission's effectiveness and responsiveness remains limited.

In 1994, the Declaration on HIV and AIDS stated that HIV status is a private issue of PLHIV (i.e., a personal and private health condition). The UN HIV/AIDS Theme Group of Turkey was founded in 1996.

Other international institutions providing support are the United Nations Development Fund for Women (UNICEF) and the United Nations Population Fund (UNFPA). In 1999 the Human Resource Development Foundation (HRDF), a member of the National AIDS Commission from its inception, participated in preparing the National AIDS Plan of Turkey and proposed a report called the "Turkey National AIDS Commission."²⁵

The Declaration of Commitments on HIV/AIDS was adopted by the UN General Assembly Special Session on HIV/AIDS on 27 June 2001. The European Union has also started a process of reflection, research and renovated efforts to understand and combat the epidemic in Europe and neighbouring partner countries. Turkey has a different support frame because it is already a candidate country. The main concerns in Turkey are the accuracy of health information systems and the stigma associated with HIV, which prevents many people from undergoing voluntary testing.

In 2002 an Action Plan was developed with national objectives and strategies for 2002-2006. Two important projects supported by European Union and Global Fund also started during this time.

The target areas of EU support include training, upgrading selected health facilities, improving surveys and research, and increasing prevention activities for HIV and other STIs in Turkey. The main projects specific for combating HIV/AIDS in Turkey are the following:

²⁵ United Nation) Declaration of Commitment on HIV/AIDS, 2001.

Reproductive Health Programme in Turkey (European Union Projects): The aim of this programme is to improve the sexual and reproductive health status of the Turkish population, especially women. Specific objectives of the programme are to increase the utilisation of services related to sexual and reproductive health and to improve the policy environment to better support human rights and choices. The programme provides direct support to the Ministry of Health (MOH) in implementing the National Strategy for Women's Health and Family Planning, which aims to increase the accessibility and quality of services.

Some projects from the EuropeAid funding programme are as follows;

- *Mass Media Campaign for Increasing Community Awareness on Maternal and Neonatal Health Issues.* The programme includes campaigns about STI and HIV/AIDS.
- *Supply of Laboratory Equipment for Ministry of Health Provincial Laboratories and Refik Saydam Hygiene Centre.* HIV/AIDS testing is performed in all of these laboratories.
- *Operations Research on Key Sexually Transmitted Infections (STIs) and Human Immunodeficiency Virus (HIV) in Turkey.*²⁶

More recently, the Ministry of Health has been carrying out the “Turkey HIV/AIDS Prevention and Support Project,” supported by the Global Fund (2005-2007). The project aims to cover sex workers, IDU, MSM, and prisoners. The objectives of this project are to increase the accessibility of preventive services to sex workers, IDU, and MSM; provide public access to voluntary counselling services; provide PLHIV with access to psycho-social support services; amend legislation to provide PLHIV with legal support; and increase the accessibility of HIV prevention programs in prisons. Some governmental organizations and NGOs are currently engaged in this project (e.g., The Skin and Venereal Disease Hospital and Dispensary, New Health and Education Association, DOKARGENÇ (East Black sea Region Youth Association), Positive Living Association, KAOS-GL (Gay and Lesbians Association), KLIMIK, and HRDF).

Although projects to support PLHIV have been initiated within the framework of the HIV/AIDS Prevention and Support Programme, the well-being of PLHIV does not have priority in existing policies. But the draft report for the 2006-2010 National Action Plan includes initiatives to

²⁶ European Parliament: Combating HIV/AIDS in the Neighbouring Countries of the EU, Briefing Note, December 2006

strengthen the accessibility of treatment, counseling services, legislation, and social support. The draft also includes the following topics: a more powerful surveillance system for sexually transmitted infections (STI) and HIV/AIDS; a national surveillance and evaluation plan; services to prevent the transmission of HIV from mother to child; and prevention services for groups at heightened risk. This plan remains under development and has not yet been announced.

Legislation addressing HIV and AIDS

In the Constitution of the Turkish Republic, there is no reference to the fundamental rights and freedoms of PLHIV. The Prevention of AIDS Report²⁷ provides some information about civil liberties for PLHIV (see Annex 3). A Report on the Violation of Rights of People Living with HIV in Turkey²⁸ stated that a total of 103 rights violations have been reported. For example, the report reviewed findings showing that some clinics have denied care to PLHIV, that HIV-positive mothers have been forced to give birth to children in non-obstetric wards, and that PLHIV have received poor dental treatment. Other documented rights violations include:

- Denial of educational rights.
- Termination of employment.
- Compulsory HIV testing of sex workers. The results of these tests have been announced by non specialist authorities.
- Invasion of privacy and personal discretion.
- Compulsory HIV testing of people who apply for military service, student dormitories and other positions.

Stigmatization and discrimination related to high-risk groups, such as MSM and IDUs, are widespread in Turkey. In 1987, a compulsory serologic test was applied to individuals in some of the vulnerable groups. For example HIV tests were compulsory for individuals in prisons and in the military, which caused discriminative practices.²⁹ These procedures not only violated individuals'

²⁷ Human Resources Development Foundation The Prevention of AIDS Report, National AIDS Commission. 1999.

²⁸ Positive Living Association, A Report on the Violation of Rights of People Living with HIV in Turkey, 2007.

²⁹ Y.T.Demircan, , Yasalarda HIV/AIDS ile ilgili Durum Analizi Yapılması, İstanbul. 2006; Positive Living Association, 2007.

privacy, but also took no precautions to prevent the dissemination of information about individuals' HIV status. The widespread discrimination against vulnerable groups has made these individuals hard to reach, complicating the implementation of targeted prevention activities.

Access to education

There are no specific legal arrangements addressing the educational rights of children living with HIV, although these children can benefit from more general Constitutional rights. The Constitution of the Turkish Republic and related laws support non-discrimination in principle, but legal discrepancies have caused some children to be denied their rights. Though there is no legal arrangement specifically for PLHIV, some Constitutional Rights such as articles 2 and 10 are related to HIV-positive individuals.³⁰

In 2003, a seven-year-old HIV-positive child (Y.O) faced tragic discrimination at school. Twenty-nine parents who did not want their children to be in the same class with Y.O protested by not sending their children to school. Although the Educational Directorship of Izmir supported Y.O to continue his education, parents insisted on their protest.

The lack of legal arrangements for children living with HIV in the education system is a significant gap in Turkish law, which may allow the rights of HIV-positive children to be violated. Therefore, there is an urgent need to develop policies in the area of education.

Access to employment

According to [The Labour Act of Turkey](#) (Law No. 4857, dated 22.05.2003, Article 5.) no discrimination based on language, race, sex, political opinion, philosophical belief, religion and sex or similar reasons is permissible in an employment relationship.

Discrimination against people living with HIV has implications for policies and structural frameworks aiming to protect workers' rights in Turkey. Some applications of the legal framework can contribute to negative discrimination against PLHIV, such as Law No. 4857 (dated 22.05.2003).

³⁰ (<http://www.die.gov.tr/CIN/childrights.html> and <http://www.die.gov.tr/CIN/legislation-general-principles.htm>).

According to this law, an employee's contract can be terminated if he or she is infected with a non-work-related illness; it is unknown whether this article can be used against HIV-positive employees. According to the Positive Living Association report³¹ violations of employee rights are common.

Access to health care

In Turkey the right to medical care is protected in the constitution and can be summarized as "Everyone has right to medical care without discrimination." The 17th article of the Constitution of the Turkish Republic states that "everyone has the right to life." A detailed policy of health rights is presented in the 3rd section and 56th article of the Constitution, under the heading of "Social and Economic Rights and Duties."

It is well known that the health care system is constantly changing. Since the founding of the Republic, health and health care services have been given priority in the government and efforts have been made in every term to improve health care services and the health care system. However, health care services in Turkey have still not fulfilled all of the nation's objectives.

The legal basis for patient rights in Turkey are founded on the Medical Ethics Code of 1961. The Patients Bill of Rights, which was published in the official gazette and became valid on 1 August 1998,³² is a more recent step. This bill sets out human rights in the health care arena, discussing all institutions and establishments that provide health care services. It sets out methods and principles that are intended to enable all patients to take advantage of their rights, to gain protection from rights abuses, and to use legal methods to protect their rights and human dignity as necessary.³³ The document was based on the Constitution of the Turkish Republic, supplemented by other regulations and international legal texts. Patient rights are defined as "the rights of individuals who have a need for health care services," which are guaranteed to all because they are a person under the Constitution of the Turkish Republic, international treaties, laws and other regulations.³⁴

³¹ Positive Living Association's report , 2007.

³² Positive Living Association, İnsan Hakları ve Hasta Hakları Bağlamında HIV/AIDS, İstanbul,2006.

³³ A.D. Erdemir & Ö.S. Elcioğlu, Patient's and Physican's Rights regarding Medical Ethics, Ankara, trükiye Klinikleri Pub., 2000.

³⁴ Ibid.

Although the right to health care is protected in the Constitution, it is important to note that only 30% of the Turkish population is covered by social security.³⁵

Health care services are the most important services for PLHIV. According to the Positive Living Association's report,³⁶ 63% of human rights violations alleged by PLHIV have involved access to health care.

Social security for PLHIV in Turkey

All aspects of health care for PLHIV in Turkey are financed by various health insurance systems (including Emekli Sandığı, Sosyal Sigortalar and BAĞ-KUR). PLHIV are guaranteed HIV and AIDS-related medical treatment, including antiretroviral therapy (ART), which is provided free by the state. In 1994 a new procedure was instituted for poor individuals who are not covered by insurance; the state now guarantees health services to all individuals who lack financial means or health insurance. People who use state-provided (or subsidized) health services are given a "Green Card" which they present to appropriate health providers. PLHIV who lack social security are eligible for a Green Card.

However, one of the main problems in Turkey is that the costs for treatment are very high compared to income. Sex workers who are officially registered might benefit from health services; however, unregistered sex workers have limited access to health care.

Health services for PLHIV in Turkey

In the face of increasing vulnerability to STDs and HIV, the Ministry of Health gives higher priority to curative health services. The emphasis given to primary and preventive health care is considerably limited and concentrates mainly on neonatal care and family planning. "Although the existing health care system has serious problems and requires radical reform, it still embraces a significant amount of trained personnel and ample health infrastructure as well as considerable institutional

³⁵ M .Tokat. Turkish Health Care Expenditures and Financing in 1997. MoH General Directory of health Project,1997

³⁶ Ibid.

experience.”³⁷ PLHIV are also affected by the infrastructure of the existing health system, including any institutional problems.

Care and treatment of PLHIV

The Ministry of Health (MOH) in Turkey is primarily responsible for regular monitoring and evaluation of the implementation of the National Strategic Action Plan. In relation to the response to HIV and AIDS, the MOH follows the recommended control strategies of the World Health Organization. The MOH monitors HIV infections and also is responsible for providing both preventive and treatment services. Furthermore, there are a number of AIDS associations such as the Istanbul AIDS Eradication Association, the Izmir Anti-AIDS Association, the Hacettepe Research Center, and other university centres.

Other services available for PLHIV

NGOs are the most active and devoted national stakeholders in the process of addressing HIV and AIDS in Turkey. The scope of their activities is limited, but most of them have experience with advocacy and information, education and communication (IEC) activities, such as training programs for adolescents, students, the public, and specific vulnerable groups. The mandate of most of the experienced NGOs is reproductive and sexual health, which includes HIV and AIDS-related activities³⁸.

Some NGOs provide support to PLHIV, such as the Positive Living Association (established in 2005), which has started a support centre in İstanbul. The Positive Living Association provides expert medical, psychological, legal, and nutritional support; it also assists PLHIV in accessing medical treatment and other services. More recently, the Association of Positives (PODER) has begun providing care services especially to PLHIV. Nevertheless, there is still an urgent need for a stronger governmental policy to address the rights of PLHIV and enable them overcome service barriers using legal, ethical and social means.

³⁷ (www.unescap.org/esid/psis/population/5appc/doc/Turkey_country_report.doc - 12/22/2003)..

³⁸ (www.unescap.org/esid/psis/population/5appc/doc/Turkey_country_report.doc - 12/22/2003).

