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# TECHNICAL REPORT: REGIONAL PLHIV CAPACITY BUILDING

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## **DISCLAIMER**

The author's views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development (USAID) or the United States Government

The USAID Quality Health Care Project is a five-year program designed to improve the health of Central Asians by strengthening health care systems and services, particularly in the areas of HIV/AIDS and TB care and prevention. The project assists governments and communities to more effectively meet the needs of vulnerable populations, with the aim of increasing utilization of health services and improving health outcomes. The Quality Health Care Project is part of USAID's third objective of investing in people as part of the US Strategic Framework for Foreign Assistance.

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# CONTENTS

<b>Acronyms</b> .....	<b>7</b>
<b>Executive Summary</b> .....	<b>8</b>
I.1.1 Temirtau Field Trip .....	8
I.1.2 PLHIV Participatory Workshop .....	9
<b>Temirtau Field Trip 16-17 may 2011</b> .....	<b>12</b>
I.2 Background .....	12
I.3 Strengths of the HIV service system in Temirtau .....	13
I.3.1 PLHIV clinical services provide multiple entry points to care .....	13
I.3.2 Multidisciplinary teams and cross-sector collaboration .....	14
I.3.3 Medically Assisted Treatment for opioid dependence .....	14
I.3.4 The importance of the community-based response .....	15
I.4 Strengthening issues for Temirtau’s HIV service system .....	15
I.4.1 Insufficient clinical staff to meet demand .....	15
I.4.2 Intensity of MARP-targeted services / escalating the level of CBO involvement in clinical services .....	15
I.4.3 Difficulties when PLHIV seek clinical help outside the HIV service network .....	15
I.4.4 HIV testing algorithm .....	16
I.4.5 Insufficient CD4 and viral load tests available result in long waiting times .....	16
I.5 Conclusions .....	16
<b>Improving health services for PLHIV: a participatory planning meeting with Quality Health Care Project</b> .....	<b>18</b>
I.6 Introduction .....	18
I.7 Background .....	
<b>Error! Bookmark not defined.</b>	
I.8 Objectives of the meeting .....	18
I.9 Summary: PLHIV participatory planning workshop .....	18
I.9.1 Session One: Opening Remarks and Introductions .....	18
I.9.2 Session Two: ‘What’s on your mind?’ .....	19
I.9.3 Session Three – What is the USAID Quality Health Care Project? .....	23
I.9.4 Session Four – Strategies of the Quality Health Care Project for Improving Services for PLHIV .....	23

I.9.5 Session Five – The personal stories of PLHIV .....	24
I.9.6 Session Six – Regional Success Stories.....	32
I.9.7 Session Seven: What can the Quality Health Care Project do to support existing initiatives? .....	35
I.9.8 Session Eight: Closing Remarks.....	35
<b>Annex A: List of participants .....</b>	<b>iii</b>
<b>Annex B: PLHIV participatory planning workshop.....</b>	<b>v</b>
<b>Annex C: Bibliography .....</b>	<b>vii</b>

## LIST OF TABLES

Table 1: Strengths and weaknesses in the HIV service system in Temirtau.....	9
Table 2: Strengths and weaknesses in the HIV service system in Temirtau.....	16
Table 3: Success stories identified by participants.....	30
Table 4: Key issues identified as needing support from Quality Health Care Project.....	34

## LIST OF FIGURES

Figure 1: The HIV Service System in Temirtau, Karaganda.....	12
Figure 2: Issues identified as having got worse.....	19
Figure 3: Issues identified as having improved.....	20
Figure 4: Issues brought up in the ‘Have Your Say’ session.....	21
Figure 5: Key themes from PLHIV stories.....	23

