

CAPACITY Project

Central Asian Program on AIDS Control in Vulnerable Populations

Capacity of the Organizations Established by People Living with HIV in Kazakhstan, Kyrgyzstan, Tajikistan and Uzbekistan

Assessment Report

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Summary

One of the “youngest” and most dynamic HIV epidemics in the world is developing in Central Asia. According to UNAIDS, by the beginning of 2008, more than 40,000 cases of HIV had been identified in Kazakhstan, Kyrgyzstan, Tajikistan, and Uzbekistan. Injection drug use and sexual intercourse without condoms are the main ways that HIV is transmitted. Several outbreaks of nosocomial HIV infections among children were registered in the region in the middle of 2000s.

The countries of Central Asia are referred to as developing countries. The international community provides assistance to these countries to fight epidemics. Thanks to these efforts, today, many HIV infected adults and children receive access to antiretroviral therapy. Even in the most vulnerable communities, it has become possible to carry out disease prevention programs built on outreach work. But still, medical aid is less accessible for drug users, their families, and for people living with HIV (PLHIV) residing in rural areas. Social and psychological support is very limited and is accessible for only some PLHIV.

In each of the above mentioned countries, PLHIV (HIV-positive people, their families, and friends) are making efforts to help themselves and other people who are in similar conditions. More than 25 non-governmental organizations which have been set up by PLHIV (PLHIV NGOs) operate in these countries. More than 130 PLHIV are employed by either PLHIV NGOs or other non-governmental or public institutions. From January 2008 to April 2009, up to 3,000 other PLHIV received their assistance and support.

In February 2009, an initiative group of PLHIV NGOs announced the establishment of the Central Asia Network of PLHIV.

In April-May 2009, the USAID-funded CAPACITY project initiated an effort to assess the capacity of PLHIV NGOs. The survey has shown that:

1. PLHIV NGOs provide social support to the most socially vulnerable HIV-infected people and their families. *These NGOs are important potential partners of government and international organizations and helping to provide universal access to HIV prevention, treatment, care and support.*
2. PLHIV NGOs - just like the PLHIV community - are rather young and are going through the initial development stage. All of these NGOs are *leader-driven organizations, thus, the support of PLHIV leaders is crucial for further development of PLHIV NGOs, the increase in their capacity to provide assistance to PLHIV, and the consolidation of the PLHIV community.*
3. PLHIV NGOs are carrying out their activities on the local level. Many significant decisions are adopted on the national and regional levels, however. In order to get involved in the decision-making process, *PLHIV NGOs have to establish networks*

on national and regional levels that follow the principles of transparency, coordination and democratic selection of representatives from each organization/country.

4. Today, international organizations and local government entities act as the principal partners of PLHIV NGOs. *PLHIV NGOs must develop constructive partnerships with national government agencies and NGOs established by other communities affected by the HIV-infection epidemic.*
5. The financial resources accessible to PLHIV NGOs today are provided by international organizations. That is why the activities of PLHIV NGOs cannot be characterized as stable. In some cases, the activities do not even correspond to the priorities of PLHIV. With the purpose of ensuring a stable operation and a more accurate consideration of the needs of the community, the *PLHIV NGOs must utilize resources which are available inside of their community by promoting the self-support among their members. It is also important to encourage a wider involvement of PLHIV into the decision-making process and implementation of programs on local, national, and regional levels.*

Introduction

Central Asia network of PLHIV¹ (hereinafter referred to as *Network*)² was established in February 2009. Network plans to join PLHIV organizations in four countries: Kazakhstan, Kyrgyzstan, Tajikistan and Uzbekistan. In the future, the Network may expand its coverage and incorporate more countries of this region. The strategic objectives of Network are as follows³:

- To strengthen capacities of PLHIV organizations and communities.
- To ensure universal access to prevention, treatment, care, and support related to HIV-infection for PLHIV.
- To increase the involvement of PLHIV in the decision-making process regarding counteraction to HIV/AIDS epidemic and its negative consequences on all levels.
- To promote the protection of human rights in the context of HIV/AIDS.
- To reduce stigma and discrimination related to HIV-infection.

For the purpose of preparation of the Network's work plan for 2009-2011, has been decided to conduct the needs and capacity assessment among PLHIV NGOs and other NGOs where PLHIV are meaningful part of decision-making and work implementation, i.e. organizations which would be the Network members.

With the aim of the assessment conduction and the development of proposals of further activities of the Network, a consultant has been invited who has examined all the appropriate documents and conducted meetings in the countries associated with the Network with the following groups of people:

- workers and heads of PLHIV NGOs and other NGOs,
- initiative groups and leaders of PLHIV,
- representatives and employees of the key partner organizations such as governmental and municipal organizations that provide care and support to PLHIV, international experts, donor organizations, and projects.

Methodology

The meetings were conducted in the form of semi-structured interviews without word-for-word recording. The questionnaire has been elaborated on the basis of the Terms of References designed and compiled by the "Kazakhstan Union of PLHIV" and USAID

¹ The term "persons living with HIV" or PLHA implies those persons who have been infected with HIV or somehow still affected by HIV epidemic. First of all these are members of families or close friends of HIV-infected persons.

² Report from the working group meeting to develop Regional PLHV Network in Central Asia, Almaty, Kazakhstan.

³ Ibid

CAPACITY project. All meetings were conducted with participation of representatives of the organizations which initiated the establishment of the Network.

The assessment's cities visited, as well as the organizations and initiative groups met by the expert that would attend these meetings, have been identified and approved by representatives of the USAID CAPACITY project and the Network in coordination with the consultant. As a result of this work, the below listed populated localities have been selected:

- Kazakhstan: Almaty, Ust-Kamenogorsk, Shymkent
- Kyrgyzstan: Bishkek, Osh, Tokmok, Dmitrovka
- Tajikistan: Dushanbe, Khodjent, Kurgan-Tyube
- Uzbekistan: Tashkent, Navoi, Namanghan

About 100 respondents were interviewed by the consultant. The list of the respondents is attached to the given report. **(See Appendix 1)**

In parallel with the assessment, there was a certain amount of work aimed at increasing the capacity of the local PLHIV NGOs in assessment of PLHIV's needs as the basis for an efficient design and evaluation of their projects and programs. For that purpose, the mini-workshop on "Needs Assessment" for staff of the PLHIV NGOs and PLHIV activists was held in each country. Upon the completion of these workshops, the attendees had to fulfill the practical exercise on collection of data regarding PLHIV's needs in their cities/oblasts and mapping of existing services for PLHIV.

Results

1. Situation overview

Individual cases of HIV infection were officially registered in Kazakhstan, Kyrgyzstan, Tajikistan, and Uzbekistan in the late 1980s. All of these cases were linked with sexual intercourse in homosexual and heterosexual couples.

At the start of 2000s, the situation started changing dramatically and in many countries there were dozens or hundreds of cases registered annually among males and females using injection drugs (IDUs). This trend continues today and injection drug usage is still the leading means of HIV transmission in these countries. In mid-2000s, there were a few cases of nosocomial HIV infection outbreak registered, namely in children. An analysis of the registered new cases of HIV indicates the growth of sexual transmission of HIV, especially among sexual partners of IDUs. This trend creates all preconditions for the transformation of the epidemic from concentrated into generalized form.

Based on the estimates of UNAIDS⁴, the number of HIV infections in these four countries amounts to more than 40,000 cases. The most rapidly developing epidemic has been observed in Uzbekistan where the number of cases of HIV infection increased eightfold from 2001 to 2008, while in the remaining three countries, the rate has increased fourfold.

There are national programs for prevention of HIV/AIDS and decreasing negative social and economic consequences of the epidemic. In all of these countries, antiretroviral therapy (ART) is accessible for significant number of PLHIV who are in need. A problem associated with accessibility of ART exists among PLHIV using drugs or residing in remote rural areas, however. Work is being carried out in the four Network countries aimed at preventing HIV infection among vulnerable populations, namely: IDUs, commercial sex workers (CSWs), prisoners, migrant workers, etc. Among those who less covered by the prevention programs are men who have sex with men (MSM) and people living in rural districts. Counseling before and after HIV testing remains poorly developed in spite of a high accessibility of testing.