Conclusion

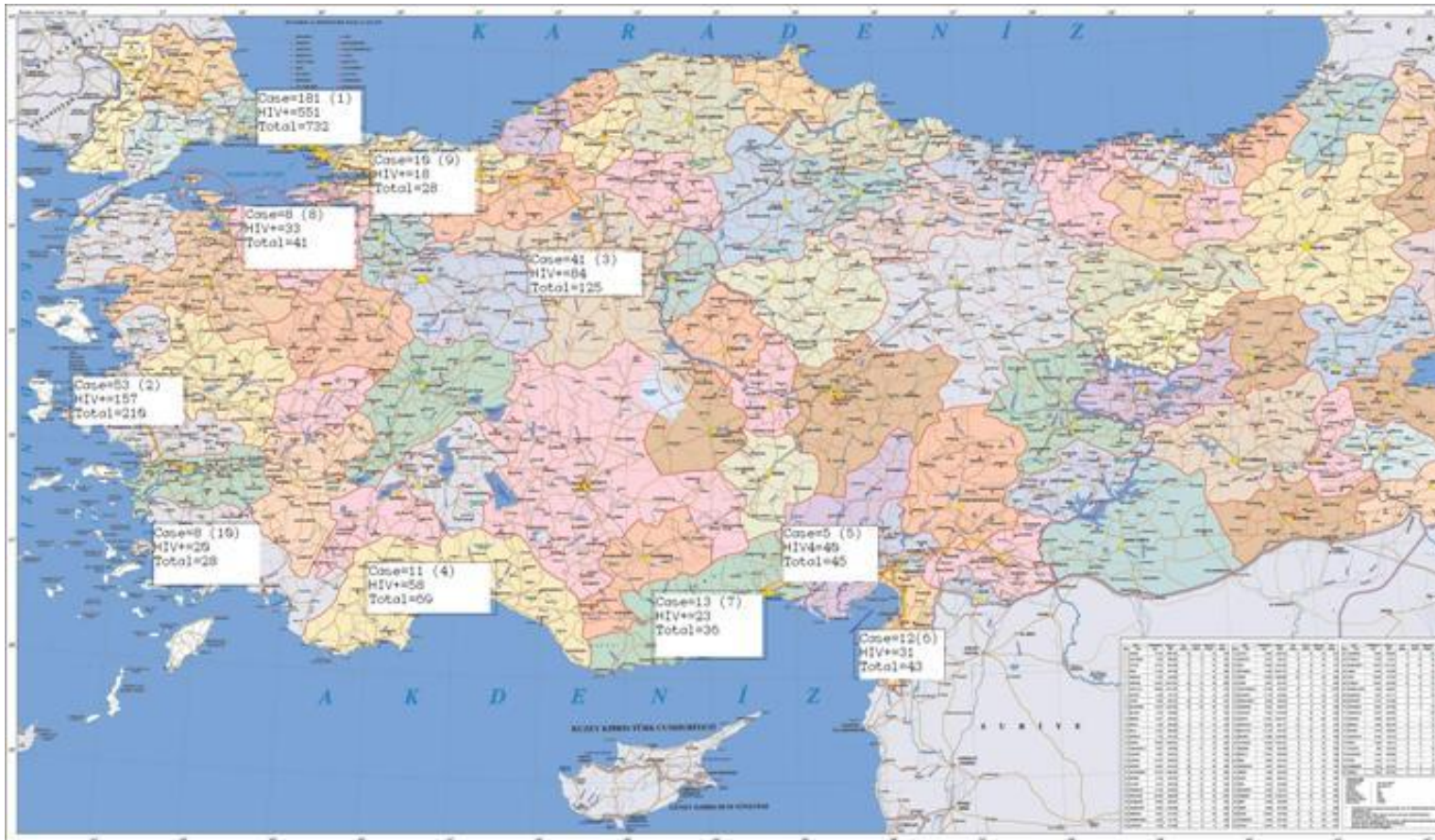
Current data arguably underestimate the prevalence of HIV and AIDS in Turkey. The surveillance system does not include sufficient monitoring and testing for determining HIV and AIDS prevalence. The lack of statistics on the number of sex workers, MSM, and IDU further challenges accurate data collection and decreases the ability to target prevention activities and awareness-raising initiatives. As described in Turkey's Country Report (2006), the demographic, social, and economic characteristics of Turkey may facilitate the rapid spread of HIV.

CHAPTER 2: Community Mapping

Geographical distribution of PLHIV

Although PLHIV are represented in almost all urban areas, most are from Istanbul, Izmir, Ankara and Antalya. HIV and AIDS cases have been identified in all provinces, but most PLHIV are registered in Istanbul, where more than 15 million people live.

Map 1: Distribution of HIV and AIDS prevalence in cities of Turkey



Data Source= Ministry of Health, 2006. www.saglik.gov.tr

Selection of regions for the study

HIV and AIDS cases have been identified in 76 provinces in the seven regions of Turkey. Four regions - Marmara, Aegean, Mediterranean, and Central Anatolia - have the highest populations of PLHIV in Turkey. Most PLHIV are in coastal regions. Three regions were selected for the sample in this study. Two are coastal regions (Marmara and Aegean) and the other is the central region (Central Anatolia).

The main criteria for the selection of districts were as follows:

- The district should be a high-risk province in terms of HIV prevalence;
- The district should be a high-risk province in terms of immigration;
- The district should provide considerably advanced public services (health, education, employment, etc.).

One province satisfying the above-mentioned criteria was selected from each of the three regions. The rationales for selecting the regions and districts/provinces for the study are presented in Table 3.

Table 3. Selection criteria and rationale

REGION	DISTRICT	RATIONALE
Marmara	<p>ISTANBUL Population = 10,018,735 (in 2000) Annual growth rate of population (‰) = 33.09 (1990-2000) Population density = 1928 (in 2000) Migration = 920,955 (in 2000) Rate of net migration (‰) = 46.09 (in 2000) HIV-positive (593) + Case (184) = Total 777</p>	<p>Immigration from other regions makes Istanbul more vulnerable to HIV.</p> <p>Istanbul is dominated by immigrant people from all over Turkey and situated on the national highway between Europe and Asia. Its border districts (Kocaeli, Bursa) also have large numbers of PLHIV.</p> <p>Istanbul is a mega-city and is located in the urban industrial area.</p>

<p>Aegean</p>	<p>IZMIR Population = 3,370,866 (in 2000) Annual growth rate of population (‰) = 22.39 (1990- 2000) Population density = 281 (in 2000) Migration = 306,387 (in 2000) Rate of net migration (‰) = 39.88 (in 2000) HIV-positive (168) + Case (56) = Total 224</p>	<p>Izmir is a province of Turkey in Western Anatolia on the Aegean coast. Izmir is the third largest city in Turkey and has the second largest harbour (industrial city). Izmir is the second highest risk area because of the large number of reported cases. Izmir is a compelling site for this study because it was the first documented place where an HIV-positive child experienced problems in the educational system.</p>
<p>Central Anatolia</p>	<p>ANKARA Population = 4,007,860 (in 2000) Annual growth rate of population (‰) = 21.37 (in 2000) Population density = 163 (in 2000) Migration = 377,108 (in 2000) Rate of net migration (‰) = 25.59 (in 2000) HIV-positive (86) + Case (41) = Total 127</p>	<p>Ankara is the capital city of Turkey. As a metropolitan area, Ankara has a considerable number of immigrants. Ankara is identified as a high-risk area because it is a metropolitan city. Ankara also represents PLHIV from rural areas since most of these individuals receive their therapy/treatment here.</p>

CHAPTER 3: Methodology

In order to understand the conditions of PLHIV in Turkey, this study used three different data collection techniques. These included:

1. Literature review (desk-review),
2. In-depth interviews with PLHIV, and
3. Focus group discussions with representatives of education, health and employment institutions.

After finalizing the desk review (presented in Chapters 1 and 2), the research team carried out 20 in-depth interviews: 16 with PLHIV, three interviews with parents of HIV-positive children (one father and two mothers), and one with the wife of an HIV-positive individual. (The relatives were not HIV-positive.) Researchers also conducted four focus group discussions to address the project aims. The individual interviews and focus group discussions were all carried out during the period of April-July, 2007.

Individual interviews with PLHIV

The study adopted purposive sampling that reflected an appropriate distribution of the PLHIV population in Turkey. Participants were recruited from the Positive Living Association (16 participants), the Hacettepe University Treatment and Research Center in Ankara (HATAM; three individuals) and the Numune Hospital in Ankara (one individual).

Design

The team carried out interviews in Ankara and Istanbul using face-to-face or telephone interviewing. Whenever possible, the team tried to interview respondents in person. However, the team conducted telephone interviews when the respondents preferred phone contact or refused to participate in a face-to-face interview. For these participants, the team received the phone numbers from HATAM or the Positive Living Association to make appointments for the interviews.

Interviews were semi-structured, and an interview questionnaire (topic guide) was used to explore the respondents' experiences related to accessing education, employment and healthcare. Interviews generally lasted between 40-60 minutes.

During the interviews, researchers first introduced themselves and explained the objective of the research. After establishing a rapport, the participant's oral consent was requested. Once the interviewees provided their informed consent, all the interviews were tape-recorded. Interviews were not tape-recorded in two cases due to participants' request. The recorded interviews were transcribed; detailed notes were taken for non-recorded interviews. Portions of the transcripts were translated into English, and all transcripts were anonymised. Data analysis was conducted using NVivo package software.

Sample characteristics

PLHIV in Turkey represent the target population for this study. Almost all participants were recruited from urban areas, corresponding to the concentration of the Turkish HIV and AIDS cases in Istanbul, Izmir, Ankara and Antalya. Recruiting participants in Turkey was difficult, despite concerted efforts by the research team and their collaborative organizations. While the sample has strong representation from Istanbul, where most PLHIV live, the study was also able to recruit some residents from Ankara and other cities like Malatya, Konya and Iğdır.

The team tried to recruit an equal number of participants from each target risk group identified by the UNDP: sex workers, MSM, and other PLHIV. The team faced difficulties finding and recruiting IDU due to a lack of systematic information about this group in Turkey. Neither governmental (police institutions) nor the Positive Living Association NGO could provide any data or access to HIV-positive IDU. The research team carried out 20 in-depth interviews: 16 with PLHIV, three interviews with parents of HIV-positive children (one father and two mothers), and one with the wife of an HIV-positive individual. The majority of PLHIV in the sample were of heterosexual sexual orientation (n=11), in addition to three interviews conducted with MSM and two with sex workers. Seven

participants were female and nine were male. Ages ranged from 24 to 42 years. Levels of education also varied: one participant was illiterate, five had a primary school education, two had completed secondary education, and the remainder (n=8) had a university degree.

Key areas of discussion in interviews included the following:

- Demographic characteristics of the PLHIV
- HIV history: time since diagnosis; treatment and medication
- Attitudes toward PLHIV and what it meant to live with HIV
- Changes in the lives of PLHIV, including changes in their behaviour towards other people
- Obstacles related to living with HIV
- Obstacles related to accessing educational facilities and employment
- Experiences accessing and receiving healthcare services
- What PLHIV expected from the state and powerful others
- Expectations from and participation in NGOs
- Other important issues related to discrimination and stigma of people living with HIV.

The research team also collected quantitative information, following instructions from the UNDP.

Focus groups

The research team carried out four focus groups total: one each with representatives of school systems and the business sector, and two with representatives from health-related institutions. The objective of focus group discussions was to understand general ideas about and attitudes toward PLHIV in each of these sectors. Three focus groups were originally planned, one for each sector (employment, health and education). However, after a suggestion from the Positive Living Association NGO, an additional focus group

was carried out with representatives of the health sector. Focus group studies were carried out in Ankara (2) and Istanbul (2).

During the focus group sessions, the moderators/facilitators used a semi-structured guide to cover the key topics and themes, but participants were also encouraged to share their experience and ideas freely. An ‘observer’ was also employed for each focus group session to help collect reliable data. Participants and institutions remained anonymous during data collection. All focus group discussions were tape-recorded with the informed consent of participants. The recorded focus group discussions were transcribed by the moderator to avoid missing any important details. All data are presented anonymously.

To recruit institutional representatives, the research team identified the most relevant institutions for participation in each focus group. For the focus groups conducted in Ankara, a team member called up the officials and invited them to join the group. The focus groups conducted in Istanbul were organized by the Positive Living Association. Focus groups moderators for the Istanbul groups were from the Sociological Association, and the observer was from the Positive Living Association.

Sample characteristics for the focus group sessions were as follows:

	Place	Date	Participants
Health	Ankara	12.06.2007 2 hours	Two physicians One nurse One health director One pharmacist
Health	Istanbul	24.07.2007 1.5 hours	Three physicians (gynaecologist, paediatrician, infectionist) One dentist One nurse One Biologist
Education	Ankara	22.06.2007 2 hours	Two primary school counsellors

			Five high school teachers One assistant director of a high school
Employment	Istanbul	24.07.2007 2 hours	Two managers from large-scale organizations Two managers from medium-size organizations One manager from a small organization

Data analysis

During the data analysis phase, the full transcriptions of all interviews and focus groups were entered into the software (NVivo7). As the first step, categories based on each question were created. Then, the transcribed interviews were coded case-by-case into these categories. This classification helped the researchers to see all the replies from the interviewees separately in one category. As the second step, sub-categories were created by browsing through the answers of interviewees. These sub-categories reflected participants' "own words" in all their richness. In the third step of analysis, the researchers created new categories to reclassify the codes according to the research aims and objectives. These new categories were "obstacles in access to healthcare, education and employment". These categories encompassed data gathered from both the focus groups and in-depth semi-structured interviews.

To assure the validity and reliability of the findings, all the categories and the coded data were examined by the three experts in the project team. In this process, the retrieving and searching functions of the software allowed the researchers to control the completeness of the coded data.

Following the project aims, the researchers prepared a "consistency matrix" to present the findings and the logic between the recommendations (see Appendix 1).