# ACRONYMS

<b>AIDS</b>	Acquired immune deficiency syndrome
<b>APMG</b>	AIDS Projects Management Group
<b>ART</b>	Antiretroviral treatment
<b>ARV</b>	Antiretroviral medication
<b>CBO</b>	Community-based organization
<b>CCM</b>	Country Coordinating Mechanism
<b>FSW</b>	Female sex worker
<b>GFATM</b>	Global Fund to fight AIDS, TB and Malaria
<b>HIV</b>	Human Immunodeficiency Virus
<b>HR</b>	Harm Reduction
<b>HTA</b>	High transmission areas
<b>IDUs</b>	Injecting Drug Users
<b>MARPs</b>	Most At-Risk Populations
<b>MAT</b>	Medication Assisted Treatment
<b>MSM</b>	Men who have sex with men
<b>MOU</b>	Memorandum of Understanding
<b>NGO</b>	Non-governmental Organization
<b>PLHIV</b>	People living with HIV
<b>STI</b>	Sexually Transmitted Infection
<b>TB</b>	Tuberculosis
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNICEF</b>	United Nations Children's Fund
<b>USAID</b>	United States Agency for International Development
<b>VCT</b>	Voluntary Counseling and Testing

# EXECUTIVE SUMMARY

This report describes the Quality Health Care Project's work with people living with HIV (PLHIV) in May 2011, together with plans for follow-up activities. Consultants Zoryan Kis and Scott Berry undertook a field visit to Temirtau from May 16 through 18, 2011, and facilitated the PLHIV Regional Participatory Workshop held on May 19-20, 2011, with support from Elena Kudussova, the Kazakhstan HIV Director for the Quality Health Care Project.

## KEY FINDINGS

### 1.1.1 TEMIRTAU FIELD TRIP

The Temirtau HIV service system demonstrates that establishing local HIV health service systems is achievable in Kazakhstan and across Central Asia. Through well-considered planning, design, implementation and resourcing of HIV services, Karaganda has succeeded in forming a multiple entry point system for MARPS and PLHIV; however, the system still has continuing limitations.

The effectiveness of Karaganda's HIV service is due to:

- Cooperation and regular communication between service providers and a network of non-government, community-based organizations. Such cooperation supports the meeting of clients' needs.
- The use of multidisciplinary teams in cross-sector collaboration appears to be a core strength of the HIV service system in Karaganda, supporting both HIV testing and the retention of PLHIV within the health care service system. The Karaganda AIDS Center reports an increased collaboration with TB Centers and specialists. During the field visit, investigators observed that PLHIV clinical services are delivered in a polyclinic in Temirtau in collaboration with the local AIDS Center, leading to a decrease in mortality amongst PLHIV who are co-infected with TB.
- A MAT service site in Temirtau reports positive results in improving patients' health, cessation of clients' drug-use, and their successful return to the workforce.
- A small-scale 'expert patient' program operates through some AIDS centers in Karaganda and may be an effective strategy for the support of PLHIV in clinical settings.

As is the case in any health service system, there are areas that need to be further strengthened. Participants described (and investigators observed) some systems in need of improvement in Karaganda and Temirtau. These include:

- Discrimination of PLHIV appears to be common when they seek health services outside the established HIV service system, including in child and maternity as well as emergency services.
- Logistical problems and the inadequate supply of surrogate market test kits result in long waiting times for patients requiring treatment.
- Blood samples are sent to Almaty for confirmation, resulting in unnecessary and extended waiting periods for clients at VCT sites.
- Services targeting at-risk groups appear insufficient. The incorporation of PLHIV and MARPs into mainstream clinical services is strongly promoted by clinical practitioners interviewed during the field trip.

- Community-based organizations are under-utilized and their increased involvement in clinic settings could dramatically decrease the workload of clinical staff, while simultaneously improving hospital-to-community support.