By the end of the 1990s, certain projects aimed at providing informational and psychological assistance to the vulnerable groups and PLHIV had been launched. A considerable expansion of these services began in 2004-2005, when Global Fund to Fight AIDS, Tuberculosis and Malaria (hereinafter referred to as GF) gave grants to these countries. At present, these services are directed mainly at the families of HIV infected children and partially to IDUs and CSWs. Through these social assistance programs, PLHIV may receive foodstuffs, aid for restoration of lost documents or receiving of governmental welfare payments (the above mentioned allowances are called 'social support'). Special informational events with interactive elements are moderated by the employees of these organizations as part of the informational and psychological support programs for PLHIV. The respondents often name these events as 'self-support groups'⁵. In addition, counseling provided by psychologists and lawyers is accessible in some of the cities.

The countries where the Network is planning to get involved and to launch its activities are very different on the basis of average per capita income. Thus, Kazakhstan can be referred

⁴ UNAIDS (2008) "2008 Report on the Global AIDS Epidemic".

<http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/default.asp>

⁵ There are many other examples of incorrect use of various terms. For example, outreach workers and social workers are often called "volunteers". In all countries the principal recipient of the financial resources allocated by GF is referred to as 'The Global Fund' and if your interlocutor is talking about a decision made by the Global Fund then it will be reasonable to clarify who specifically made that decision. None of the respondents was able to give a satisfactory explanation and therefore the meaning of certain terms was misrepresented. It is important to note that an incorrect application of the terms complicates understanding of a situation and evaluation of the conducted activities' effectiveness.

to as an 'above average' income level country, while the remaining three countries are the states with 'low income levels'⁶.

For the purposes of the implementation of HIV/AIDS programs each country obtains financial and intellectual support provided by international organizations and agencies. Based on respondents' estimates, the donor financial resources make up to 50-60% of the programs budgets in Kazakhstan and up to 85-90% in Kyrgyzstan and Tajikistan. The activities and involvement of the PLHIV NGOs are fully funded by the international or foreign donors with some minor exceptions. Mostly likely, the situation with the sources of funding and subsidization of PLHIV NGOs will not change in the next 3-5 years⁷.

The largest financial contributor is the Global Fund (GF) which provides these countries with \$190 millions US dollars⁸ within 8 rounds of grants to counteract the spread of HIV infection and to respond to adverse consequences of the epidemic (including already transferred sums and obligations for future).

Considerable financial assistance is being delivered by governmental agencies (such as USAID, DFID, GTZ, MATRA, the European Union's programs) within the framework of regional and national projects (e.g. CAAP projects, CARHAP, USAID CAPACITY project), and non-governmental donors like OSI, Aga Khan Foundation, Tides Foundation, and amFAR.

UN agencies and programs, and international non-governmental organizations such as JSI, AFEW, GRM International, World Vision, International HIV/AIDS Alliance, PSI International, and Christian Aid provide technical assistance, facilitation in fundraising, and programs' management.

2. Assessment of PLHIV's needs in and accessibility to psychosocial and medical services

2.1 Needs of PLHIV in psychosocial support and assistance

The survey on PLHIV's needs carried out in these countries in 2004-2008⁹ showed that the principal needs were a supply of food and the provision of accommodations and employment. During the meetings conducted by the consultant in April-May 2009, the

⁶<http://web.worldbank.org/WBSITE/EXTERNAL/DATASTATISTICS/0,,contentMDK:20420458~menuPK:64133156~pagePK:64133150~piPK:64133175~theSitePK:239419,00.html>

⁷ EurAsEC [2009]. Regional strategy on HIV counteraction in Central Asia (draft). [in Russian]

⁸ <http://www.theglobalfund.org/en/>

⁹ - UNDP (2005). Needs assessment of PLHIV in the Republic of Kazakhstan. [in Russian]

- Results of sociological survey among PLHIV. «Koz Karash», Bishkek, 2006 [in Russian];

- AFEW (2008). Results of the PLHIV needs assessment in Kyrgyzstan. [in Russian]

-UNDP (2008). Quality analysis to assess social consequences of HIV/AIDS and prioritize advocacy efforts in Uzbekistan. [in Russian]

respondents in Kyrgyzstan, Tajikistan, and Uzbekistan reported that their priority needs stayed the same. Only in Kazakhstan had the priorities slightly changed since 2007¹⁰. The priorities here in 2009 were issues related to stigma and discrimination and accessibility to medical aid and employment. But even in Kazakhstan, only 15% of PLHIV can be referred to as socially adapted people capable to care on themselves (i.e. people who have more than a secondary school education, own a residence, and are employed)¹¹.

Some of the reasons that explain why the situation has not changed at all or has changed insignificantly are:

1. Programs designed to provide assistance and support to PLHIV are evolving too slowly to serve the growing number of newly emerging cases of infected persons;
2. Lack of demanded services or their low effectiveness;
3. Static behavior patterns of PLHIV, absence of good personal examples of quality life among PLHIV, that limits PLHIV and specialists which provide them with care and support in vision of possible strategic directions of further development, . One of the respondents called this situation an ‘intellectual deficit’.

Taking into account the relatively «young age» of the active epidemic process, a low income level of the citizens of these countries, and the fact that the majority of PLHIV can be referred to as marginal groups in society, it is most likely that the first two reasons listed above are the main ones for the stagnancy of the situation, although, the third reason must be taken into consideration as well.

The majority of the HIV-positive respondents interviewed by AFEW in Kazakhstan and Kyrgyzstan in 2007-2008¹² desperately needed treatment of associated infections like tuberculosis (10% out of selected respondents in Kazakhstan and 8% of respondents in Kyrgyzstan) and hepatitis C (almost half of the respondents of Kyrgyzstan). Treatment of tuberculosis is carried out in accordance with the state programs and projects funded by GF, while treatment of hepatitis C is accessible for a few patients only.

During the meetings held in April-May 2009, the respondents reported the same medical needs and noted that adherence to treatment is a significant problem. Additionally, almost all the respondents stated that along with the treatment of HIV infection and tuberculosis, there is a need in narcological care. One physician working at the Family Group Center in Tokmok, Kyrgyzstan, stated: “*People die mainly of drugs*”.

Many PLHIV, such as IDUs and even those who do not use drugs, talked about stresses, lengthy depressions, and other mental disorders (which can be defined as neuroses) they

¹⁰AFEW (2008). Capacity building of community organizations and social integration of PLHIV. [in Russian]

¹¹ Ibid

¹² Ibid

had experienced. There is a description in the report prepared by the AFEW¹³ stating that: «...life after the detection of HIV infection has drastically changed. Many persons experience an emotional crisis related to comprehension of the meaning of life....Fear has become a standard condition for many respondents,». But in April-May 2009 none of the respondents out of the physicians and workers of international organizations reported on the development of psychiatric care to PLHIV in their countries.

One of the most likely reasons for depression and neurosis could be a low quality or even a lack of counseling before and after HIV testing. In the above mentioned surveys made by AFEW, only half of the HIV-positive persons received counseling before testing and only 75% received it after testing. This counseling boils down to general recommendations on healthy life-styles and information about responsibility in case of intentional infection of other persons.

During the meetings held in April-May 2009, the respondents in Kyrgyzstan, for example, shared some stories about doctors who told a few rural women whose children had been infected that they were powerless and the women would have to wait for their children's death, while another woman also living in the countryside in Kyrgyzstan after getting positive test results was told not to worry because the defined virus would pass off in three years without any treatment.

These are single cases but they are actively discussed by other PLHIV and become the ground for numerous fears and myths.

2.2. Accessibility of medical and non-medical support services for PLHIV.

Medical treatment and care

ART is the principal and integral part of medical care for PLHIV. At present, these drugs are procured from the GF grant money so their mid-term availability is stable. But long-term perspective of ART accessibility is strongly depends on continuation of funding from GF and other donators. But the accessibility of ART is not only dependent upon the availability of the financial resources.