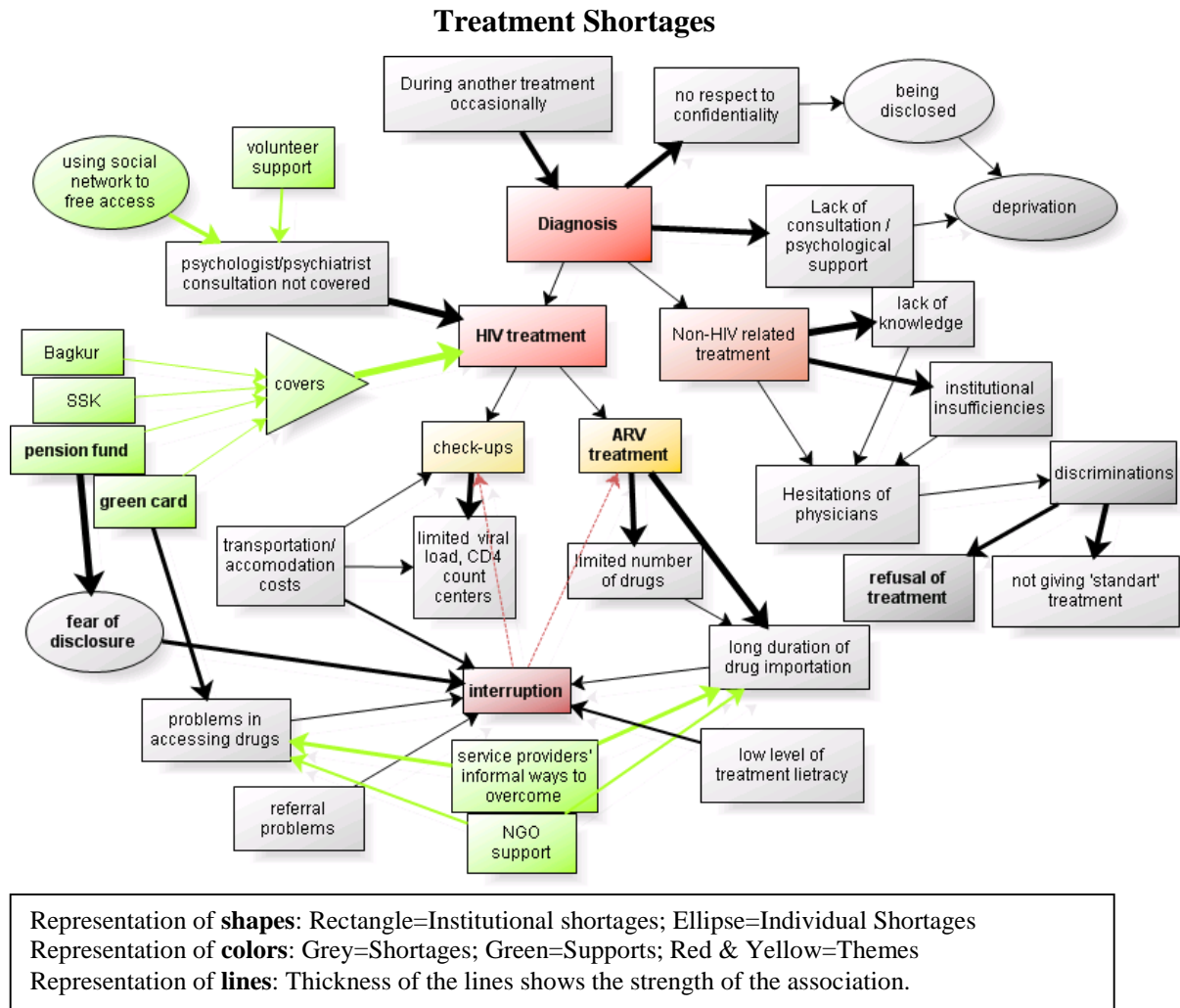
CHAPTER 4: Living with HIV and AIDS in Turkey

This section of the report presents key findings gathered from both the semi-structured interviews with PLHIV and focus groups with representatives from health, education and employment institutions. These findings highlight perceived stigma and obstacles affecting access to services among PLHIV.

Access to health

This sub-section uses an “event-state model”³⁹ to present an overview of health issues and experiences with medical institutions among PLHIV regarding HIV-related and non-HIV-related. This model was developed to expose “treatment shortages” experienced by PLHIV in accessing health.

³⁹ Gibbs, 2002



In this model, there are three main themes (events): *diagnosis*, *HIV treatment* and *non-HIV related treatment*. The left side of the model presents the shortages in non-HIV related treatment while the right side represents HIV treatment shortages. In the bottom part of the model, the shortages are associated with the “interruption of the treatment” by the links (lines) showing the strength of this association. For example, while “long duration of drug importation” is a main shortage in ARV treatment, its association with “interruption” is represented with a thinner line because there is support of both service providers and NGOs, which prevents interruption.

Diagnosis and disclosure

As depicted at the top of the model, the process by which participants learned of their diagnosis can be problematic. Most of the participants stated that they had learned their diagnosis during the course of other health treatment.

I didn't know any information about HIV, and I learned that I am HIV-positive suddenly. I went to the doctor for another illness and s/he asked for another test from me. After the results, the doctor told me that I am HIV-positive. I thought that I was going to die at that moment. I didn't know that it can be treated. P7

Two participants said that they learned that they are HIV-positive on the phone.

I learned it on the phone. They said that the result of the test was positive. Thank God my sister was with me at that time. P10

Problems with HIV-status notification include missed opportunities to provide counseling and education to patients about their diagnosis, which may have negative psychological consequences for the HIV-positive person. One service provider highlighted the negative impact of this problem:

But in general HIV-positive patients might be diagnosed during their routine examinations, before operations by surgeons, or during follow-up by gynecologists. The worst thing is to learn their situation by this way ... When the patients arrive at the HIV treatment center they also might have learned much information from the Internet and newspapers. If this happens, it is not easy for us to motivate them again. Contrary to this, if we diagnose and send them for verification and if they get psychiatric support in accordance with our care, we get more successful results. We also try to convince them to tolerate their situation, and in this stage we don't allow families to intervene. SP1

Moreover, lack of respect for confidentiality may also affect the lives of PLHIV. One of the participants reported experiencing a dramatic change after unauthorized disclosure:

I didn't disclose. The assistant, who had done my tests, left it open on the desk and my mother learned by reading it. The carelessness of the assistant could cause any other person to learn my diagnosis. If my father learned, he might have killed me instantly. You know that families are different and I would not have been able to make it acceptable for my father. P11

This participant, a 26-year-old woman, left her town to escape from the rumors in her small community. Being HIV-positive for an unmarried woman is *de facto* proof that she has had sex before marriage. Thus, she had a great fear of being disclosed to her father, because under traditional gender roles she has no right to have sex before marriage. *Here* we see the gender dimension related with traditional sex roles that plays an important role in stigma and discrimination.

Unfortunately, practices of involuntary disclosure existed even in infection clinics.

We use coded names in order to ensure confidentiality. My real name is...I saw that my blood test results coming from Western Blot stayed for several days on the desk. The nurses and several people use that room. One of my friends could also enter that room and see my real name and surname.P15

As this participant stated, there are certain practices in place to guarantee confidentiality. Even so, there are some careless service providers in practice. Thus, disclosure is a good example of shortages in practice.

HIV treatment

More than half of the interviewees reported participating in regular anti-retroviral treatment (ART). Among the 16 HIV positive participants, six of them had not yet started treatment. One reported receiving treatment on an irregular basis. The ones getting regular treatment declared that their life standards had improved, that their problems had decreased, and that they had started to feel more secure.

I have been getting good antiretroviral treatment for 14 years. There was the possibility of not being able to get the drugs or suspending the treatment. The effect of such a case would be similar to breaking up a relationship. That is to say, if I did not get the drugs it would not affect me physically but psychologically. P16

In Turkey, ART is accessible and free to all who have social security. If an HIV-positive individual does not have a social security, the state gives him or her a “Green Card” to receive treatment free of charge. Although treatment is free, there might exist some

difficulties in accessing drugs. If a HIV-positive person's immune system develops resistance to the drugs, the long duration of importing new drugs can be a reason for some undesired interruptions. As in the quotation above states (P16), these interruptions can lead to negative psychological effects.

There are additional problems for people living with HIV who have a "pension fund" (social security). Participants who had pension funds highlighted the problem of unwanted disclosure. An employed person under the coverage of pension fund faces the problem of being disclosed at his or her place of employment. Under a required procedure, an employee with pension fund faces possible disclosure because they must have a report on their diagnosis or treatment signed by relevant personnel at their workplace. Although this problem is not unique to PLHIV, it affects them more negatively compared to individuals with other illnesses. As the quotation below (P5) reveals, HIV-positive individuals might try to find alternative ways to access treatment without being disclosed at the workplace, even though they have social security. This problem also might result in interruptions in the treatment process.

I have social security but I do not make use of it in my work place. I try to overcome it somehow. I do not want to be disclosed, so I do not get drugs from my organization.
P5

There are also some problems with Green Cards. As stated above, the state guarantees health services to all who can prove financial need by issuing a "Green Card," which qualifies them for free care at health clinics. In principle, there should be no difference in treatment coverage for people with Green Cards, but in reality people with Green Cards may have problems accessing treatment. These difficulties are related to low socio-economic status. For example, one participant lives in a small village and must travel to Istanbul to receive medical treatment. The added costs of transportation and accommodation hinder her access to treatment.

Another problem is that my Green Card has expired. I need to renew it but I neglected it. I need to have a checkup each month but I cannot. That's bad. I have economic difficulties having check-ups. P7

Another shortage in HIV treatment is the limited number of drugs that are actually available. (provide some description of ARV provision and supply issues in Turkey) Consequently, if an HIV-positive person's immune system develops resistance to available drugs, the need to import a new drug emerges. In this case, importation of any new drug takes a long time and can lead to interruptions in treatment.

To overcome these problems associated with social security and bureaucratic processes, both service providers and Positive Living Association staff members support PLHIV by providing informal solutions to the problem of accessing drugs. A service provider explains their informal solution as follows:

Sometimes patients come claiming that [the] governmental district officer didn't provide their medications. If this happens immediately we give a ring to [the] district officer in order to get monthly medications. But it does not always work, and there are still serious difficulties because the Ministry of Health does not always have information about the need for medication. There is no clarification about when the pharmacies will get the medication and which kinds will be used. They say that they will provide the medication in two months. But we should find a way to get their medications on time. In practice, in order to solve this problem we order these medications three months earlier than the patient needs them. Then we collect all these medications and let patients use them when they are needed. This is the finest way to solve the problems. If the medications are not urgently needed, or if the patient passes away, all medications are stored either in my or the principal nurse's office. Since this is known by all patients, they call me back to ask for lacking medications. They take and give back by counting.(SP1)

This solution, founded by service providers and the NGO, does not run the risk of giving PLHIV inappropriate or expired medications, because the physicians (infectionists) have the control of the process. For example, the NGO provides drugs only under the advice of the infectionist. The only negative aspect of this solution is to have limited number of drugs in their stock.

The other main shortage is the lack of systematic psychological support. Currently, social security policies do not cover treatment by psychologists or psychiatrists for PLHIV. Participants stated that they use their social networks (both by having the support of psychologists whom they already know, and by using references from their friends to find

psychologists) to access those services freely. Moreover, only a limited number of psychologists and psychiatrists exist who currently provide free services to PLHIV.

The problem of centralized health services is another obstacle to the provision of high-quality treatment to PLHIV who do not live in major urban centers. The basic problem of PLHIV living outside İstanbul, Ankara, and İzmir is that they have to travel to those cities for treatment. This causes extra charges such as travel and accommodation expenses.

To sum up, although the social security in the country covers HIV treatment, there are still some problems with Green Cards and the pension fund. The confidentiality problem stops PLHIV from benefitting from their social security.

Non-HIV related treatment

As seen in the model, the main shortage in non-HIV related treatment is the hesitations of physicians to be in close contact with an HIV-positive person.

I went to a physician some time ago. S/he wanted me to take off my T-shirt. But when s/he saw my diagnosis on the paper, s/he did not even touch or examine me. P3

I do not want to blame anybody but I have seen two doctors and neither of them really examined me. They just gave some drugs. That's all. P7

Most of the participants stated that they faced difficulties receiving “standard” treatment at clinics that did not specialize in HIV. Despite having a relatively strong general health care sector and adequate numbers of trained professionals, medical personnel in non-HIV related clinics are far from giving “standard” treatment to people living with HIV due to their hesitation. Respondents suggest that this is due to lack of knowledge about HIV and AIDS, fear of contagion, and the invisibility of HIV and AIDS due to the low prevalence of infection. Indeed, participant narratives suggested that because of this invisibility of PLHIV in Turkey, physicians have very limited contacts with HIV-positive people and hesitate to provide treatment when they encounter an HIV-positive patient.

Furthermore, health professionals in focus groups stated that the lack of protective tools and technologies - such as latex gloves, needlestick dispensaries, and post-exposure prophylaxis - also increases the reluctance among medical personnel to treat HIV-positive patients. They also noted the lack of support in case of an occupational accident.