**Table 1: Strengths and weaknesses in the HIV service system in Temirtau**

No.	Key System strengths	No	Strengthening issues worth considering
1	Multiple clinical and community entry points into the HIV service system.	1.	Insufficient clinical staff to meet demand.
2.	Multidisciplinary teams and cross-sector collaborations.	2.	Lack of intensive targeted services for MARPs.
3.	Medically assisted treatment for opioid dependence.	3.	Discrimination in mainstream medical services outside the HIV service system.
4.	Strong involvement of communities at risk and PLHIV.	4.	Waiting times for confirmatory tests
		5.	Long waiting times for PLHIV seeking surrogate market testing.

The Temirtau HIV service model has not been formally evaluated. No evaluation reports or client satisfaction reports were available when requested by the investigators during the field trip. Documenting and sharing the Temirtau model with other regions in Kazakhstan and other countries in Central Asia would be useful. It is recommended that in-depth, qualitative research be undertaken in Temirtau, in order to validate the observations of this field report and inform the development of models for testing by the Quality Health Project.

## **1.1.2 PLHIV PARTICIPATORY WORKSHOP**

A PLHIV Participatory Workshop was held in Almaty on May 19-20, 2011, and was facilitated by consultants Zoryan Kis and Scott Berry. The Quality Health Care Project sought the views of PLHIV in relation to their current challenges in accessing HIV prevention, treatment, care and support services in Central Asia, and the workshop documented successful strategies utilized by PLHIV community organizations to overcome these challenges.

Seven sessions were undertaken over the two days to determine (a) the major priorities for PLHIV in the region, (b) stories from PLHIV about their access to health care services and (c) what PLHIV in the region need from the Quality Health Care Project.

### **1.1.2.1 PRIORITY SETTING**

The results of the priority setting exercise highlight the diversity that exists from setting to setting. Issues raised included: illicit drug use, broader health needs including pre- and antenatal care, and access to treatment and diagnostics.

Access to treatment and diagnostics was rated as having worsened by seven participants, and having improved by eleven people. While overall there have been improvements in treatment and diagnostic access in the region, there is clearly an urgent need for better access to medication assisted therapy (MAT) and TB and hepatitis diagnostics and treatment. Another important issue that was highlighted was inconsistent care offered to pregnant women with HIV.

On the whole, participants were critical of the lack of integration and cooperation across sectors, particularly within health care settings. Examples of areas needing further development include: increased peer counseling and care and support for PLHIV; better input by the community into health systems, and for medical practitioners to build partnerships with their patients.

## **Recommendations**

Three priorities emerged:

1. **Stigma and Discrimination** – the attitudes of health care service providers toward PLHIV needs attention; in particular, respecting medical confidentiality.
2. **Treatment and Logistics** – ARV and OI treatment and diagnostics, MAT, TB and hepatitis diagnostics and treatment.
3. **Improving the quality of health care services** – pre- and antenatal care, medical services and support for children and mothers and the integration of a wide range of clinical and community services into HIV health care systems.

### **1.1.2.2 PLHIV STORIES**

Workshop facilitators asked participants to write down a personal story about living with HIV. Facilitators invited participants to tell positive and negative stories from their experience of accessing the health system.

Seven themes emerged from the story telling session:

1. Children, pregnant women and families affected by HIV.
2. Confidentiality in the health care system.
3. Prison and cross-border experiences of HIV health care.
4. Experiences of the health care system in Central Asia.
5. HIV and injecting drug use – stories of discrimination.
6. Employment and HIV.

Almost all of the stories highlight the stigma and discrimination experienced by HIV positive patients by the Central Asian Region's health care systems. The stories provide a 'lived reality' of what it means to experience stigma and discrimination. They are reproduced in their entirety as a means of informing HIV policymakers working across the Central Asia region.

### **1.1.2.3 HOW CAN THE QUALITY HEALTH CARE PROJECT HELP?**

Facilitators asked participants to discuss and document in their regional, national or oblast/city level groups how the Quality Health Care Project can contribute to supporting and working with PLHIV in the region and build on already existing PLHIV initiatives.

Common issues that emerged were: the need for increasing financial resources; human resources training for health care providers, and skills building training (including communication skills) for PLHIV.