IDUs comprise the majority of the PLHIV. Sexual intercourse with IDUs/PLHIV without condoms became the reason for the increase in HIV incidence among women for the last years.

In addition to the fact that more than 70% of registered cases of HIV infection in these regions are related to injection drug use, practice of injecting of illegal drugs continues

¹³ [AFEW \(2008\). Capacity building of community organizations and social integration of PLHIV. \[in Russian\]](#)

after getting the ‘HIV-positive’ diagnosis. According to the reports of the respondents, 70-85% of those who got infected after drugs injections kept injecting drugs. Considering that most IDUs get imprisoned at least once in their lifetime, where prevalence of TB, including MDRTB, is high, it is possible to assume that rates of TB among IDU population are also significant^{14 15}.

Some of the physicians who were interviewed in April-May 2009 considered it pointless to prescribe ART for IDUs due to their low adherence to treatment. These patients immediately suspend treatment once the control from the physician’s side is decreased. Other physicians are ready to prescribe ART for IDUs but consider it to be ineffective due to the lack of adherence to treatment.

Substitution therapy (ST) of opiate addiction is a key element of ensuring IDUs’ adherence to treatment. In Kazakhstan, ST is introduced in two pilot cities (Temirtau and Pavlodar); in Kyrgyzstan, methadone is available in 3 oblasts (Chui, Bishkek and Osh), but only in urban areas; and in Uzbekistan, ST is implemented in limited volume with buprenorphine. In Tajikistan, despite the scheduled plan to launch the ST application in 2009, the Ministry of Health has not yet approved the appropriate decree. In all the countries the funding of ST is being carried out through the GF grants.

In respondents’ opinion, the currently existing ST programs are of low quality since they are limited only to distribution of methadone and buprenorphine and do not incorporate activities aimed at socialization of the clients. This ST system is taken as useless by some of the clients and is even seen as more detrimental as compared to the use of illegal drugs. The respondents discussed incidents when the ST clients take psychoactive substances not recommended by the physicians (from diphenhydramine hydrochloride to heroin) concurrently with methadone and buprenorphine.

Therefore, accessibility of ART and prevention and treatment of tuberculosis for IDUs are needs which are not being adequately satisfied.

The drug addiction treatment programs based on the rejection of all drugs (detoxification with a further psychological and social adjustment and rehabilitation) is accessible in all these countries but either the patient capacity or quality of care is low.

Another problem which decreases the accessibility and effectiveness of ART is limited access for PLHIV to high quality and timely diagnostics. This is mainly related to the viral load monitoring. Even in Kazakhstan, where this type of testing is accessible, about half of

¹⁴ (http://www.drugabuse.gov/Nida_Notes/NNVol14N2/tearoff.html).

¹⁵ “Collaborative TB and HIV Services for Drug Users”, Christian Gunneberg, WHO, IHRA Conference, Bangkok, 2009.

the HIV-positive persons have not had such a testing for the last year¹⁶. The accessibility of diagnostics and treatment of opportunistic and associated diseases is rather low. About forty-three percent of HIV-positive persons in Kazakhstan think that they do not receive required medical care and about 28% think they do not get it always when it is needed¹⁷.

There are several reasons for this problem. The first one is associated with the limited accessibility of diagnostics for PLHIV residing beyond the capital cities. The second reason is a low adherence of PLHIV to clinical examination (which is one aspect of adherence to treatment). A majority of HIV-positive persons avoid visiting physicians up until the moment when their health condition deteriorates dramatically. The third reason is the problem of HIV related stigma and attitudes that some health professionals hold towards PLHIV.

It is worth noting that in addition to technical and legal aspects, the relationships between the care providers and patients/clients are accompanied by significant emotional components. Many health care providers perceive HIV-positive persons as “guilty” and “bad”. And PLHIV lacking required information and knowledge of how to treat the HIV infection and associated diseases and psychological support are apt to lengthy depressions and neuroses. Taking into consideration these premises, an effective interaction looks improbable.

Palliative medical care is not accessible in either of the variants¹⁸ in either of the countries.

Non-medical care and support

Non-medical care and support for PLHIV are poorly developed in Central Asia. At the moment, only humanitarian aid and minimal informational support (basic information about HIV-infection and ART) are accessible for PLHIV. Psychological support is accessible only for a limited number of PLHIV. There is a lack of psychologists who specialize in working with PLHIV in these countries. According to the comments made by the respondents, today, the psychological aid is concentrated mainly on the reduction of distress intensity. Due to the lack of elaborate and resourceful voluntary programs of mutual support between PLHIV, there are only isolated self-support groups. There are no

¹⁶ In accordance with interviewing conducted by local NGOs in April-May 2009. Not less than 30 HIV-positive persons were contacted out of each 4 countries.

¹⁷ AFEW (2008). Capacity building of community organizations and social integration of PLHIV. [in Russian]

¹⁸ There are two interpretations and definitions of the palliative assistance. *The first one* is conventional. It implies the treatment, care and support of dying patients. And the *second one* was suggested in 1990 by WHO and says that: “Palliative care improves the quality of life of patients and their families facing life-threatening illness by providing pain relief and management of other distressing and debilitating symptoms. Palliative care services are appropriate from the time of diagnosis of a life-threatening illness and throughout the course of the illness”. (<http://www.who.int/mediacentre/news/notes/2007/np31/ru/index.html>)

programs aimed at assisting and supporting the families with members living with HIV or families who have had relatives die of HIV/AIDS.

Assistance in the form of food, clothes, money, or round-trip tickets to places of treatment comes from many international organizations such as the UN Food Program, AFEW, and GF funded projects. The PLHIV NGOs have extensive experience related to the transparent procedure of the distribution of humanitarian aid (e.g. “Gouli Surkh” in Tajikistan, “Krik Zhuravlay” (Crane’s Call) in Kyrgyzstan, and Initiative group of PLHIV, Navoi, Uzbekistan).

Based on the estimates made by the respondents, the humanitarian aid programs cover up to 5-7% of PLHIV registered in the countries on occasion or a regular basis. The majority of the recipients of this humanitarian aid are the families affected by HIV.

As a result, PLHIV continue to be socially isolated and unsuccessful, confirming the prevailing societal opinion that their lives do not deserve to be paid attention to and therefore reinforcing the existing stigma.

3. Capacity of PLHIV NGO in the region

3.1. Resources and capacity of PLHIV NGOs to provide care and support services to PLHIV on the local level

The number of PLHIV NGOs in the countries where the assessment was done is low. For example, there are about 10 such organizations operating in Kazakhstan and Kyrgyzstan, 5 in Tajikistan and 1 in Uzbekistan. But at the same time, at present an active process of establishing new PLHIV NGOs is taking place in these countries (several initiative groups in Kazakhstan; about 1-2 groups in Kyrgyzstan and Tajikistan; and 6-7 initiative groups in Uzbekistan which are striving to get registered as networking NGOs). In fact, this situation corresponds to the way the epidemic processes are occurring in the countries.

There are PLHIV NGOs operating for three or more years in each of these countries and they are experienced enough to render social assistance to PLHIV, as well as aid to access to necessary health services (“Victoria”, “Shapaghat”, “Kazakhstan Union of PLHIV” in Kazakhstan; “SPIN+” and “Gouli Surkh” in Tajikistan; “Ishonch va Khayot” in Uzbekistan; and “Ranar”, “Matrix-2005” in Kyrgyzstan). The majority of PLHIV NGOs were established recently. As respondents reported, actually all PLHIV NGOs had been set up with the direct or indirect help of international organizations. At present, they are capable of operating exclusively using the resources allocated by the international entities and organizations, except in Kazakhstan, where some PLHIV NGOs along with other non-governmental not-for-profit organizations have access to municipal grants, although the sums of these grants are very meager and the procedures of their awarding are not always transparent.