If you catch the virus during the job, nobody remains faithful ... that is to say, if you become subject to it during the work, there is nothing to do. Nobody remains faithful to that doctor, nurse, personnel. You catch it, that's it. SP9

For example, I was taking a hemo-culture. The injector stressed while injecting the blood out, and all the blood splashed on my eyes, nose, I don't know where. I felt terrible at that moment. They gave glasses after that instance, but if I had those glasses at that moment, I would not have had such a stress. I used medicines for a month. SP7

These quotations demonstrate the institutional insufficiencies in both HIV and non-HIV related treatment. The lack of knowledge and the institutional deficiencies play an important role in providers' refusal to administer treatment (especially in operations) and the lack of treatment outside HIV specialist clinics.

Improving access to health care

Since March 2005, after the implementation of a new policy, fundamental changes have affected access to healthcare services for HIV-positive patients. One of the interviewees talked about those changes:

In those years, when the diagnosis was established, the signatures of three doctors, reports from the medical board and the chief administrator of hospital were obligatory. But it was impossible to find the three doctors at the same time, and the dates were always terminated. I also needed to go to three different hospitals and get stamps on which "this drug is not found in the hospital" should be written. Under these circumstances, I was able to get only one of my drugs but not the other one. The doctors were always ignorant and they had to get in contact with the regional directors. The pharmacy stores were always causing troubles about the existence of the drugs, and they were lying. They always found some problems with the prescriptions upon which the doctors were in agreement. In those days, the doses of the drugs used to be delayed to an unpredictable date. I remember getting into the queue at 10.00 and taking my drug at 18.30. When the hospitals agreed with private pharmacy stores I started to get my drugs on time. I was 39 kilos than, now I'm 51 kilos. I really feel terrible when talking about those days. They moved heaven and

earth to cause difficulties. I used to think that I would never be able to work again in those days. I used to spend too much time at hospitals. One test used to follow another. You need to be really healthy and to have an influential person behind you to finish your work at a hospital. I used to be treated at X hospital once upon a time. But I had a problem at the hospital; they refused to treat me anymore. They sent me to Y hospital but the transfer had 5 phases. First I needed to take a demand paper from the doctor of Y hospital, take it back to X hospital and then Y hospital again where the secretary signed it, then back again to X hospital. Likewise, there were 5 phases for taking the drugs. P3

The main expectation of PLHIV, in relation to the quality of health services, is improvements in the training and sensitivity of medical personnel regarding services for PLHIV (including both HIV-related and non-HIV-related care).

Medical personnel were more prone to emphasize the institutional/structural shortages. Even so, some thoughts about discrimination also emerged during the focus group discussions. For example, based on his experiences with patients who have hepatitis, one physician openly stated that there might be some differences in the social relationship between the doctor and an HIV-positive patient.

When you ask whether they are treated differently, I can answer no. For example they are treated as equals, exactly like patients with diabetes. We do all the necessary tests. But I think we put some social pressure on them. I am not sure. I think, I am not empathetic with a patient living with HIV. HP3

For that reason, in order to change providers' attitudes and judgments, this participant emphasized the need for the education of younger physicians:

Maybe this problem can be overcome by the new generation of doctors. I think that my attitudes can hardly be changed after all these years... Maybe I can learn from them, but we are used to a certain ways of thinking. Even when I get home, I cannot read. I have to read, but I only read what is expected of me, nothing more. Nothing else interests me. HP3

This is a unique perspective which clarifies the type of education needed by health professionals to improve the services provided to PLHIV.

The general consensus among all health professionals in the focus groups was that there is a lack of institutional support for auxiliary health personnel regarding protective tools.

During our training visits to the periphery, when you tell a nurse to use gloves while having lessons, she laughs. I asked one why she laughed, and she said they have no gloves. They were never given gloves, they say. SP1

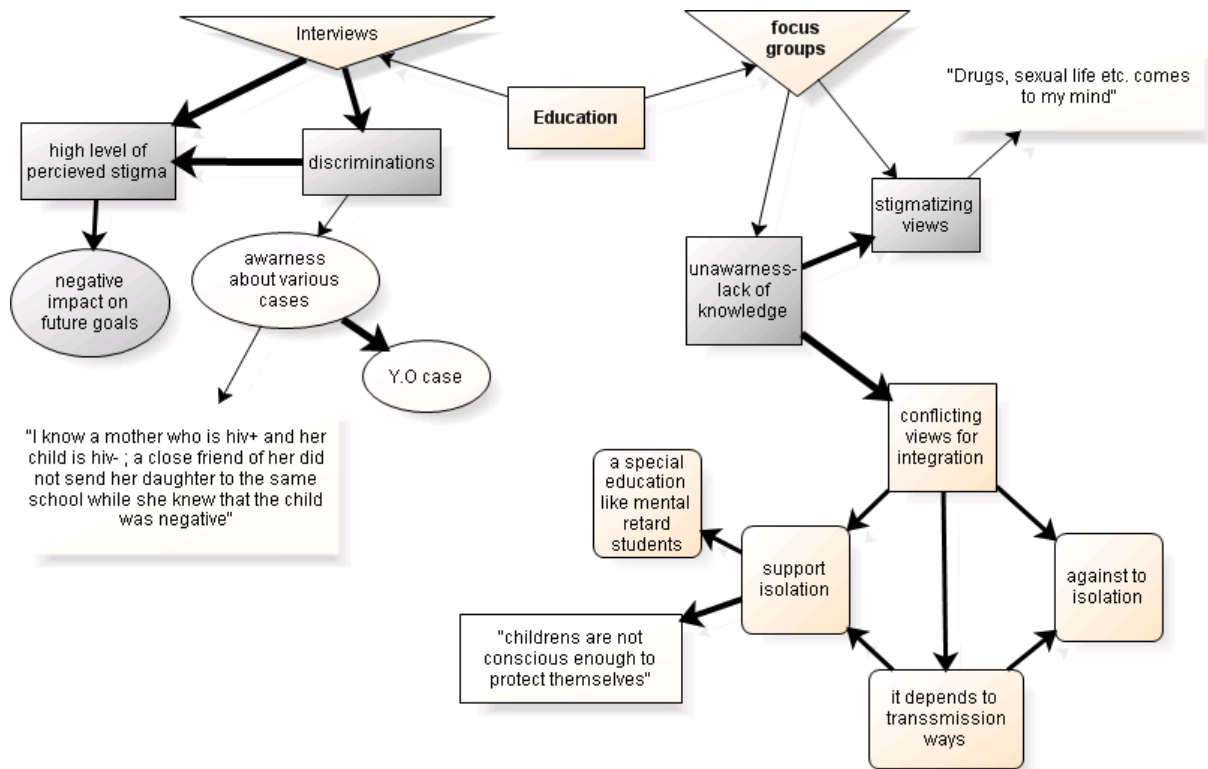
As this quotation reveals, the institutional or structural insufficiency is more common in the periphery (hospitals outside the main cities) than it is in the central hospitals.

Access to education

This subsection presents findings related to disclosure, discrimination and access of PLHIV to education, using a model based on both individual interviews and the education focus group.

Since none of the HIV-positive interviewees were continuing their education, all information and experiences relating to the educational system are based on events the participants had heard about or witnessed.

Education Shortages



Representation of **lines**: Thickness of the lines shows the strength of the association.
 Representation of **shapes**: Ellipse for individual level and rectangle for institutional level.

Individual interview findings revealed that the participants perceive substantial anti-PLHIV stigma in the educational sector. As described earlier, participants from the education sector were familiar with the case of “Y.O.” and its implications for school policies and practices with children affected by HIV.

Among the education specialists, the lack of knowledge and awareness seemed to be the most important factors leading to stigmatizing views in the school setting. During the focus group, there was a discussion among teachers about the isolation of the HIV-positive student Y.O. This discussion revealed conflicting views based on their prior knowledge about the issue. While some educators were openly opposed to any kind of isolation of HIV-positive children, others were insistent on isolation and proposed special education classrooms, as in the case of mentally retarded students. The teachers who supported

isolation claimed that the children are not aware enough to protect themselves. It is also interesting that there was a third group stating that their decision about isolation was related to the mode of transmission. At the end of the focus group discussion, the teachers agreed that HIV-positive students should not be isolated. For example, the teacher who had originally favored isolating HIV-positive students eventually accepted the anti-isolation position:

E4: *[T]he HIV+ student should be trained to be more conscious about his or her situation, for example telling her that she would be a killer if she didn't behave carefully so as not to transmit the infection to others.*

E3: *Then you would accept her to be in the same classroom?*

E4: *(laughs) I accepted because my heart didn't allow me to isolate.*

Concerning the current conditions, educators also highlighted the need for confidentiality; if HIV-positive students are integrated into the education system, their status should not be disclosed to other students or parents, and perhaps should not be disclosed to the administration or teachers. They stated that even teachers are not ready to encounter with this situation. They also stated that parents might react strongly against an HIV-positive student, and this reaction would threaten the integration of other HIV-positive students into the education system.

Improving access to education

The comments most frequently heard from both PLHIV and teachers included the need for the “training of the trainers” in collaboration with other related professionals. The teachers said that in order to ensure equal access to education for HIV-positive students, the relevant Ministries (Education and Health) should cooperate to give information to teachers and parents:

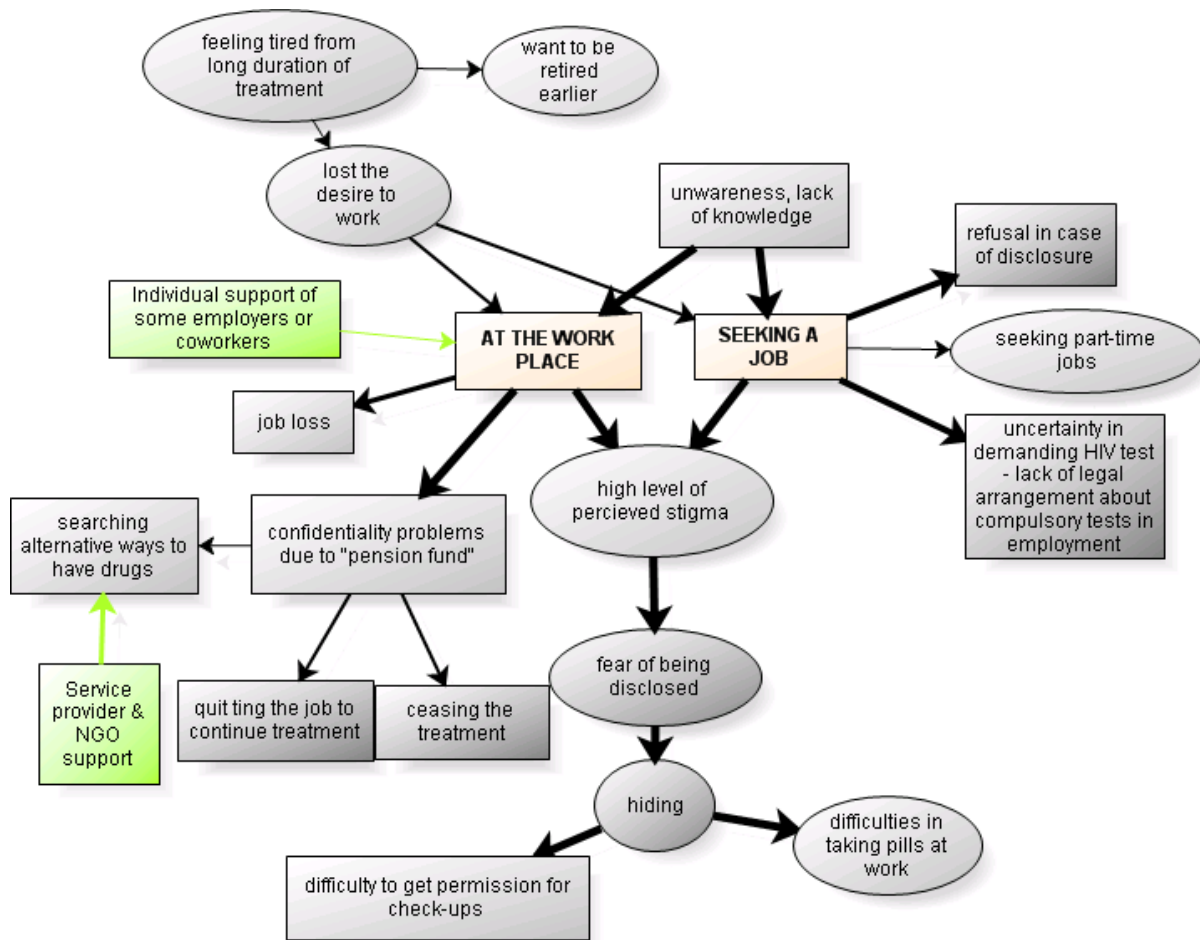
The Ministry of Education and Health should organize a cooperative study; they should establish a new unit to give information to adults, and especially the students' awareness and consciousness should be increased ... then we can work on the curriculum ... this is a utopia, but it is not something impossible. ED2

Access to employment

This section presents findings from the individual interviews and focus groups related to the difficulties of PLHIV in obtaining and retaining jobs.

Eight of the 16 interviewees were working full-time, three worked part-time, and five were unemployed. Three of them are paid workers in NGOs working in the field of HIV and AIDS. Two were officials employed in the public sector, five were employed in the private sector, and one owned a company.

EMPLOYMENT SHORTAGES



Representation of **shapes**: Rectangle=Institutional shortages; Ellipse=Individual Shortages
 Representation of **colors**: Grey=Shortages; Green=Supports.
 Representation of **lines**: Thickness of the lines shows the strength of the association.