Other emerging themes were the desire to learn and share experiences from PLHIV in the region and across Europe, related to PLHIV advocacy and leadership. At the regional level,

activities that are required include: better analysis of existing legislation, a regional PLHIV needs assessment, and advocacy initiatives targeted at governments and key politicians.

At the national level, advocacy is needed for the adoption of international standards of treatment and care, and technical assistance across the spectrum of HIV prevention, treatment, care and support services. At the oblast/city level, facilitation is required to help increase cooperation between the medical and community (including PLHIV) sectors.

### **1.1.3 NEXT STEPS**

The needs of PLHIV are being taken into account in the work by the Quality Health Care Project in target localities. This work will concentrate on facilitating increased cooperation between the medical and PLHIV sectors, including replication and improvement of the model used in Temirtau. A training process will be initiated toward the end of Year 1 to ensure that PLHIV groups are well-trained in the core activity of running PLHIV support groups, and capacity building to address other issues identified at the regional workshop will be carried out in Years 2-5 of the project.

# TEMIRTAU FIELD TRIP 16-17 MAY 2011

The Quality Health Care Project field visit to Karaganda and Temirtau was undertaken from May 16<sup>th</sup> through 18<sup>th</sup>, 2011, in order to provide a preliminary description of the HIV service model in use in Temirtau. Consultants Zoryan Kis and Scott Berry undertook the investigation with support from Elena Kudussova, the Kazakhstan HIV Director for Quality Health Care Project. In preparation, a desktop scan of available references on the Internet was undertaken, followed by a series of site visits to medical and non-governmental sites in Karaganda and Temirtau. In some cases, the field visit team conducted individual interviews (with Karaganda and Temirtau AIDS Centers) while at other times, the team conducted group interviews (with Temirtau Polyclinic, NGO Shapagat and Temirtau Narcology Clinic). Following these meetings, discussions occurred with Dr. Kudussova, who was previously employed in this particular region and has detailed knowledge of the service system.

## 2. 1. BACKGROUND

The HIV epidemic in Central Asia is concentrated in particular geographic areas along drug trafficking routes, that run from Afghanistan through Tajikistan, Uzbekistan, Kyrgyzstan and Kazakhstan (USAID 8:2011). According to 2010 official statistics, the HIV prevalence rate in Kazakhstan is 73.1 per 100,000 people and 15,318 HIV positive people have been registered in total. Of these, 95% are between the ages of 15-49 years. Injecting drug use is the main driver of HIV infection in the Republic (NAC 2010).

The main aim of the Karaganda field visit was to provide an overall description of the system of HIV service delivery in the industrial town of Temirtau. Between 2000 and 2001, when the incidence of HIV began increasing in the Republic of Kazakhstan, Karaganda and Temirtau were identified as high transmission areas (HTA) for HIV (USAID 2:2003). In order to combat HIV transmission in this HTA the Kazakhstan National AIDS Center collaborated with USAID and other international agencies and donor organizations to increase the range of HIV services in both these regional towns. In 2003, USAID released the *PLACE Assessment* that provided valuable information about the sites attended, the risk behaviors engaged in, and the service needs among people who use drugs, sex workers and other groups, such as young people in Karaganda. A series of HIV services were established in Temirtau including 'trust points' for people who use drugs, 'friendly cabinets' in AIDS centers and specialized HIV services at specific polyclinics. As well as providing HIV testing and counseling and STI diagnosis and treatment, Temirtau's City Polyclinic #2 also provides outpatient services that include ARV treatment and monitoring for PLHIV.