Contact and cooperation with local, national, and state health and non-medical facilities is one of the key elements of the resources of PLHIV NGOs which enable to deliver assistance and support on the local level. State entities (AIDS Centers, hospitals, narcological dispensaries, etc.) treat PLHIV either positively or neutrally and cooperate with them. Actually, all PLHIV NGOs involved in the meetings have partnership liaisons or coordinate their activities with the state health facilities.

The attitude of the government structures towards PLHIV NGOs in these countries is different. In Kazakhstan, a process of integrating PLHIV NGOs into the national programs through their involvement into decision-making procedures started (“Kazakhstan Union of PLHIV”, Social Fund “Shapaghat”, and Social Fund “Protection of Children from AIDS”) and municipal grants have been given out (Social Union “Kuat”, “Association of AIDS-servicing Organizations”), while in Kyrgyzstan and Tajikistan the governments try to ignore the activities of existing PLHIV NGOs, whenever possible. In Uzbekistan, the situation is controversial: from one side, the government is trying to control the activities of NGOs as much as possible and from the other side, they are trying to find a compromise by creating an umbrella NGO, such as “NANNOUZ”.

In all the countries, PLHIV NGOs are involved in the implementation of national programs on HIV infection control in terms of providing social support and assistance to PLHIV. Most often, they act as ultimate service providers realizing the programs initiated by state and international organizations. To a small extent, they impact the decisions made on the national level regarding the distribution of resources available to provide care and support to PLHIV.

The interrelation between PLHIV NGOs is one of the complicated and essential issues which influences their capacity to deliver care and support to PLHIV. In Kazakhstan, these relations can be characterized as a gentle rivalry. The majority of existing PLHIV NGOs has been established under the auspices of the ‘Kazakhstan Union of PLHIV’, and is integrated into the national network together with the old-established PLHIV NGOs like, ‘Shapaghat’ and ‘Victoria’. There is a certain rivalry but not a contradiction between these organizations that allows building links with the donors and government and providing working resources to all the members of the national network. In Tajikistan, due to the insufficient number of these organizations which are overlapping geographically or by target groups, there is no open confrontation between them but there is no active cooperation, either.

In Kyrgyzstan, the situation is different and the relations between PLHIV NGOs can be described as an undisguised and active confrontation which considerably undermines their capacity to attract resources and develop services. The conflicts arising within these organizations are mainly related not to the viewpoints on needs of PLHIV and methods of operation, but more to personal miscommunication between the PLHIV NGOs’ leaders.

The issue of constructive and stable leadership plays a significant role especially in the context that these PLHIV NGOs are *leader-driven*, i.e. their existence and activities are the result of the efforts of a couple of individuals and not the outcome of a steady mechanism within a community. Besides, there is no mutual support between PLHIV leaders in the form of *coordinated common priorities and a mutual support system*, when different PLHIV NGOs and their leaders assist each other in meeting commitments of donors, the government, and the community. The given situation can be partially explained by the fact that the majority of PLHIV NGOs in the countries were set up recently and some time is required for the consolidation of a strong PLHIV community.

In addition to the above mentioned conflicts arising between the heads of the PLHIV NGOs, there is another essential factor which impacts the activities of PLHIV NGOs: some of the socially active PLHIV are drug users.

As practices from different countries show (Ukraine, the United Kingdom, Holland, USA, and others), drug abuse among the leaders of the communities is solvable if the narcological aid is accessible in a country. A more serious problem is a lack of strategic support rendered for the PLHIV leaders from government agencies and international organizations including training and aid for prevention of burn-out syndrome.

At present, PLHIV NGOs provide PLHIV with the following care and support:

- Distribution of humanitarian aid (foodstuff and clothes),
- Informing on HIV-infection, ART, tuberculosis, and their treatment,
- Peer-to-peer counseling and peer-support groups,
- Support in restoration of lost documents (passports),
- Assistance in getting required health services, including treatment of drug abuse (detoxification and subsequent psychological-social rehabilitation),
- Assistance in getting psychologist's advice,
- Social assistance of PLHIV to each other within voluntary programs.

With the purpose to inform PLHIV on HIV-infection and TB and their treatment, almost all the PLHIV NGOs use informational materials provided by other organizations (CAPACITY project, AFEW, and AIDS Centers). Some of the PLHIV NGOs publish their own materials, copying the most exciting examples cited by International HIV/AIDS Alliance – Ukraine, the Ukrainian Network of PLHIV, and European AIDS Treatment Group (*EATG, STEP project*).

PLHIV NGOs experience a lack of informational materials published in the national languages. These materials are scarce and one can assume that the quality is not high due to the lack of developed and established set of technical terms in Uzbek, Tajik, Kyrgyz, Kazakh, and Russian languages. Also, there is a lack of knowledge of English which is the

principal language in international communication with regard to HIV-infection and ‘delivery’ of many terms.

In addition to the distribution of the informational materials, all the PLHIV NGOs conduct group sessions (which are either called ‘seminars’ or ‘self-support groups’, depending on the requests of the donors). Very often these sessions are conducted by experts from the AIDS Centers or other medical facilities. The attendees of these workshops are PLHIV, including IDUs, incarcerated persons, and females who have HIV–infected children.

Some of the PLHIV NGOs are well experienced in arrangement of the supporting groups (e.g. “Zhan Zholdass”, “Kuat”, “Protection of Children from AIDS”, Kazakhstan; “Matrix 2005” and “Krik zhuravlay” (Crane’s Call), Kyrgyzstan; Initiative Groups of PLHIV in Navoi and Tashkent, “Ishonch va Khayot”, Uzbekistan), and self-support groups (“SPIN+”, Tajikistan). This experience was gained during realization of harm reduction and rehabilitation projects targeted to drug abusers and based on the “*therapeutic community*” principle (“SPIN+” and “Matrix 2005”). The organizations which has no such an experience could have successfully used the conventional *local social networks* (“Krik zhuravlay” (Crane’s Call) and “Protection of Children from AIDS”). The Social Fund “Kuat” conducts support groups in the hospital where PLHIV receive regular medical care. The leaders of these support groups are mainly health professionals and psychologists.

Peer-to-peer counseling is provided by all the PLHIV NGOs and it is one of the key services delivered. This service provides PLHIV with the information they need and moreover gives emotional and psychological support which are extremely significant and play a vital role, given the high-level stigmatization of PLHIV, and especially IDUs and MSM

However, the PLHIV NGOs have no clear understanding of what is implied by the peer counseling¹⁹ and it results in the absence of a peer consultants training system and prevention of burn-out syndrome among the consultants.

Despite the fact that all PLHIV NGOs carry out informational events, the level of awareness of their own workers still remains low. The specialists of state agencies often noted that the fact that the knowledge of some peer consultants and PLHIV leaders is limited impedes cooperation. As they assess, many peer consultants and leaders cannot

¹⁹ There are two options for peer-to-peer counseling. The *first* and likely the most effective one is implementation of *voluntary programs as a part of the social adaptation of the PLHA* which is leading by social specialist or psychologist. Being trained, working as a consultant and getting support while working as the consultant, a HIV-positive person obtains the skills, knowledge and experience which enable one to feel over time more confident and capable to take care of oneself and one’s relatives. Upon receiving all these required, the person gets out of the program and the next person can come to the program. The *second* option: when *someone out of PLHA is trained/searched to play a role of consultant and become the permanent worker of the organization* responsible for counseling, and having professional skills and knowledge required for consultant, and knowing on his own what life with HIV is like.

competently explain the need for clinical examination not less than twice a year or what side effects be observed during taking ART drugs and how often they may be observed.

All the PLHIV NGOs assist their clients in getting access to different types of health services, advice of psychologists, and many even help in restoration of lost documents. The referral system for health services is based on agreements of cooperation between the PLHIV NGOs and state health facilities. Most often, users of the services provided by the PLHIV NGOs are active IDUs residing in remote areas away from the location of the state facilities (poor rural citizens). Other PLHIV have no problems with referring for care directly to the facilities with all needed services available. In other words, “assistance in receiving health services” is in fact outreach work to attract groups with difficulty accessing services, i.e. IDUs and residents of the remote areas for passing tests and clinical examination.