Seeking a job

Findings showed a high level of perceived stigma among HIV-positive participants in relation to employment. Almost all of the interviewees expressed that obtaining a job would be impossible if they said they were HIV-positive. One of the interviewees told of her experiences at a job interview:

I had taken an exam a few days ago and then passed through the interview. They later sent me to an infirmary for a check-up. The doctor checked my eyes and legs to see if I had varicose veins. Since I am a truthful person, I informed him/her about my illness. I said "I just have my tests semi-annually and then continue my work as usual. It does not cause any difficulties. When I have too much pain, only my knees ache and in such cases I will come and take medicine from you." After informing them

about this they said if they had known this they would not have hired me. They wrote my name on the standby list than. P11

The fear of disclosure also takes place during the job-seeking process. Although, generally, there is no compulsory HIV test when applying for a job, different organizations or companies have different practices. Some of the participants stated their fear of disclosure when applying for a job at an international company, because some companies specified openly that they demand HIV test results. The lack of legal support for PLHIV in the workplace causes uncertainty among PLHIV and increases their fear of disclosure when applying for a job.

All of the participants stated that they lost their desire to work after they learned their diagnosis. They stated that this was due to their initial lack of knowledge about the disease, which caused them to think that they would die in a short time.

It almost killed my desire to work. I started to think that since I am ill, what is the difference if I work or not? I will die surely. I couldn't work, I could not concentrate on work. I thought I lost my abilities. It took some time to adapt, but now I am all right. P11

Some participants who had lived with HIV for more than 10 years stated that they felt tired and had lost their desire to work. For this reason, they preferred to work at part-time jobs. But the general tendency among participants with full-time employment was to state that they were capable of doing their jobs properly. They claimed that taking their pills and continuing treatment regularly allowed them to work as well as HIV-negative employees.

At work

Almost all of the participants reported hiding their status at the workplace. The main reason for this was a high level of perceived stigma. The participants feared disclosure at the workplace, because they were aware of other HIV-positive people who had lost their jobs after being disclosed.

One of our friends was working in X company. S/he went to America for language education and got infected there. When the company discovered this, they annihilated his/her working rights. They

asserted his/her incompetence to work. This is a really interesting case since they found him/her so successful before that they sent him/her to America. P14

The participants reported that wrongfully terminated PLHIV usually avoid suing for their rights.

People cannot seek for their legal rights in order not to be disclosed. If you bring this case to court, you can never be sure that your name will not be mentioned in the newspapers, that you will not be disclosed with your pictures in the newspapers. Therefore, people do not bring these cases to court. P14

Even though there is no anti-discrimination law to protect PLHIV, employers usually dismiss HIV-positive employees under pretexts that are legally acceptable. This situation increases PLHIV's fear of disclosure at the workplace.

Maintaining secrecy not only challenges the psychological well-being and self-esteem of PLHIV, but it can also negatively affect compliance with treatment. Firstly, PLHIV may have difficulties obtaining permission to attend for treatment and follow-up appointments. Secondly, the difficulties of taking pills at the work can adversely affect compliance.

We have a friend living in X city. He is a worker and he can't carry his medication with him since he has an unlocked shared locker. He can't use his medication because he fears his friends will learn about his situation. P14

As mentioned earlier, though all the social security policies in the country cover HIV treatment, the bureaucratic procedures of the "pension fund" brings about a confidentiality problem. That is, an HIV-positive employee with a pension fund cannot take his or her drugs without a signature from his or her manager at the workplace. This requires disclosure at the workplace. For that reason, an HIV-positive employee with a pension fund cannot benefit from his or her social security while accessing treatment. For example, one of our participants who chose not to disclose his status stated that he was continuing his treatment by buying drugs on his own. His access to treatment was partially assisted through service providers and the Positive Living Association, who were providing medications through their own drug stock. Again, these informal strategies are neither ideal

nor sustainable, and they might have unanticipated negative health consequences for the individual.

Five managers from large companies participated in the employer focus group. Each manager describing having at least one friend who was HIV-positive. For that reason, they were very sensitive to the issue and ready to give support to HIV-positive employees. Nevertheless, they also agreed that an HIV-positive employee might encounter problems in both seeking and keeping a job. They highlighted the unawareness and lack of knowledge about HIV and AIDS among most employers. Moreover, like the education focus group participants, they agreed with the strategy of non-disclosure at the workplace, believing that confidentiality currently works in an HIV-positive person's favor.

I have friends who own their firms. If somebody goes there to ask for a job and says that he or she is HIV-positive, they will not employ that person. I am sure. I am talking about such simple information. It is not technical information: HIV does not pass to other people by means of working together, eating together, or hugging and kissing each other. We need such a simple sensitivity. We do not need a long time to understand this. EMP4

Another employer complained about his senior staff's attitudes towards AIDS:

If one of your senior administrators with 1000 years of experience refuses, you cannot employ a person with HIV in your department. There are young dinosaurs too. EMP1

The employment focus group participants also stated that they encountered difficulties with career growth and development. In this context, they claimed that a small company would be better for an HIV-positive employee, as he or she might face more minimal problems. Because there are a small number of employees in a small company, an HIV-positive employee might have more close relationships that would provide support. That is, instead of competitive relationships, more intimate relationships can form in a small company.

They can find jobs more easily in small and medium-sized enterprises. I have never thought of such a thing before ... I don't think that there will be any problems in small scale enterprises; it will be easier there. There can be more intimacy in those enterprises, so he or she can be able to disclose the situation. EMP4

Improving access to employment

The employers had pursued several initiatives to improve the conditions of PLHIV in the employment sector. These ranged from using the media and Internet to instituting quotas in favor of PLHIV, which would enable them to have jobs without discrimination. Most of the HIV-positive interviewees stated that the hardships they endured at work could be overcome by more educated employers.

Thus, the most frequent comments highlighted the need for education to change the attitudes of both employers and employees; and to increase the awareness among the public. Participants brainstormed various ways to achieve this goal.

The employers can be taught about this disease and that way, they can overcome their prejudice. Everything can be solved by education. P2

This is the biggest problem in front of you ... How the TV, newspapers and magazines can be effective today on this issue can be discussed. But I think that TV is really effective. And the Internet these days. EMP3

I would like to read such a profile on the Sunday additional of Hurriyet or Milliyet newspapers. There will not be any photos, the faces will not be seen, but [the story will] report the message that these couples are happy. They think that they will not die. They even have children. I think this can change many things. EMP1

This may be very radical...but a speech about HIV can be made in the Parliament. Because we know that nothing will be done without the wish of those people there. EMP5

Community involvement

Most of the participants were members of the Positive Living Association, who gives support to PLHIV. Although this NGO was only established recently, it has almost 200 members.

Our findings demonstrate that involvement in the NGO has a positive effect on participants' well-being. Participants stated that this was due to receiving information about HIV, receiving some services, and meeting with other HIV-positive people to share their feelings, problems and experiences. In other words, this community participation helps

them to avoid self-stigmatizing attitudes and to feel more comfortable with their new identity.

This organization is my life source. P11

Therefore, one of the most frequent demands of the HIV-positive participants was the foundation of similar NGOs in other cities around the country.

Discussion

The main research objectives were to identify the obstacles that PLHIV encounter while accessing health services, employment and education. There were 19 in-depth interviews with people living with HIV and their relatives, and four focus groups with health care personnel, education specialists, and employers.

PLHIV reported that their own fears created barriers to accessing all of these services, and that this fear has a negative effect on their quality of life. The main reason for this fear is that PLHIV perceive strong stigma and discrimination against them in general society. The HIV-positive participants not only reported a general stigma in society, but also cited their specific experiences with discrimination while accessing services.

The focus group findings revealed that stigma also exists among professionals. For example in one of the focus groups with health professionals, an expert in infectious diseases openly stated that if an HIV-positive person is a female, she is more inclined to think of her as “innocent”. This finding impressively reveals current attitudes in the health sector. The findings of individual interviews also prove this fact. Almost all of the participants reported being treated differently by health professionals, even by physicians who are experts in infectious diseases. Interestingly, the fear of contagion also exists among health professionals because of a lack of knowledge about HIV and AIDS.

HIV positive participants' fear of disclosure also affects their work life. They hide their status in order not to lose their jobs. They gave examples of other HIV-positive individuals in the country that had lost their jobs after disclosure. So, the participants' perception of stigma is high at the workplace. The fear of being disclosed at the workplace can lead to interruptions in treatment. Some of the participants gave examples of other HIV-positive people who are not able to take their scheduled medication at the workplace. After a while, this may cause them to cease their treatment. The fear of disclosure was stronger among participants with pension funds.

Because our participants had completed their education before the diagnosis, we have limited findings about obstacles to accessing education. However, the participants related the stories of their HIV-positive acquaintances or anecdotes from the media. The participants perceived stigma to be high in the educational sector. The best-known example cited by the participants was the case of Y.O., which represents dramatic discrimination. Our focus group findings with education specialists indicate that stigmatization exists among educational professionals. The teachers with a lack of knowledge about HIV and its transmission proposed discriminative solutions – such as different schools, similar to those for mentally retarded students – rather than looking into options for integrating children with HIV into educational institutions. It was very interesting that some of the teachers stated that their views would change according to the modes of transmission. Although some teachers assumed that children with HIV were “innocent”, this was not enough to remove stigmas emerging from fear of contagion.

Our focus group findings with employers were quite different with regard to stigmatization. All of the employers stated that their worldview had changed after they had met a person living with HIV. Our findings show that the fear of contagion does not exist among the participating employers. But these employers also stated the existence of stigmas among others in the workplace. For example, they stated that if an HIV-positive employee disclosed his or her status at the workplace, it would be difficult for that individual to build a career.

Most of the participants stated that they disclose their status to those whom they believe are more conscious and aware of issues related to HIV. Hence, they faced limited stigma and discriminatory attitudes in their social relationships. But they indicated that hiding their status was also harmful for their psychological well-being. In all but one case, the participants reported receiving financial and social support from their families. Additionally, the Positive Living Association plays an important role in helping PLHIV to cope with the disease. Our findings suggest that HIV-positive individuals who have a higher level of education and a profession were less likely to isolate themselves from social relations. That is, their socio-economic status enabled them to construct and maintain social relations.

As a conclusion, it appears that HIV/AIDS is an invisible issue in all three sectors – health, education, employment - as well as in general society. Therefore, stigmatizing attitudes continue to be the main obstacle preventing PLHIV in Turkey from achieving a high quality life. To overcome this problem, both the HIV-positive participants and the professionals who participated in the focus group interviews mentioned the need to make this issue more visible through the media, education by courses and seminars, NGO activities, and state policies.

Our findings revealed the actual situation of PLHIV in Turkey in terms of the obstacles they encounter in accessing health, education and employment. This study also found that human right violations are widespread in all of these sectors, as indicated in the 1999 National AIDS Commission Report.

CHAPTER 5: National Consultations

First Roundtable for the Vulnerability Assessment of People Living With HIV in Turkey

The roundtable with NGOs was carried out on 12 November 2007 in Taksim Hill Hotel in Istanbul. The meeting began at 10:30 and finished at 13:30. There were 11 participants in total (see Annex 8).

A description of the project (including its aims, findings, and recommendations) was distributed as a hard copy to all of the participants and presented by Dr. Elif Kuş. The participants discussed their recommendations regarding the issues. Some of the participants also emailed their recommendations after the roundtable meeting.

Key discussions and recommendations

- The 170 YTL income limit for having a Green Card creates many problems; some HIV-positive people cannot have Green Cards because they have 400 YTL (regular incomes for a family living with two persons).
- The new Social Security Law will change the current “total coverage of HIV treatment.” In this system, for example, a person who earns an income of 500 YTL will have to pay extra for social security for an expensive treatment like ART. Thus, there could be a new legal arrangement for medical services, especially HIV treatment.
- In primary and middle schools, there should be a “life skills” course.
- There is a need to improve the health sector at the institutional level; there is also a need to create “standards” for all institutions that provide health services.
- Some student hostels require an HIV test; there is a need to arrange this issue legally to guarantee a standard application (which would not ask for an HIV test) in all hostels.
- It is necessary to create a legal arrangement addressing the situation of HIV-positive orphans in almshouses.
- There is a need for a legal arrangement for HIV-positive refugees.

- The syndicates should improve themselves to support HIV-positive employees. Currently, they lack knowledge about HIV/AIDS-related issues.
- In a job-seeking process, men have to show their situation about the military service (it is compulsory in Turkey). This situation creates big problems for HIV-positive men who want to avoid disclosing their status when seeking a job. Thus, a specific arrangement is needed to address this problem.
- Current HIV/AIDS counseling centers do not work efficiently; the counselors' qualifications are insufficient.
- There should be a general law addressing discrimination.

Second Roundtable for the Vulnerability Assessment of People Living With HIV in Turkey

The National roundtable meeting was carried out on 29 November, 2007 in Ankara University's ATAUM convention center. After welcoming speeches (delivered by UNDP local representative Berna Bayazit and Vulnerability Assessment Project Coordinator Prof. Dr. Aytül Kasapoğlu), the project coordinator delivered a comprehensive power point presentation of the empirical research findings. During and after presentations participants made some comments, which were noted seriously. After a short coffee-break, three policy recommendations made by the research team were discussed. Each policy suggestion made by the participants was discussed and incorporated into the report. Therefore all recommendations were revised in a constructive and interactive process. During national round table discussions, the project coordinator moderated discussions, and project team members also helped the participants to avoid missing important points. The meeting started at 10.00 AM and lasted until 13.30 PM (see Annex 9).