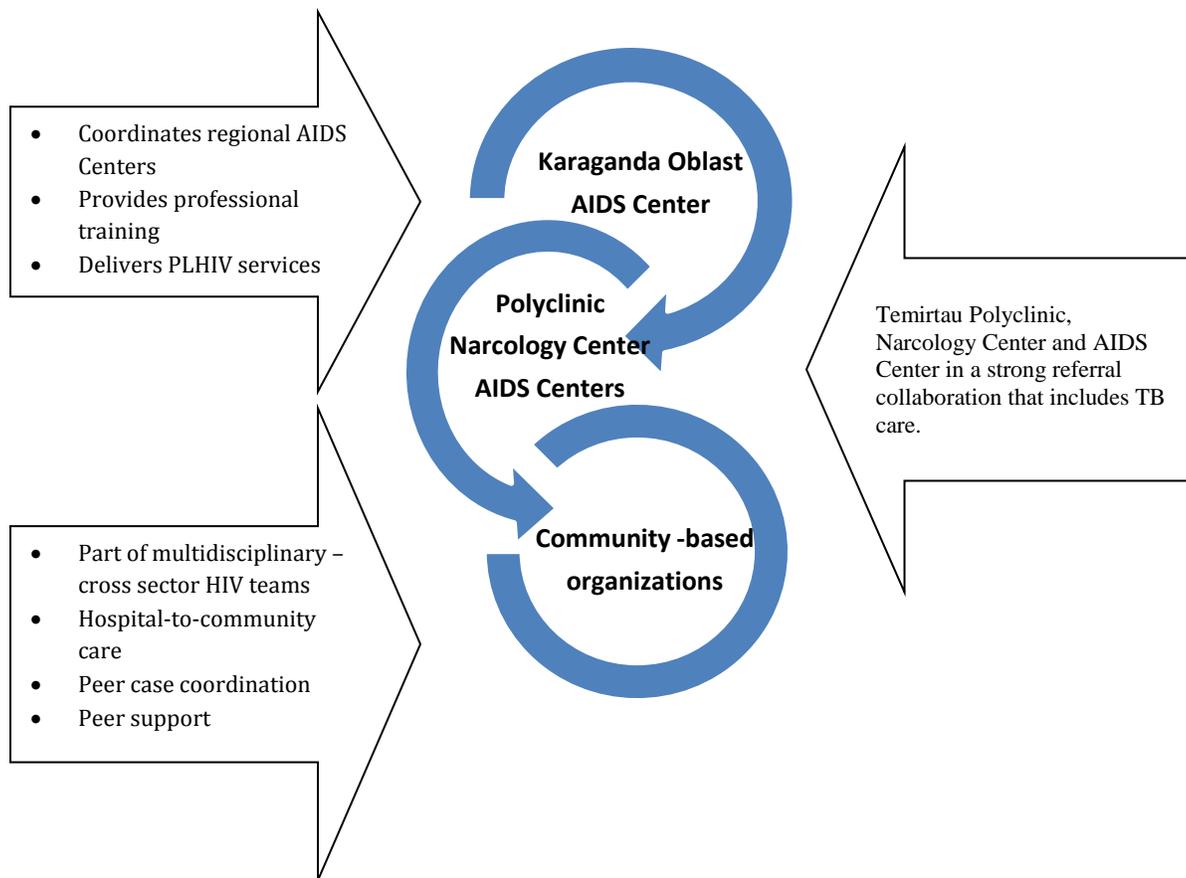
Kazakhstan began providing ARV therapy in 2005. In 2008 a pilot site for MAT was opened in Temirtau to provide methadone and related services, for up to 50 people who inject drugs. In 2009, USAID initiated the *Dialogue on HIV & TB Project* (formerly known as the *Health Outreach Project*) to provide technical assistance, training and direct outreach services. The *Quality Health Care Project* was launched in 2010 to provide technical support, training, equipment and commodities to assist Central Asia in improving the quality, scope and coordination of health services, including for HIV (USAID 9:2011).

Three thousand people have been officially registered as having HIV in Karaganda oblast. Approximately one thousand HIV positive people have died since the 1990s, and it is estimated that 70% of these deaths were due to complications from co-infection with tuberculosis. Thirty-five per cent of HIV positive people in Karaganda (1,900 people) are under observation for ART, with 350 currently receiving ARV treatment (Field Interview: Dr. Beibit Sagimbaev, Karaganda AIDS Center).