Social support is the most significant part of the activities of the PLHIV NGOs since it encourages the consolidation of the community and overcoming the consequences of stigma and discrimination in the daily life of PLHIV. Regrettably, this work is being carried out only occasionally and on a small scale (e.g. in “Krik zhuravlay” (Crane’s Call» and “Matrix 2005’, Kyrgyzstan; “Zhan Zholdass”, Kazakhstan; “Gouli Surkh”, Tajikistan; Initiative groups of PLHIV in Navoi and Tashkent – Uzbekistan). The most common type of mutual support program is assistance rendered at home and care of children, visits to each other if somebody gets sick and is at home or in the hospital, as well as communication with each other to discuss current events. Uniting of PLHIV for tackling daily problems and taking care of each other *is crucial for the creation of a socially friendly environment which enables PLHIV to overcome the consequences of stigma and psychological problems that accompany an HIV-positive diagnosis.*

The options for mutual support for PLHIV are restricted and probably the deficit of useful ideas is associated with the lack of PLHIV NGOs’ attention paid to the development of voluntary programs encouraging mutual support of each other. As a rule, the more intensive the experience, the more new ideas which will be generated and new opportunities revealed.

It is interesting that this mutual support is mostly rendered beyond any projects or grants. Once PLHIV NGOs get involved in certain projects, the activity of mutual support between PLHIV participating in PLHIV NGOs as workers or volunteers decreases. There are no special programs assisting PLHIV to create social mini-networks (social centers) in the countries.

Material resources of PLHIV NGOs

The majority of PLHIV NGOs do not possess an adequate material base. For example, many PLHIV NGOs own one or two out-of-date and old-fashioned computers, printers,

telephones, and facsimile devices. Some of the recently established organizations do not own any computers. Almost all the organizations, including the initiative groups, have their own office space (e.g. in Uzbekistan), but only a few of these offices enable the workers to provide good-quality services to PLHIV to conduct meetings, workshops, or seminars in rather large premises, to provide a space for a psychologist or a consulting physician, or to organize the office itself separately from the rooms where the work with clients is carried out (“SPIN+”, Tajikistan; “Krik zhuravlay” (‘Crane’s Call’) and “Matrix 2005”, Kyrgyzstan; “Association AIDS–servicing organizations” and “Protection of children from AIDS”, Kazakhstan). Besides, these facilities are rented and it implies that they will be lost once funding provided from the external financial outlets ceases.

Personnel of PLHIV NGOs

Personnel working for the PLHIV NGOs is mixed since it consists of PLHIV and specialists who have not been affected by HIV-infection and who are employed by government agencies (AIDS Centers, scientific-research institutes, etc.) In the opinion of some respondents, the involvement of the state workers can be a positive factor enabling the steady operation of the organization, since these workers get income from the state and can maintain the organization’s operation even if there is no funding for the PLHIV NGOs. Besides, these workers will be interested in building relations with other state agencies and government organizations and will take advantage of their contacts and status.

As a rule, PLHIV act in the position of leaders of PLHIV NGOs or conduct work which does not require a long-term special training, such as outreach workers or ‘social workers’. There are many experienced and professional outreach and social workers among PLHIV in many PLHIV NGOs.

Links of PLHIV NGOs with PLHIV community

Based on the comments made by the respondents, at present in the four countries, the *number of PLHIV participating in the work of the PLHIV NGOs, other NGOs, and government agencies as paid workers may include more than 130 people*: about 40 people in Kazakhstan, Kyrgyzstan, and Uzbekistan, and about 15 workers in Tajikistan. In less than a year and a half (from January 2008 through April 2009), *they delivered assistance and support to not less than 2,500-3,000 PLHIV* in these countries in total: up to 1,500 PLHIV in Kazakhstan, 1,000 PLHIV in Uzbekistan, 300 in Kyrgyzstan, and about 200 in Tajikistan.

Quality of organization management and implemented projects

As it was mentioned above, actually *all the PLHIV NGOs are ‘leader-driven’, therefore their operation and work first and foremost depends upon the skills and knowledge of the leaders of the organizations and their vision of current situation and prospects.*

One of the respondents in Tajikistan expressed her opinion saying that in poor countries with low incomes, many citizens, including the leaders of the PLHIV NGOs, do not see the prospects for a period of 12 months (a period of 12 months is a common term for projects designing). People are in a constant search for ‘bread and butter’ (means of living) and these conditions make the people more likely to immediately react to grasp any chance to earn a living. Therefore they do not *schedule any concrete plans and formulate concrete expected results for more than 3-4 months*. This attitude makes the operation of PLHIV NGOs less stable, more donor-oriented, and more irresponsible in dealing with the clients (‘no money – no work’). Certainly, it is impossible to rapidly change the work style and timeframes of a hundred PLHIV NGOs’ workers in the region. But delivering on-going assistance and support to the PLHIV leaders by helping them to acquire new knowledge and skills and by involving them in joint long-term project implementation on the national level will enable adequate levels of stability and responsibility of PLHIV NGOs, in order to reinforce ‘the backbone of the community’.

As respondents from international organizations note, the main areas requiring the improvement of PLHIV NGOs skills are situation analysis, including needs assessment, performance monitoring and evaluation, funding applications preparation, and reporting.

Respondents from state agencies think that the main problems encountered by the PLHIV NGOs are associated with a poor knowledge of the specific peculiarities of state organizations and government institutions, as well as inefficient information exchange and, to be more precise, not informing key partners (government and state institutions) about on-going work, outcomes, and prospects of PLHIV NGOs.

As the managers of the PLHIV NGOs assess, the main problem is a need of a support for attraction of additional funding and training of the staff.

Based on the survey data received, one can conclude that the experience of the PLHIV NGOs management is founded on the management of projects lasting not more than one year and may be evaluated as low-profile.

- Except for the ‘Kazakhstan Union of HIV-positive persons’, none of PLHIV NGOs has any experience of management of sub-grant programs;
- None of PLHIV NGOs has any experience with managing long-term programs lasting two or more years or incorporating several concurrently executed projects;
- None of the PLHIV NGOs has its own monitoring and evaluation system oriented to monitor the work of an organization as a whole, not only the selected grant, and based on needs of NGO workers but not requirements of donors;
- Only a few PLHIV NGOs carried out strategic planning and have a strategic plan developed;
- Only a few PLHIV NGOs have regulations for internal management and coordination and partnership relations with other organizations;

- None of the PLHIV NGOs have developed plans for increasing the capacities of their workers and volunteers including prevention of burn-out syndrome;
- None of the PLHIV NGOs have regulations for attracting PLHIV to work as workers or volunteers, including creating working conditions for PLHIV relating to their HIV status.

Due to the lack of any strategic visions of the targets and prospects of their activities, it might be possible that the positive experience acquired by PLHIV in the process of their work may be disregarded, ignored, or the collected data may get lost.

When asked about the ways that data collected by the outreach workers may be utilized, one of the workers of AIDS Center who also works in the project for support of IDUs in one country said that *'this information is not used at all because none of the specialists need it'*. This information is not being used by PLHIV NGOs either.

3.2. Successful examples of cooperation between PLHIV NGOs and governmental institutions

It is important to note that with the exception of newly established PLHIV NGOs, all of the PLHIV NGOs are involved in the implementation of the projects funded by GF and agencies for international development which happened primarily due to the terms posed by the donors and support rendered by the assisting agencies and donors and UN programs. Thanks to the participation in these projects, the PLHIV NGOs began cooperating with government institutions.

Because the majority of the PLHIV NGOs were established recently, the scheme of their collaboration with the state institutions is very similar. In all cases, the cooperation is based on the following responsibilities distributed between PLHIV NGOs and state institutions:

- Government institutions provide health care and specialists' counseling;
- PLHIV NGOs attract representatives of relatively inaccessible groups of the population for passing tests and clinical examination, rendering psychological support, assisting in distribution of humanitarian aid, and providing support to maintain adherence to treatment, helping to restore lost documents, and arranging documents for receipt of pension by PLHIV and social allowances.