As already reported to the UNDP (Bratislava) by the project coordinator, the suggestions made by NGOs in the Istanbul meeting were minor: they addressed some wording of the report, future risks related to possible changes in the general health system, and the cost of

drugs and coverage of insurance policies. The team considered all suggestions by adding them into the models where necessary and sharing them with the roundtable participants.

Key Discussions and recommendations

There was only one major criticism of the report. During the presentation of research problem by the coordinator (indicating insufficient interest of related institutions in HIV/AIDS), the representatives of Ministry of Health declared their opposition to this research problem definition as well as those statements which were modified previously by the Positive Living Association in the desk review section. Although those high level bureaucrats agreed with the limitations, especially about insufficient budget allocations by the state, it was obvious that they were uncomfortable about a specific sentence referring to “National AIDS Commission’s failures and its establishment principles (see. Desk Research p.9, 20). The local UNDP representative and project coordinator both promised to revise that sentence once more carefully. It should also be noted that the reaction of the Ministry of Health staff was not a surprise, and the project team expected this criticism based on its experiences with the Positive Living Association. Actually, previous modifications by the Positive Living Association in some parts of the desk review, including this sentence, had been accepted by the research team after several cross checks and careful inspections.

How recommendations will change or be integrated into the country report

Although the roundtable participants agreed with the three policy suggestions, they also wanted to rank education as the most important recommendation (instead of the second most important). During the discussions, the research team also felt that most of the improvements depend on education. Therefore after education, legislation was ranked as the second most important recommendation, and support for NGOs took the third place. Notably, some of the legislative arrangements were embedded into the educational suggestions.

As a result, there was not much change reflected in the national report. As sociologists, research team members believed in the importance of legislative changes, which generally come “from the top down,” especially in developing countries. However, during and after the roundtable, the team was convinced by national stakeholders, who were presumably better acquainted with existing laws and their implementation.

During discussions, participants were also encouraged to give concrete examples in order to develop more operational policy suggestions.

Summary

In sum, the roundtable meeting was carried out successfully. The majority of the participants were experts and voluntarily spent extraordinary effort to evaluate research findings and to develop policy suggestions. Finally they expressed their sincere gratitude to the Sociology Association for its full support.

Important note:

The following are the concrete policy suggestions made by the roundtable participants and approved by the research team. Therefore, the sub-section reported below will be the final section of the Country Report .

Policy suggestions

1. Education: Formal (school) and informal (distance and public) educational activities should be improved.

- In order to provide coordination and effective education about HIV/AIDS, one health educator should be assigned in every Provincial Health Directorate of the Ministry of Health. Furthermore, this health educator should train key teachers for primary and secondary schools that depend on the Ministry of National Education.

- Education and support must be provided to encourage individuals to seek their rights. In other words, patients should be educated about their rights.
- Primary and secondary school curricula must be expanded to include information about HIV/AIDS.
- In order to expand the content of primary and secondary education curricula related to HIV/AIDS, the Ministry of Health should send an official letter directly to the Ministry of National Education.
- Education related to HIV/AIDS should be provided for children as early as possible.
- Both counseling and other principal teachers in primary education should be trained on HIV/AIDS.
- The informal and distance education channels of national broadcasting (TRT) should be used to make people more aware of HIV/AIDS .
- During the preparation of educational programs, successful examples elsewhere in the world should be taken into consideration.
- Necessary steps should be taken to accelerate the decision-making processes of the Ministry of National Education.
- Preventive measures and preventive education should cover and address all sections of society.
- Because women are the most neglected and vulnerable part of the population, they should be covered by the HIVAIDS training programs.

- Public Centers of the Ministry of National Education should be used for the training and developing awareness about the educational rights of HIV-positive people.
- Since education is a human right, the Ministry of National Education should not reduce the educational problems of PLHIV simply to health-related matters.
- Education about HIV/AIDS should be provided for the staff of Social Work Services.

1.1. Education for the employment sector

- Education should be provided for co-workers who work together with PLHIV.
- Trade unions should be trained to assert the employment-related rights of PLHIV.
- The private sector should be encouraged to take responsibility for supporting activities that will decrease the vulnerability of PLHIV in the fields of education and employment.

1.2. Education for the health sector

- Survey results regarding each hospital's service and patient satisfaction should be assessed continuously in order to provide more effective health services. Patients also should be trained to be more aware of the value of these surveys.
- Counseling and a consultation must be provided for everybody before and after the ELISA test.

2. Legislative arrangements: Necessary regulatory modifications should be made to ensure the sufficient and appropriate implementation of existing laws concerning the basic human rights of PLHIV, including the rights to health, education and employment.

Although the majority of participants agreed that there were not many problems with prevailing laws, they also agreed that this report should mention crucial problems stemming from the implementation of existing laws.

- Legislative changes should be made in order to decrease the duration of bureaucratic processes that are required to import drugs necessary for HIV/AIDS treatment. At present, three institutions are responsible for imported drugs: the Social Insurance Institution of the Ministry of Labor, the Ministry of Health and the Association of Pharmacies.
- The law should provide for a health educator for each Provincial Health Directorate of the Ministry of Health. This is the only way to ensure that AIDS education will be provided during primary and secondary education.
- Furthermore the state should not only use the results of ELISA tests for statistical purposes. Decision-makers should consider making necessary measurements to increase the budget of the Ministry of Health, in order to use the data to refer PLHIV for treatment.

3. More support for NGOs is needed.

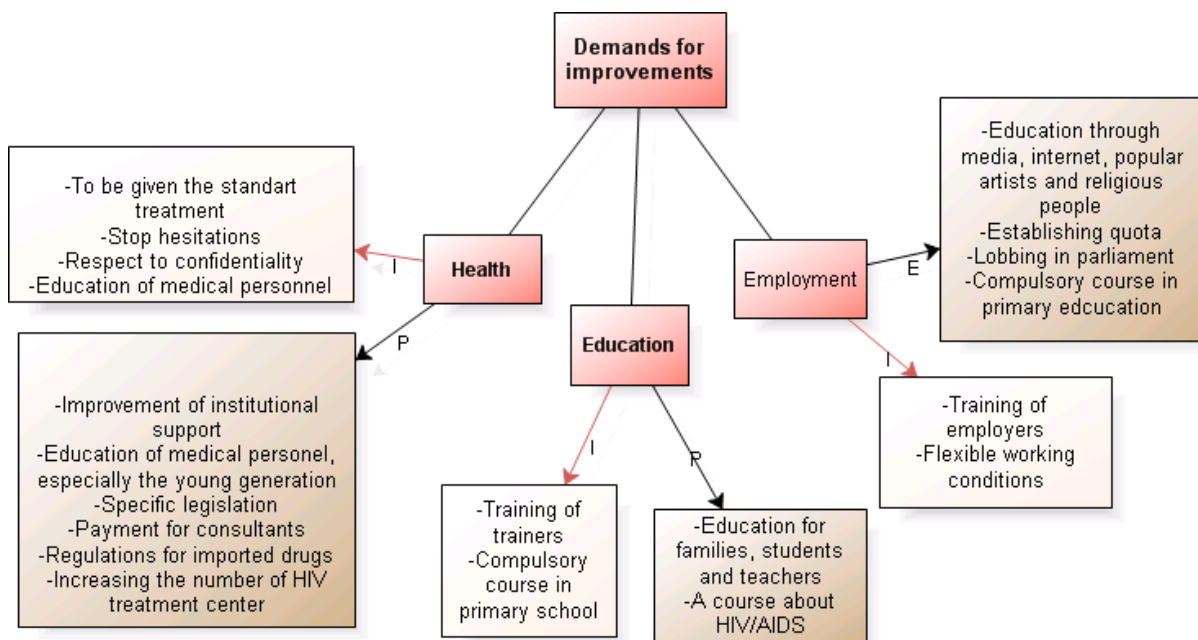
- Since most NGOs lack sufficient human capital, their capacity and sensitivity towards PLHIV should be improved.

- Important and powerful professional organizations, such as the Turkish Employers Association and the Turkish Trade Association, should be encouraged to support activities related to the response to HIV/AIDS.
- Since NGOs are not well-developed in Turkey, necessary support should be provided to strengthen them.
- Because there are relatively few NGOs assisting PLHIV in Turkey, NGOs established for other purposes (e.g., woman and children, youth rights, or professional rights) can expand their objectives by providing HIV/AIDS-related services.

CHAPTER 6: Recommendations

Based on the research findings the research team developed a model to present the “demands” of PLHIV on the one hand and of service providers in health, education, and employment on the other. In other words, this subsection focuses on demands and makes recommendations.

Demands for Improvements*



- The HIV-positive participants’ main demands regarding the health sector are the improvement of the health personnel through education (both formal education in the university and mandatory continuing education workshops for professionals). The participants assumed that education would form the basis for other improvements including the protection of confidentiality, a greater readiness among physicians to treat PLHIV, and the improved availability of ‘standard’ treatment. Interestingly, there are no demands of the participants concerning their treatment regime and related care. This might be because their main goal is to reduce discrimination and violations of their rights, which are especially likely to occur during non-HIV-related treatment process.

* Representations in the model:

I = Individuals’ demand; P = Professionals’ demand; E = Employers’ demand

- The demands of health professionals focused on both the institutional level and on issues of legitimacy. To make more appropriate treatment available to PLHIV, health professionals emphasized the need for institutional support (e.g., the provision of protective tools and support in case of occupational accidents).
- Physicians dealing with PLHIV stated the need for special legislation. They also demanded a regulation in which payment for consultations takes place in order to overcome the lack of systematic psychological support.
- Participants demanded new regulations to govern the drug import process to reduce delays.
- Decision-makers should prioritize funding for psychological services for PLHIV, which should focus specifically on helping these individuals address internalized stigma.
- The health professionals highlighted the need for education (e.g., a university course) to improve quality of care. They emphasized the need for education relating to HIV/AIDS, especially for the younger generation of physicians.
- All of our participants had been diagnosed with HIV after they had completed their education. For that reason, they only recommended instituting HIV/AIDS education for the educators, including a compulsory course to prevent discrimination. The education specialists also emphasized the importance of education not only for students and their parents, but also for the teachers. The demands regarding education were quite general because of the lack of experience of the participants (which was clear from both the in-depth individual interviews and the focus group participants).
- The HIV-positive participants' most frequent demand regarding the employment sector was education to inform employers about HIV/AIDS. While some of the

participants emphasized their capacity to work without demanding any other extra treatment; some stated the need for more flexible working conditions.

- Our employment focus group participants had no experience with HIV-positive employees. During the group, they also stated that they lacked of knowledge about the issue; however, they suggested some of the difficulties that an HIV-positive employee might encounter. For the employers, the main need was increasing the awareness of the general public, employers, and employees. They proposed different channels like the media, the Internet, and compulsory courses to make individuals more aware. Additionally, they highlighted the need for pro-PLHIV lobbying in the parliament to have more powerful support.
- The employers also agreed on the need to establish a quota for employing PLHIV, like current policies for disabled citizens.
- It should also be mentioned that HIV-positive participants did not criticize the Positive Living Association. However, they emphasized the need to increase the number of NGOs providing support to them.
- All of the participants assumed that the role of the state would be very crucial to realizing of all the demands presented in this section. They gave priority to the state to meet these demands, suggesting the need for specific legislation supporting NGOs, as well as funding to establish collaborations among related departments of the state and private sector.