## 2.2 STRENGTHS OF THE HIV SERVICE SYSTEM IN TEMIRTAU

All participants described HIV services in Temirtau as being well integrated: crossing sectors and disciplines and resulting in a localized, HIV service network. Members in this network include AIDS centers, polyclinics, narcology centers and non-government organization (see diagram).

**Figure 1: The HIV service system in Temirtau, Karaganda**



### 2.2.1 PLHIV CLINICAL SERVICES PROVIDE MULTIPLE ENTRY POINTS TO CARE

Karaganda oblast established a pilot program in Temirtau in 2008. The pilot delivered PLHIV treatment and monitoring services at Polyclinic #2 in Temirtau, with a view to expand HIV treatment and surrogate market testing services across polyclinics in Karaganda region. The pilot supported the development of relationships between sites providing HIV services in Temirtau including: ‘trust points’ for people who use drugs, ‘friendly cabinets’ within AIDS Centers and effective links to TB services, a MAT clinic in Temirtau, and NGOs.

We asked participants to describe the key challenges they faced establishing and maintaining this pilot program: they cited resistance by the heads of the polyclinics to treat PLHIV alongside other patients. At first, doctors at polyclinics would separate HIV positive patients or accompany them throughout their clinic visits, and clinic staff would wear several pairs of gloves and a facemask, in the presence of HIV positive patients. The Oblast Health Department played a key

role in helping to change these practices, through policies implemented across local health services in Karaganda.

Regular communication and support between leaders and staff was described as being crucial in the development of the pilot program. Some medical staff split their service hours between the polyclinic and the AIDS center, helping to strengthen links between the two sites. The polyclinic team explained how their clinical staff's attitude towards PLHIV changed over time as they got to know their HIV positive patients.

Karaganda oblast is now establishing a team at the Karaganda AIDS Center that will visit AIDS clinics across the region and expand the Temirtau model. The services of this team will be expanded to serve increasing numbers of polyclinics and to collaborate with medical teams treating HIV patients incarcerated in prisons.

### **2.2.2 MULTIDISCIPLINARY TEAMS AND CROSS-SECTOR COLLABORATION**

One of the strengths outlined in the Karaganda HIV service system is the existence of multidisciplinary teams who work across sectors, in close collaboration. This multidisciplinary approach brings doctors, nurses, psychologists and peer counselors together. The cross-sector collaboration takes two forms:

- **Expert Patients:** PLHIV patients attending AIDS centers are recruited and trained to work at the centers to provide support to their fellow patients: they are called 'social workers'. In Temirtau they play a role similar to those in the internationally recognized Expert Patient Program. A key challenge reported by Karaganda Oblast's AIDS Center is recruiting and retaining PLHIV within the expert patient program.
- **NGO participation:** The NGO Shapagat, a non-government, community-based organization (whose members include PLHIV, at-risk populations and those affected by HIV) works in partnership with a range of clinical services in Temirtau to increase access and provide follow up care and support. Support includes online and face-to-face support groups and peer-led case management services.

We asked participants to describe the key challenges they faced establishing multidisciplinary teams. According to Dr. Sagimbaev, the Director of Karaganda Oblast AIDS Center, a major challenge is ensuring ARV adherence amongst PLHIV. Dr. Sagimbaev says the multidisciplinary teams have a particular focus on helping those who stop treatment to start again. There are currently 200 patients in the multidisciplinary caseload and the aim is to increase this number to 350 patients in the coming year.