The most successful examples illustrating cooperation between PLHIV NGOs and state facilities are brought forward below.

1. Public organization "Kuat", Kazakhstan

Ust-Kamenogorsk is located in Eastern Kazakhstan Oblast, where the incidence rate of HIV-infection is one of the highest in the Republic of Kazakhstan. However, at the

moment, the number of HIV-positive persons in the city is not that high and considering a significant stigma society exhibited towards them, it was rather complicated to call on these people to have group meetings or individual consultations in the NGO office. It was more realistic to arrange counseling and information/training events while the PLHIV were receiving treatment in the hospitals. But hospital administration was concerned about the peer PLHIV consultants, who could disturb the hospital administrative system.

Public organization “Kuat” employed a doctor-infectiologist who was responsible for scheduling and conducting regular visits of PLHIV who were in the hospital. This approach complied with the requirements of the hospital administration and as a result of this methodology, there have been seminars and advisory sessions for PLHIV held on a regular basis for more than one year. Also, PLHIV are being updated on the activities of the Public organization “Kuat”.

2. Social Fund “Matrix 2005”, Kyrgyzstan

A few of the ART drugs such as efavirenz and nevirapin impact the metabolism of methadone and cause symptoms which of abstinence syndrome. If a patient is prescribed one of these medications and methadone, the dose of methadone has to be either increased and/or split into two.

Delivery of methadone in Bishkek is carried out through the narcological dispensary once a day. One of the female patients of substitution therapy (ST) had to split the daily dose of methadone into two in order to avoid abstinence syndrome symptom, but the workers of the dispensary did not want to stay at work for some hours waiting for the visit of only one patient.

On the initiative of the SF “Matrix 2005” the delivery of methadone for that patient was arranged based through this PLHIV NGO. A nurse working in “Matrix 2005” receives a double dose of methadone for that patient in the narcological dispensary and delivers that medication for her in the office of ‘Matrix 2005’. A lock box was provided for storage and a special log book is being kept (similar the one at the narcological dispensary). This procedure of receipt and delivery of methadone has been approved by the AIDS Center and narcological dispensary.

3.3. Capacity of PLHIV NGOs to participate in the decision making process at the regional, national and local level.

In general, the activities of the PLHIV NGOs are focused on the local level. Therefore, the overwhelming majority of the PLHIV NGOs are experienced in participation in decision-making process on the municipal and oblast levels. But counting *a specificity of the funding process* when the majority of financial resources comes from international organizations or the national budget and *many ethical issues arises in the process of arrangement and implementation of prevention and treatment projects, which significantly*

politicize the HIV-infection related work, only a small amount of decisions are made on the local level. Almost all decisions are made on the national and international levels and only their execution to a large extent depends upon the local health institutions, social establishments, and administrative and legislative entities.

At present, only a few existing PLHIV NGOs participate purposefully (consciously) in the decision-making process on the national and regional levels. Among them are the following organizations:

- “Kazakhstan Union of HIV-Positive Persons”, Kazakhstan,
- “SPIN+”, Tajikistan,
- “Gouli Surkh”, Tajikistan,
- “Ishonch va Khayot”²⁰, Uzbekistan,
- “Protection of Children from AIDS”²¹, Kazakhstan

A capacity for involvement in the decision-making process consists of:

- Access to the decision-making persons and public opinion leaders;
- Possibility to provide information significant for quality decision-making and analyzing,
- Possibility to promote the execution of the decisions made.

Accessibility to key decision makers

At present, many of the PLHIV NGOs have many opportunities for regular access to key decision makers both in government institutions and international organizations. All the PLHIV NGOs are interacting and cooperating with the local and national state institutions which assist PLHIV. There are PLHIV representatives in country coordination mechanisms (except in Uzbekistan, where CCM has been recently restructured and at the moment there are no spokespeople from PLHIV yet). In each country the PLHIV NGOs or PLHIV activists are regularly invited to all the meetings organized by UN agencies and programs or international organizations and projects.

All the coordination centers, international, and regional network unions have their websites and own e-mail list-servs, and they can disseminate not only their information but information of local PLHIV NGOs and initiate discussions.

The following coordination centers and regional networks operating in Central Asia have active electronic list-servs:

- Country Coordination Mechanisms;
- UN thematic groups on HIV/AIDS;
- National networks of AIDS-Servicing NGOs (in Kazakhstan and Kyrgyzstan);

²⁰ The management of the organization was changed. The new administration has no adequate experience.

²¹ The management of the organization was changed. The new administration has no adequate experience.

- National Networks of harm reduction NGO (in Kazakhstan and Kyrgyzstan);
- PLHIV National Networks (in Kazakhstan and Kyrgyzstan);
- «Eastern-European and Central Asian Union of PLHIV» (ECUO);
- Eurasian Harm Reduction Network (EHRN);
- International Treatment Preparedness Coalition (individual membership).

Each of the international organizations and projects operating in Central Asia has a web site.

Some of the PLHIV NGOs representatives or their partnership organizations are incorporated into the organizational and thematic committees of international conferences (e.g. Kamilla Fatykhova with NANNOUz (Uzbekistan) is a member of the “Leadership” Committee of the International AIDS Conference, Vienna, 2010). This membership provides an opportunity to impact the selection of topics and spokespeople of these conferences.

Opportunities to provide information which is important for quality decision-making and analyzing

The PLHIV NGOs have such opportunities and they are capable of:

- Collecting data on behavior patterns (including ones in terms of risky behavior) and the needs of hard to reach groups of PLHIV such as IDUs, MSM, and PLHIV residing in rural districts;
- Assisting in designing and ensuring quality research concerning the interests of the PLHIV (e.g. by creating ethical committees);
- Assisting in the evaluation of designed, planned, current, and completed programs of care and support to PLHIV (*client driven evaluation*), including the analysis of reasons explaining insufficient adherence of PLHIV to treatment.

With rare exceptions, all the PLHIV NGOs have already acquired experience in cooperating with state institutions and international organizations on survey design and conduction including sentinel surveillance. Some of the PLHIV NGOs were initiators of surveys.

Opportunities to facilitate the execution of the decisions made

PLHIV NGOs are well connected with different groups of PLHIV, have acquired a certain experience of collaboration with local entities, and can act in the capacity of immediate executives of the decisions made as advocates of these decisions at the local level.

Besides possessing a certain experience of funding and attraction of volunteers, the PLHIV NGOs are capable of facilitating the attraction of additional resources to realize the decisions made:

- Attracting some of the PLHIV and their close relatives/friends as volunteers;

- Drawing attention and support of the international community via international networks in which they participate and events such as international conferences;
- Conducting an active fundraising campaign among foreign agencies and funds and occasionally among the domestic business circles (there are examples of receiving support from commercial organizations for the conduction of events and programs aimed at the support of the PLHIV in Kazakhstan – “Kazakhstan Union of PLHIV”, Social Fund “Protection of Children from AIDS”, in Kyrgyzstan – Social Fund “Krik zhuravlay” (Crane’s Call) and in Uzbekistan – NANNOUz).

Obstacles impeding the use of capacities

The principal obstacles impeding the use of the PLHIV NGOs’ capacities for involvement in the decision-making processes and arrangement of partnership relations on the national and regional levels are the following:

- Lack of coordinated and explicit standpoint with regard to the strategic priorities and efficient approaches for the development of assistance and support to PLHIV;
- Elusive mechanisms of legitimate representation of the interests of local PLHIV-NGOs at the national, regional, and international levels (such gear is validly operating only in Kazakhstan at the “Kazakhstan Union of PLHIV”);
- Elusive communication links between the entities and partners, including the conflict solutions;
- Insufficient experience in organization of stable voluntary programs to involve PLHIV;
- Lack of steady and efficient external support for the local leaders of PLHIV community.