ANNEXES

Annex 1. Consistency Matrix

Research question	Literature review	Source*	Individual in-depth interviews	Question numbers**	Focus-group discussions	Question numbers**
What are the main obstacles faced by PLHIV in education?	Discrimination Stigmatization Lack of knowledge/information Prejudgment Human rights violations Low level of education Lack of specific legal arrangements Geographic location of Turkey Young population Student mobility (going to former States of the Soviet Union) Limited number of NGOs and activities Preparedness of state	5, 7, 10, 11, 12, 15, 20, 24, 29	Discrimination Stigmatization Disclosure Insufficient knowledge Lack of specific legislation	3.1; 3.2	Discrimination Isolation Insufficient knowledge	4
What is/can be done?	Improvements in human rights	5, 7, 10, 11, 12, 20, 24	Training of trainers	3.10	Education	1; 2

	Conducting more scientific research Specific legal arrangements in the education system		Specific legislation		Coordination among related Ministries	
What are the main obstacles faced by PLHIV in health?	Human rights violation Discrimination (gender and economic) Stigmatization Tourism Rapid change Population characteristics e.g., urban and youth Invisibility Unawareness/ignorance Health information systems (statistical recording system) Insufficient activities of NGO's High cost of health services Insufficient prevention programs (including closed institutions such as the army and prisons) Insufficient number of confirmation centres Difficulties in accessing NGO activities Insufficient budget allocation Focusing on curative health services	3, 4, 6, 13, 14, 15, 22, 29, 30, 32	Lack of psychological support Difficulties in the referral system Discrimination Stigmatization Doctors' fears Centralized health services Insufficient legal arrangements Meeting with different doctors for each treatment	5.3; 5.5; 5.6; 5.8; 5.9;	Discrimination Stigmatization Insufficient legislation Insufficient knowledge of personal health Bureaucratic barriers Stocking problems of imported pills Interruptions of services provided by doctors Violation of privacy and confidentiality	3; 4; 5; 7; 1; 4

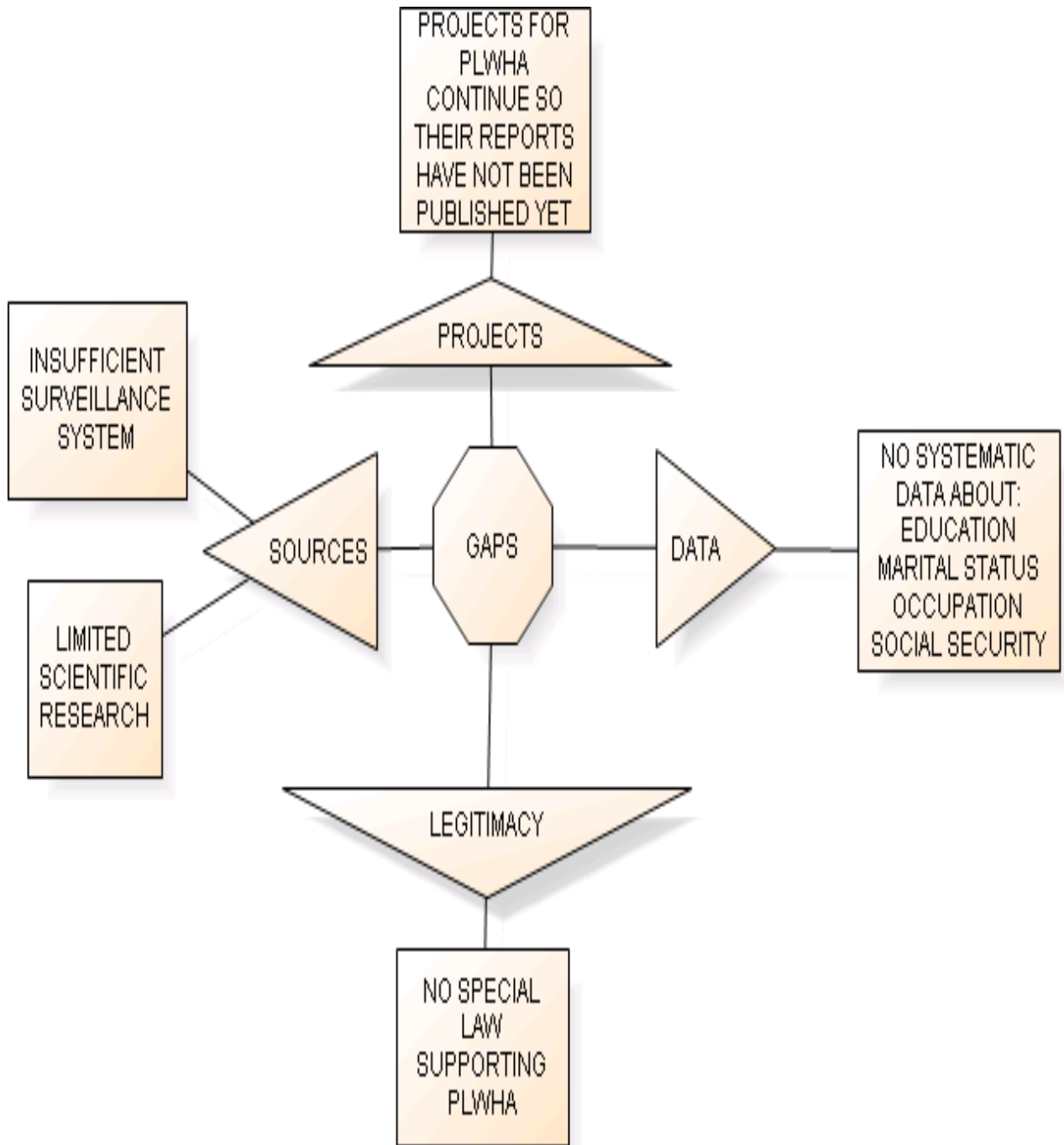
What is/can be done?	Improvements in human rights Conducting scientific research Making use of international funds (e.g., EU and GF) Preparedness of the state	6, 15, 32	Education (public and formal education at schools) Self-education of PLHIV Legal arrangements Support for NGOs Fundraising for treatment	5.10; 5.11	New specific legislation and regulations Training of younger physicians Regulations for imported drugs	3
What are the main obstacles faced by PLHIV in the labour market?	Discrimination Stigmatization Unemployment Working without insurance Human rights violations Problems of insurance coverage Limited activities of NGOs Difficulties in entering legal labour market (unregistered workers)	21, 29	Finding jobs Losing jobs Disclosure in the workplace Uncertainties about planning the future Decrease in desire to work	4.2; 4.3; 4.5; 4.6; 4.7	Discrimination Stigmatization Lack of experience and knowledge	5; 2; 3; 4; 7
What is/can be done?	Improvements in human rights Conducting scientific research Public education	19, 29	Training of employers Providing more flexible working conditions	4.10; 4.11	Education through media, the Internet, popular artists and religious people Establishing quotas	8; 2; 1

					Lobbying in parliament Designing new symbols or logos Compulsory courses in primary education	
What are the overall trends in the response to HIV/AIDS in Turkey?	Nation-wide discrimination and stigmatization Human rights violations	4, 13, 22, 24, 28, 29, 33				
What can/should be done to improve the situation for PLHIV?	National action plan Improvement of prevention programs Improvements in human rights Radical reforms in the health system Radical reforms in the legal system Increasing the number of NGOs	29, 39				

* The numbers in the matrix represent the reference numbers of Desk Review.

* *The numbers in the matrix represent questions in the “individual interview with PLHIV.” and “guide for focus groups”.

Annex 2. GAPS



Annex 3. Summary of articles regarding rights and significance for PLHIV

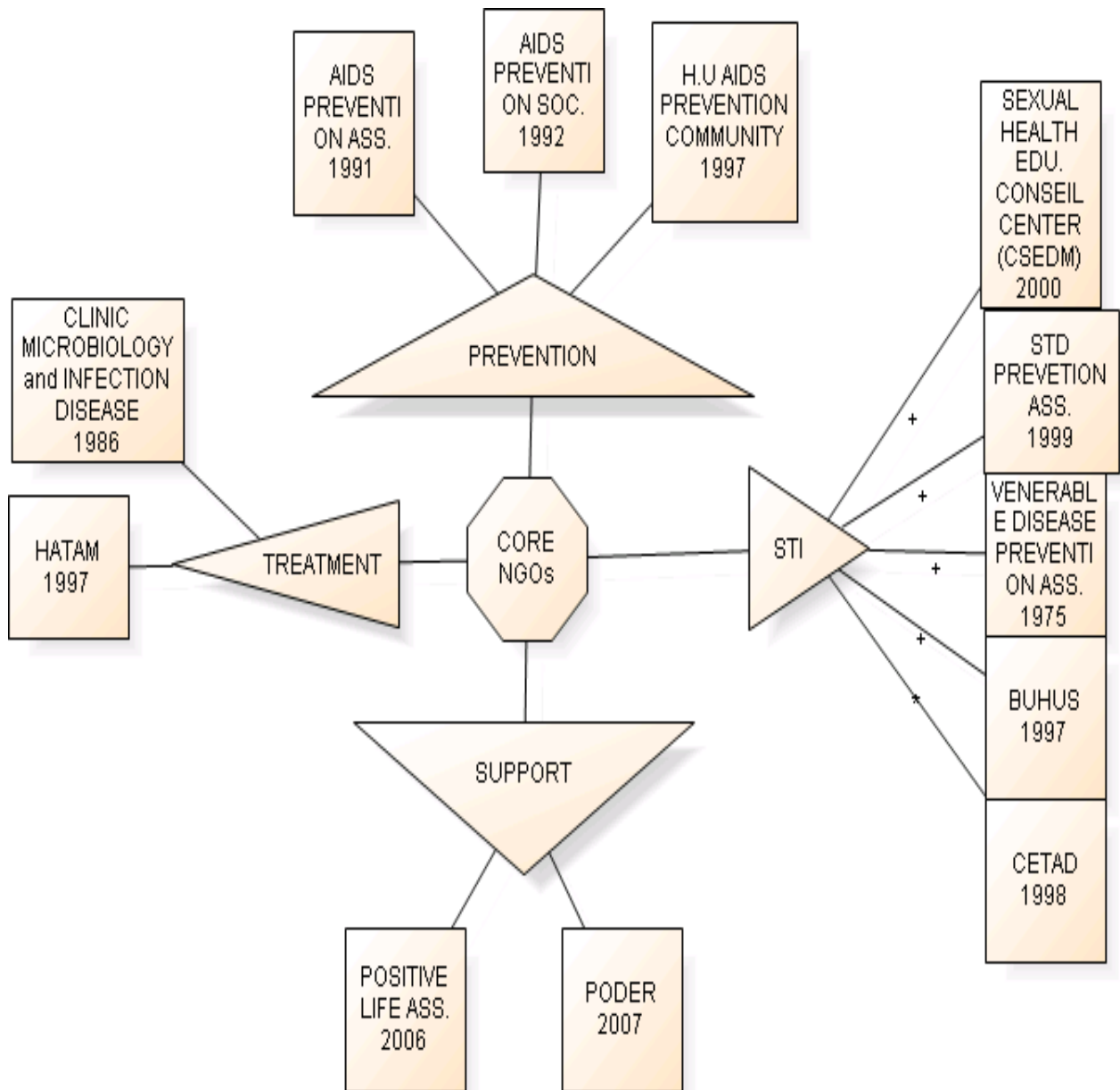
ARTICLE OF CONSTITUTION	RIGHTS/ LIBERTIES	SIGNIFICANCE FOR PLHIV
17	MATERIAL AND SPIRITUAL ENTITY OF THE INDIVIDUAL Everyone has the right to life, and the right to protect and develop his material and spiritual entity.	No person or institution (such as a hospital or workplace) can act in a way that is damaging to an individual's dignity and honour.
17	PERSONAL INVIOABILITY The physical integrity of the individual may not be violated except under medical necessity and in cases prescribed by law; he may not be subject to scientific or medical experiments without his consent.	The individual has the right to make medical decisions regarding His or her own body. As such, no one can be forced to take a HIV test. During treatment, individuals shall not be treated in a derogatory or cruel manner.
20	PRIVACY OF THE INDIVIDUAL'S LIFE Everyone has the right to demand respect for his private and family life.	PLHIV have the right to keep information about their HIV status confidential. Nobody can be forced to disclose this information, nor can they be forced to take a blood test to establish this fact.
26	FREEDOM OF EXPRESSION AND DISSEMINATION OF THOUGHT Everyone has the right to express and disseminate his thought and opinion by speech, in writing or in pictures, or through other media, individually or collectively. This right includes the freedom to receive and impart information and ideas without interference from official authorities.	This is especially important for the communication, in schools and prisons, of correct information regarding the prevention of HIV/AIDS.
33	FREEDOM OF ASSOCIATION Everyone has the right to form associations without prior permission.	Anyone can be a member of any organization. PLHIV can form associations and organizations to strengthen their solidarity.
23	FREEDOM OF RESIDENCE AND MOVEMENT	PLHIV have the right to travel freely within Turkey.

	Everyone has the right to freedom of residence and movement.	They cannot be coerced into living apart from the rest of society.
48	FREEDOM TO WORK AND CONCLUDE CONTRACTS Everyone has the freedom to work and conclude contracts in the field of his choice.	PLHIV may work in the field of their choice. As such, they cannot be prohibited from working as doctors, teachers, etc.
49	RIGHT AND DUTY TO WORK Everyone has the right and duty to work. The state shall take the necessary measures to raise the standard of living of workers, to protect them in order to improve the general conditions of labour, to promote labour, and to create suitable economic conditions for prevention of unemployment.	Nobody can be discriminated against in the workplace.
56	ENVIRONMENT Everyone has the right to live in a healthy, balanced environment.	This clause is important for PLHIV living in prisons and mental institutions.
56	HEALTH To ensure that everyone lead their lives in conditions of physical and mental health and to secure cooperation in terms of human and material resources through economy and increased productivity, the State shall regulate central planning and functioning of the health services.	Hospitals and doctors may not refuse to treat PLHIV.
60	RIGHT TO SOCIAL SECURITY Everyone has the right to social security. The State shall take the necessary measures and establish the organization for the provision of social security.	PLHIV have the right to benefit from services provided by social security institutions.
42	RIGHT AND DUTY OF TRAINING AND EDUCATION No one may be deprived of the right of learning and education.	PLHIV have equal rights to education and learning. PLWHA and their families may not be excluded by educational institutions.
40	PROTECTION OF FUNDAMENTAL RIGHTS AND FREEDOMS	Everyone whose rights have been violated has the right to apply to the relevant

	Everyone whose constitutional rights and freedoms are violated has the right to request prompt access to the competent authorities.	authorities, for compensation and fulfilment of those rights.
74	<p>RIGHT OF PETITION</p> <p>Citizens have the right to apply in writing to the competent authorities and to the Grand National Assembly of Turkey with regard to requests and complaints concerning themselves or the public. The result of the application concerning himself shall be made known to the petitioner in writing.</p>	If a social service has been wrongfully denied, the complainant may question this denial and request the service in writing.

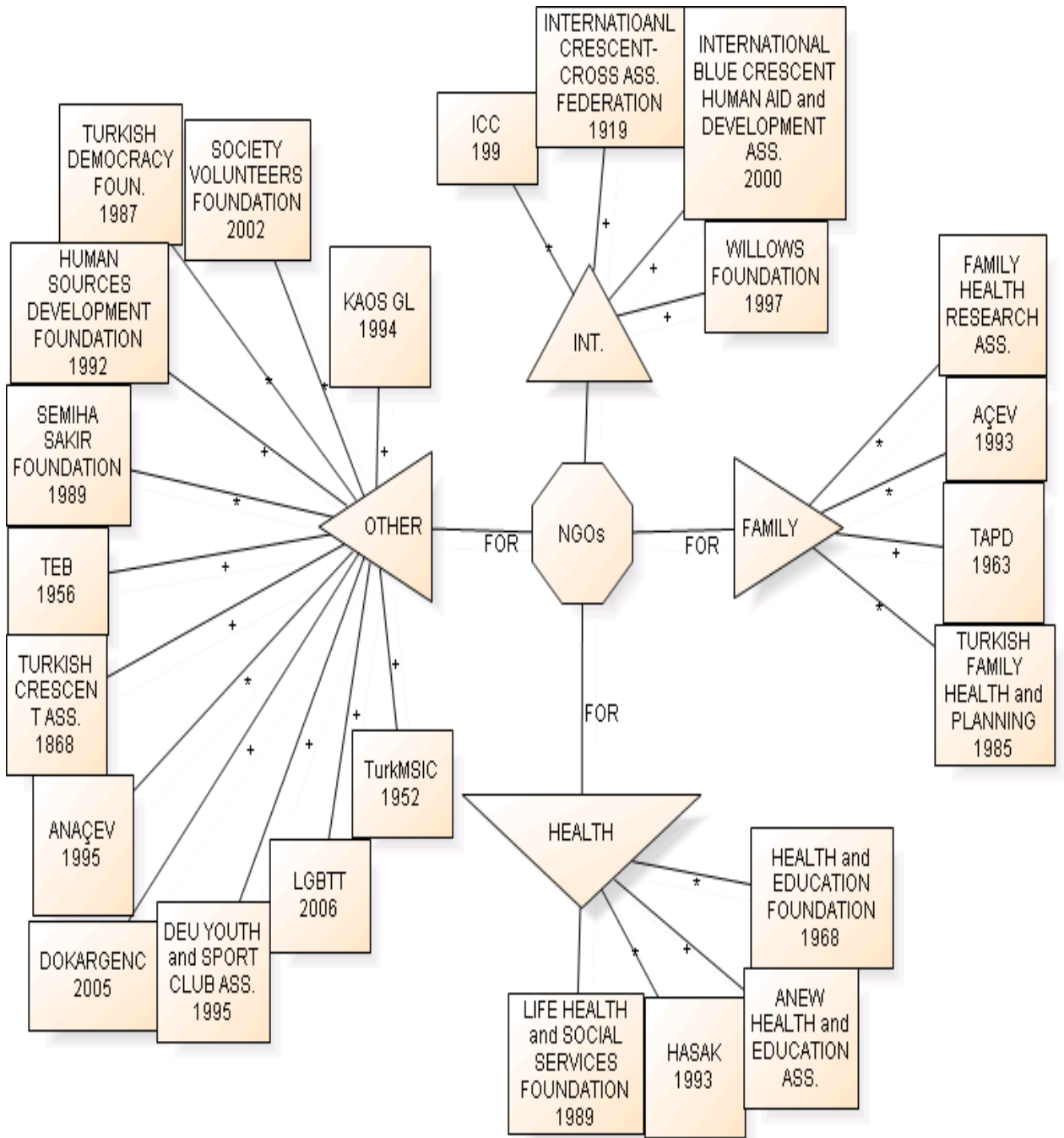
Source: Protection of Human Rights and Civil Liberties in The Prevention of AIDS Report prepared by Human Resources Development Foundation, publication of the National AIDS Commission, January, 1999.

Annex 4. Core NGOs

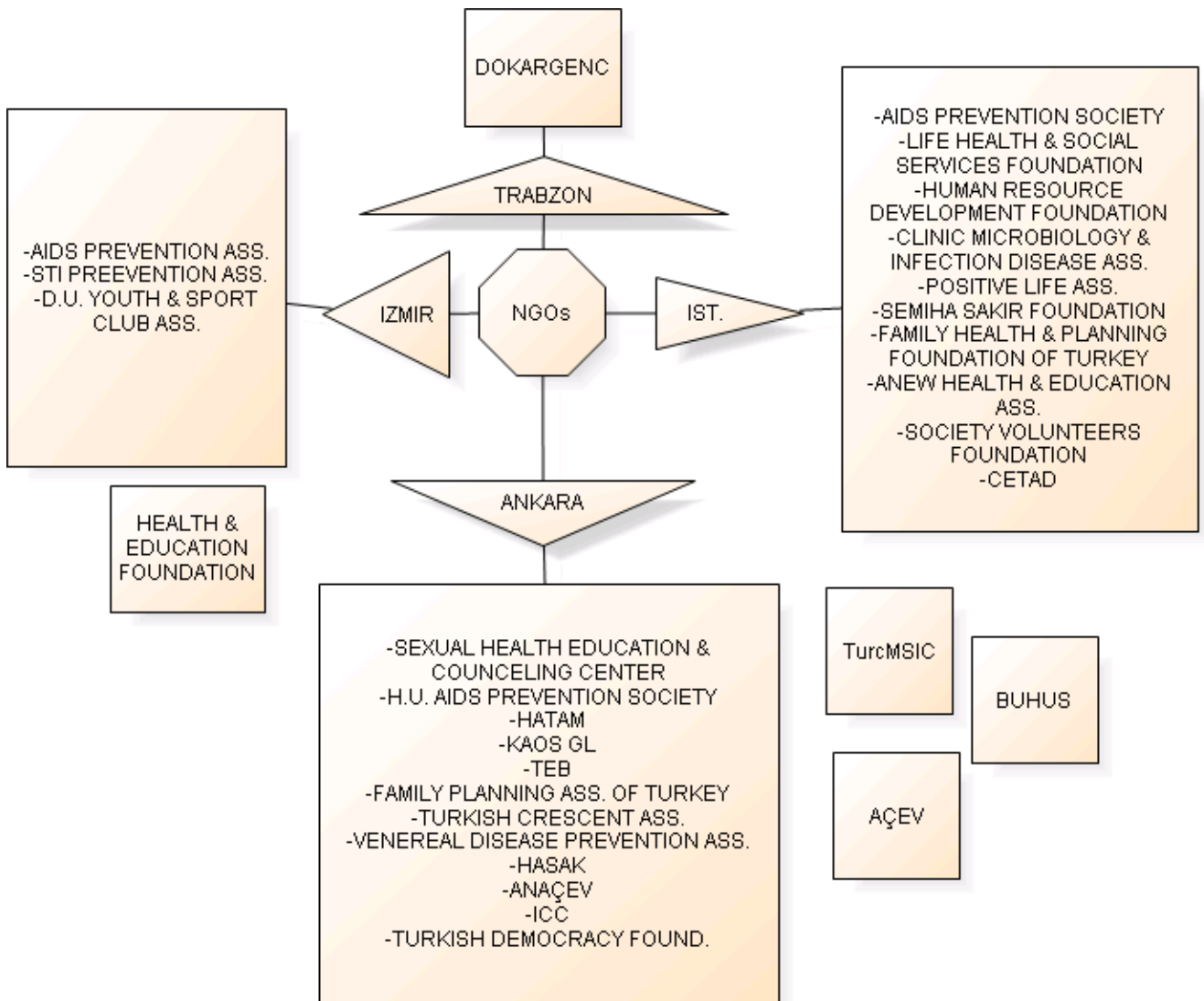


“+” indicates the projects that are implemented on HIV and AIDS; “*” indicates other related projects (e.g., STI prevention).

Annex 5. Related NGOs



Annex 6. Distribution of NGOs by city



Annex 7. Existing Data on PLHIV in Turkey

Gender		Number
	<i>Male</i>	
<i>Female</i>		789
Age	<i>0</i>	17
	<i>1-4</i>	18
	<i>5-9</i>	11
	<i>10-12</i>	5
	<i>13-14</i>	2
	<i>15-19</i>	61
	<i>20-24</i>	316
	<i>25-29</i>	380
	<i>30-34</i>	412
	<i>35-39</i>	334
	<i>40-49</i>	369
	<i>50-59</i>	221
	<i>60+</i>	102
	<i>unknown</i>	296
Mode of Transmission	<i>Homo/bisexual</i>	207
	<i>IDU</i>	120
	<i>Homo/bisexual +IDU</i>	5
	<i>Haemophilia</i>	10
	<i>Blood transfusion</i>	44
	<i>Heterosexual</i>	1343
	<i>Mother to child</i>	43
<i>Nosocomial</i>	14	
Region (cities' HIV-positive population)	MEDITERRANEAN	
	<i>Antalya</i>	71
	<i>Adana</i>	46
	<i>Hatay</i>	47
	<i>Mersin</i>	47
	THRACE	
	<i>İstanbul</i>	777
	<i>Bursa</i>	41
	<i>Kocaeli</i>	31
	CENTRAL ANATOLIA	
	<i>Ankara</i>	127
	<i>Kayseri</i>	28
	<i>Konya</i>	22
	<i>Aksaray</i>	14
	<i>Çorum</i>	11
	<i>Eskişehir</i>	14
	AEGEAN	
	<i>İzmir</i>	224
<i>Muğla</i>	30	

<i>Manisa</i>	23
EAST ANATOLIA	
<i>Erzurum</i>	6
<i>Kars</i>	3
<i>Elazığ</i>	3
BLACK SEA	
<i>Trabzon</i>	25
<i>Rize</i>	4
SOUTHEAST ANATOLIA	
<i>Adana</i>	46
<i>Gaziantep</i>	27
<i>Diyarbakır</i>	10

Source: Ministry of Health ,Turkey 2007.

Annex 8. List of Participants at the NGO Roundtable Meeting (A)

- Buse Kılıçkaya / Pembe Hayat (Pink Life) LGBTTD
- Barış Sulu / KAOS GL
- Umut Güner / KAOS GL / PEMBE HAYAT / UAÖ
- Leyla Hacıosmanoğlu / Sağlık Hakkı Hareketi Derneği (Health Rights Movement Ass.)
- Doğan Güneş Tomruk / CYBH-DER
- Ela Aktürkoğlu / UNAIDS Türkiye
- Cem Mete / PYD İzmir (Positive Living Ass.)
- Destina / Pembe Hayat (Pink Life)
- Çiğdem Şimşek / PYD
- Arzu Kaykı / PYD
- Elif Kuş / Sociological Association

Annex 9. List of Participants at the Roundtable Meeting (B)

<i>Names/İsim</i>	<i>Institution/Kurum</i>	<i>E address /Eposta</i>	<i>Tel</i>
Peyman Altan	Ministry of Health Brunch, Department of Venereal Disease/Sağlık Bakanlığı Zührevi Hastalıklar Şubesi	peymanaltan@gmail.com	433 30 24
Gonca Parlak	Health Department of General Directorate of Natural Security/Emniyet Genel Md. Sağlık Şubesi	prk@yahoo.com	412 38 74
Mehmet Yavuz	Prime Ministry/Başbakanlık	myavuz@basbakanlik.gov.tr	413 79 78
Serpil Kaya	Mother and Child Care General Directorate of the Ministry of Health/Sağlık Bakanlığı AÇSAP Gn. Md.	Serpil.kaya@saglik.gov.tr	435 05 32/154
Serap Sever	General Directorate of Social Work/SHÇEK Gn. Md.	ssever@shcek.gov.tr	310 24 60/1395
Zerrin Işık Tüfekçi	Turkish Dental Physician Association/Türk Diş Hekimleri Bir.	zerrin@evrenseldis.com.tr	466 19 96-94
Gülben Yalçın	Turkish Radio Television/TRT	Gulben.sahin@trt.net.tr	491 52 00
Necdet Şimşek	Turkish Radio Television/TRT	Necdet.simsek@trt.net.tr	470 17 64
Halil Polat	Department of Health Affairs of the Ministry of National Education/MEB Sağlık İşleri Daire Bşk.	hpolat@meb.gov.tr	413 37 98
Berna Bayazıt	UNDP	Berna.bayazit@undp.org	454 11 26
Aytül Kasapoğlu	Ankara University Head of the Department of Sociology		
Nilay Çabuk Kaya	Ankara University Department of Sociology		
Feryal Turan	Ankara University Department of Sociology		
Elif Kuş	Ankara University Department of Sociology		
Fulya Demir.	Ankara University Department of Sociology (student)		

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