Conclusions and recommendations

1. General conclusions and recommendations

1. PLHIV NGOs deliver social support and assistance to the most vulnerable HIV-infected persons and their families. Thus, they are *important potential partners for the government institutions and international organizations in terms of upgrading the quality of measures directed at universal access to HIV prevention, treatment, care, and support.*
2. PLHIV NGOs, as well as the community of PLHIV, are “young” and still being shaped. All of them are leader-driven; *therefore the PLHIV leaders’ support is crucial and essential for providing further development of the PLHIV NGOs and unity of PLHIV community.*
3. The majority of the PLHIV NGOs carry out their activities on the local level, but some decisions significant to PLHIV are made on the national and regional levels. In order to participate in making these decisions, *PLHIV NGOs must promote the*

development of partnerships with each other to set up networks on the national and regional levels. It is necessary to ensure a transparent process of coordination of the prior activities of PLHIV NGOs and of the democratic delegation of representation duties.

4. At present, the principal partners of the PLHIV NGOs are international organizations and local state facilities. For the purpose of further development of PLHIV NGOs and their effective and constructive participation in decision-making on the national and regional levels, *PLHIV NGOs must develop constructive partnerships with national government agencies and other NGOs established by other communities affected by the HIV-infection epidemic.*
5. The resources which PLHIV NGOs use today are provided by international organizations. This support is not steady and in some cases there is no coincidence of the priorities and interests with the interest of PLHIV. For the purpose of ensuring a stable operation and a more precise registration of the community's needs, *PLHIV NGOs must utilize the resources which are available within this community by creating conditions for mutual support between PLHIV. Also, it is important to promote a wide and meaningful participation and involvement of the PLHIV into the decision-making process and realization of programs on the local, national, and regional levels.*

2. Priority recommendations for capacity building of PLHIV NGOs

1. It is important for PLHIV NGOs to develop better links and relations with local communities. The role of PLHIV NGOs should be to identify needs and problems of PLHIV in the area, to mobilize internal resource of the community to solve the problems, and to build effective partnerships with local governments, other NGOs, and international partners. If existing local PLHIV NGOs will not be able to build sustainable relations with the PLHIV community and implement all the functions listed above, they will either cease to exist or will gradually transfer into the wide-spectrum NGOs that do not represent interests of any particular group. In the latter case, they will lose their competitive advantage and will not longer be able to play a role of an important partner of government or international organizations.

Considering the above, the primary capacity building goal for current PLHIV NGOs should be to integrate different components of peer-to-peer support into their menu of services as a way to attract and involve more community members into NGO activities.

PLHIV NGOs should include activities for development of peer-to-peer support groups into their working plans and adjust their organizational charts to allow structures that will help community members participate in the decision-making process. The easiest

instrument to do this is to create community supervisory boards and conduct regular surveys among community members to evaluate access to and quality of services provided.

Governmental entities and international organizations can support further development of PLHIV NGOs by including PLHIV as a precondition for selection of partners for GF funded projects and other projects, as well as by providing technical support to PLHIV NGO leaders and staff members on the provision of quality peer-to-peer support services. As experience worldwide shows, peer-to-peer support, including self-support groups and volunteers providing *buddy-care* services, are the most effective methods of work with PLHIV²².

2. PLHIV NGOs should pay adequate attention to professional capacity building of employees and volunteers, including prevention of burn-out syndrome. In order to achieve this, NGOs should regularly (at least annually) assess the capacity of their employees and volunteers and adjust training plans and other support. Considering that most employees of PLHIV NGOs can be considered vulnerable populations, this work will have dual positive effects: it will help to build the organizational capacity of the PLHIV NGO, as well as strengthen the individual capacity of people from affected populations. Since most PLHIV NGO leaders and activists have substance addiction problems, it is important to build good relations with local narcological and mental health institutions, so that people, especially PLHIV NGO leaders, can access and timely receive professional help.

Governmental entities and international organizations can support capacity building by allowing (or better, recommending) the expenditure of at least 10% of the grant money for capacity building activities of the project personnel.

3. Local PLHIV NGOs should develop and agree to use a common simple system to monitor and evaluate its activities. Without being able to receive and provide clear data about program activities and results, PLHIV NGOs will not be able to attract community members to their activities, make long-term plans, or build sustainable relations with different partners from government and international organizations.

It is important that M&E indicators are illustrative of the actual needs of organization itself and community members represented by this organization. To achieve this, PLHIV NGO should move from short-term project-oriented planning to long-term strategic planning (at least two to three years in the future) that will consider community needs and not solely the

²² Terry Carlton T., Beck R., Allen H., «Self-support groups for HIV seropositive people», American Rehabilitation, Autumn 1993; Недзельский Н., «Поддержка людей, живущих с ВИЧ», ИНФО+, 2003; Velentgas P., Bynum C., Zierler S., «The Buddy Volunteer Commitment in AIDS Care», Am J Public Health 1990; 80:1378-1380; Zuyderduin JR , «The buddy system of care and support for and by women living with HIV or AIDS in Botswana», *Int Conf AIDS*. 2004 Jul 11-16; 15: abstract no. MoPeD3752; Burrage J., Demi A., «Buddy Programs for People Infected With HIV», *Journal of the Association of Nurses in AIDS care*, 2003, Volume 14, Issue 1, Pages 52-62

donor requirements. Organizations should also mobilize internal resources of the community (volunteers, material resources available from the community members, etc).

International and national partners can support this by moving from short-term project financing to building longer-term partner relations with PLHIV NGO and better cooperation when developing goals and objectives.

3. Recommendation about the possible role of the Regional PLHIV Network.

Role of the Regional PLHIV network should be to create effective information exchange and coordination between various local PLHIV NGOs, as well as to represent the opinions and interests of local PLHIV NGOs during the decision-making process at the national and regional levels.

In the first place, the Network should be able to summarize and analyze needs and interests of different local PLHIV NGOs and help them to develop common harmonized strategies and positions to present to the national governments and regional partners (advocacy and representation).

To ensure information exchange and to facilitate advocacy at the national and regional levels, the Network should coordinate the development of standards for the quality of services provided by different local PLHIV NGOs, as well as professional terminology to be used.

The Network can initiate the development of the regional projects and programs that will include participation of several local organizations. Rationale for these projects can be based on the community needs and capacity building needs of PLHIV NGOs, as well as the interests of such communities as migrants and their families, national minorities, and populations that live near the borders.

APPENDICES

List of meetings held by the expert

No	Date	Name	Organization and position	Comments
KAZAKHSTAN				
	13.04	Workshop on needs assessment held in Almaty		10 attendees
1		Yelena Kudussova	CAPACITY project, project Director in Kazakhstan, Almaty	
2	14.04	Nurlan Sair	Head of Social Fund “Social Union in Support of PLHIV “Kuat”, Ust-Kamenogorsk	
3		Yelena Rastokina	Head of Social Fund «Answer», Ust-Kamenogorsk	
4	15.04	Serik Zheniss-Uly Zhenissov	Acting Head of the Dept. on work with youth and NGOs, Internal Policy Board of Eastern-Kazakhstan Oblast, Ust-Kamenogorsk	
5		Peter Nikolaevich Kollar	Chief Physician of Oblast AIDS Center, Ust-Kamenogorsk	
6	16.04	Bolatbek Turganbayev	Head of the Association of AIDS-Servicing Organizations, Shymkent	
7		Zhanetta Zhozepoyeva	President of Social Fund “Protection of Children from AIDS”, Shymkent	Meeting was attended additionally by 5 workers of the Fund
8		Serally Zhakypuly Zhaksylukov	Deputy Director of the Dept. for Social Protection, Labor & Employment of Southern-Kazakhstan Oblast, Shymkent	
9		Indira Otzhanova	Head of Social Organization ‘Zhan Zholdass’, Shymkent	Meeting was attended by 5 women (PLHIV and mothers with HIV- positive children
10	17.04	1 psychologist and 3 physicians	Workers of “Mother & Child” Center, Shymkent	
11		Narghiza Valerievna Nartayeva	Manager of Oblast AIDS Center for Organizational Issues, Shymkent	
12		7 PLHIV, members of mutual assistance group	Social Fund “Zhan Zholdass”, Shymkent	
13		Kanat Alsseitov	Head of Social Fund ‘Balakai’, Shymkent	
14	18.04	Nurali Amanzholov	Head of Kazakhstan Union of PLHIV, Almaty	

KYRGYZSTAN				
15	19.04	Saltanat Ashimova	CAPACITY project, Director in Kyrgyzstan, Bishkek	
	20.04	Workshop on needs assessment held in Bishkek		9 attendees
16	21.04	Elmira B. Narmatova	Chief Physician of Osh AIDS Center, Osh	
17		Ubaidylda N. Toktoraliyev	Deputy Chief Physician of Osh AIDS Center, Osh	
18		Fatima Koshokova	Chairman of Board of SF ‘Rainbow’, Osh	
19		Issa Nurmatov	Head of SF ‘Musaada’, Osh	
20		Mamasobir Burkhanov	Head of SF “Parents against Drugs”, Osh, Kyrgyzstan	
21	22.04	Aziza Kurbanova	Head of SF ‘ Krik zhuravlay’ (Crane’s Call), Osh	Meeting was attended by 3 volunteers
22		Erkin T. Tostokov	Dispensary Physician of Republican AIDS Center, Bishkek	
23		Anara B. Sultanova	Dispensary Head of Dept , Republican AIDS Center, Bishkek	
24		Martin Dawson	Head of Representation office in Kyrgyzstan, Bishkek	
25	23.04	Saliya Karimbayeva	HIV-AIDS Center coordinator, WHO Representation office in Kyrgyzstan, Bishkek	
26		2 infectiologists	Municipal AIDS Center, Bishkek	
27		Ainura Kadyraliyeva	National coordinator of CAAP Project in Kyrgyzstan, Bishkek	
28		Asel Djailoyeva	Project coordinator for children protection, UNICEF Representation office in Kyrgyzstan, Bishkek	
29	24.04	Elmira Djorbayeva	Dispensary Physician of Family Doctors’ Center, Tokmok, Kyrgyzstan Head of the SF «Ishenin Nuru»	
30		Ludmilla T. Bolnykh	Head of the Family Doctors’ Group-Dmitrovka village – Kyrgyzstan	Meeting was attended by 3 workers
31		Valery Chernyavsky	Portfolio manager, Global Fund for response to AIDS, TB and Malaria	
32		Vladimir Yermolov and Svetlana Kovalitskya	Head and His Deputy , SF ‘Matrix”, Bishkek, Kyrgyzstan	Meeting was attended by 8 workers and volunteers
33		Sergei Tsakharias	Head of SF ‘Citadel 2009”, Bishkek, Kyrgyzstan	

TAJIKISTAN				
34	25.04	12 employees of the NGOs working with PLHIV	SF “Gouli Surkh”, SF “Vita”, SF “Volunteer”, SF “SPIN+”	Meeting was held in the office of the SF ‘SPIN+’, Dushanbe
35		Makhmud Madjidov	Head of Public Organization “Marvorid”, Dushanbe	
36		Murtazakul Khadirov	Head of PO “RAN”, Dushanbe	
	27.04	Workshop on needs assessment held in Dushanbe		12 attendees
37	28.04	Mansour D. Dodarbekov	Dispensary Physician of Republican AIDS Center, Dushanbe	
38		Makhmadruzi N. Malakhov	Director of Republican Narcological Center, Dushanbe	
39		Kobildjon M. Bukhoriyev	Director of Municipal AIDS Center, Dushanbe	
40		Turakhon M. Sharipov	Dept. Head for HIV-infected persons, City Infectious Hospital, Dushanbe	
41	29.04	Abduldjalol Sh. Djabarov	Chief Physician of Sorgiisk Oblast AIDS Center, Khodzhent	
42		1. Furkat Polatov 2. Sayedkhodja Sayedov 3. Alidjon Sharipov	Staff of Public Organization “Dina”, Khodzhent 1. Head of Accessible Services Center 2. Head of NEP 3. Outreach officer	
43		Orifkhodja Aripov	Head of PO “Anti-AIDS”, Khodzhent	
44		Dmitry Son	Project Manager of PO “Young Generation of Tajikistan”, Khodzhent	
45		1. Dilorom Gafarova 2. Vasily Gisbrekht	Republican Public Organization “Safon Sugdt”, Khodzhent 1. Executive Director 2. Advisor for work with PLHIV	
46	30.04	Maria Boltayeva	UNAIDS coordinator in Tajikistan, Dushanbe	
47		Nisso Kassymova	AIDS/HIV programs coordinator, UNICEF office in Tajikistan, Dushanbe	
48		Aziza Khamidova	AIDS/HIV programs coordinator, UNDP office in Tajikistan, Dushanbe	
49		1. Nighora Abidjanova 2. Zurmat Maksudova	OSI- Tajikistan – Dushanbe 1. Public Health care program Director 2. Public Health care program Coordinator	
50		1. Ikrom Ibraghimov 2. Dilshod Pulatov	AFEW, Dushanbe 1. Representative in Tajikistan 2. Project manager	
51		Nailya Berisheva	ACT Central Asia, AIDS/HIV programs coordinator, Dushanbe	
52		Susan Pradlow	CARHAP Project, Project manager,	

			Dushanbe	
53	02.05	Davron Kurghuratov	Chief Physician of Kholton Oblast AIDS Center, Kurgan–Tyube	
54		Rustam S. Bakhridinov	Head of PO “Fidakor”, Kurgan–Tyube	
55		Aziza Pirova	PF “Legal support”, Dushanbe	
56		Sevara Kamilova	Head of “Gouli Surk’ organization , Dushanbe	
57		1. Ikrom Ibraghimov 2. Dilshod Pulatov	AFEW, Dushanbe 1. Representative in Tajikistan 2. Project manager	
58	04.05	1. Zakir Kadyrov 2. Chinara Seitaliyeva	CAAP Project coordinators, Almaty	
UZBEKISTAN				
59	17.05	1. Rakhima Nazarova 2. Rifat Sarbayev 3. Kamilla Fatykhova	1. CAPACITY project Director in Uzbekistan 2. NANNOUz Director 3. NANNOUz Coordinator	
	18.05	Workshop on needs assessment held in Tashkent		11 attendees
60		Tatiana V. Shumilina	UNAIDS Coordinator in Uzbekistan, Tashkent	
61	19.05	Experts delivering assistance and support to PLHIV and HIV-positive persons	Red Crescent Society’, Namanghan	There were 12 persons involved, including 3 specialists
62		Tulganoi Khadjayeva	Program coordinator, ‘Red Crescent Society’, Namanghan	
63	20.05	Boris S. Shelepov	Psychiatrist, assistant of Confidence and Trust point for IDUs, Republican AIDS Center, Tashkent	
64		Kamildjon Akhmedov	AIDS/ HIV programs advisor, UNICEF representation office in Uzbekistan, Tashkent	
65		Tatiana Nikitina	‘Intelish’ Scientific Union Director, Tashkent	
66		Nadira Karimova	‘Istekboli’ Scientific Union Director, Tashkent	Additionally 2 workers of the organization
67		Gregoire Odou	Attache for Science under the Embassy of France in Uzbekistan, Tashkent	
68	21.05	Hans Bedersky	World Vision , Uzbekistan , Director , Tashkent	
69		Yelena Yakovleva	AFEW, Representative in Uzbekistan, Tashkent	
70		Andrei Vlassov	Commercial Organization Director	
71	22.05	Sergei Uchayev	Initiative team member, Tashkent,	

			Uzbekistan	
72		Mamdjuda Khudjayeva	“Ishonch Hayot, Chairman of Board	5 members of Board
73		Experts rendering assistance and support to the PLHIV and HIV-positive persons	“Kaldyrghoch’ Children’s Center	Additional 7 persons including 2 PLHIV
74		Rakhima Nazarova	CAPACITY project, Director in Uzbekistan	
75	23.05	Nataliya Fedeneva	Social bureau for PLHIV ‘Khayot’, Head of Project; member of PLHIV initiative group, Navoi	
76		PLHIV, clients of ‘Khayot’ Social Bureau	Navoi	Additional 3 attendees