### **2.2.3 MEDICALLY ASSISTED TREATMENT FOR OPIOID DEPENDENCE**

On 8 December 2005, the Kazakhstan government signed an order green lighting pilot research on MAT for HIV positive people who use drugs. In 2008, pilot projects in Pavlodar and Temirtau recruited 50 subjects in total (RoK 16:2007). The availability of opioid dependence treatment is a key strength of the Temirtau HIV service system, although case numbers are still small (n=23) and significant opposition to MAT remains. The MAT program in Temirtau has had positive results in assisting patients to stop using illicit drugs, improving their health outcomes and return to work.

Participants were asked to describe the challenges they faced establishing and maintaining the MAT program: key difficulties identified were strong opposition to the program and negative and inaccurate reporting by the media. Further advocacy will be required to garner widespread support for the MAT program's expansion. One question that the investigators believe needs to be considered, if the program is to be expanded, is whether it is appropriate for MAT programs to

be located only at Narcology Centers. A person suspected of narcotic abuse in Kazakhstan is subject to medical examination and mandatory treatment. Narcology Centers form part of the mandatory treatment system and non-attendance or 'escape' results in punishment (Viktorovich, 25:2011).

## **2.2.4 THE IMPORTANCE OF THE COMMUNITY-BASED RESPONSE**

The importance of peer-to-peer support was highlighted during interviews undertaken in the field trip. One client described the intimacy offered by the NGO Shapagat, where people can talk to others living with HIV, as "magic." "We are like family and we can share problems that we cannot discuss with our families." They celebrate birthdays together and arrange to be together on public holidays. NGO Shapagat supports clients with their adherence to ARV treatment, accompanies them to HIV testing and also provides pre- and post-test counseling. Within its peer groups, NGO Shapagat assists newly released prisoners with HIV as they integrate back into society. Orientation training is provided for newcomers, the majority of whom are newly diagnosed with HIV.

## **2.3 STRENGTHENING ISSUES FOR TEMIRTAU'S HIV SERVICE SYSTEM**

All participants in the field visit interviews referred to the lack of clinical staff available to meet demand. In addition, the investigators observed a lack of targeted MARP services. While the current collaboration between clinical and community services in Temirtau provides a useful model for increasing entry points to HIV services, other regional examples of integration between clinics and CBOs might be useful to incorporate into a project, as a means of increasing HIV service entry points in Central Asia.

### **2.3.1 INSUFFICIENT CLINICAL STAFF TO MEET DEMAND**

A key theme in all clinical site interviews was the lack of clinical staff to respond to high patient caseloads. One respondent said, "we don't have sufficient doctors or nursing staff, but the number of patients is increasing day-to-day." Another participant said that the problem was not a lack of funding but of doctors. An interviewee explained that most graduates do not want to work in HIV and that work in the public health system offers few incentives: the wages are poor and the hours are long.

### **2.3.2 INTENSITY OF MARP-TARGETED SERVICES / ESCALATING THE LEVEL OF CBO INVOLVEMENT IN CLINICAL SERVICES**

While Temirtau has strong CBOs and multidisciplinary teams across the clinical and community sectors, there is still a lack of intensive, targeted services for the most-at-risk HIV populations. One solution to this problem is to increase integration between services provided by the health system and NGOs. For example, by piloting CBO staff and volunteers to provide services within clinics and hospitals alongside clinicians. Such an arrangement already occurs in other regions and offers an efficient and a cost-effective strategy for relieving the burden on clinical teams while helping to increase the demand for HIV clinical services by MARPs.

### **2.3.3 DIFFICULTIES WHEN PLHIV SEEK CLINICAL HELP OUTSIDE THE HIV SERVICE NETWORK**

The NGO Shapagat described significant problems when PLHIV seek clinical help outside the HIV service system. One story told was of a man actively engaged in drug use who was

experiencing severe kidney pain. An ambulance took him to the local hospital with his mother who was asked to confirm that her son was a drug user. After this was confirmed, the man was given an injection and told to go home. Upon returning home, his nose began to bleed, he was rushed back to hospital where they provided first aid, but then sent him home. Two hours later he died. Women at NGO Shapagat also described problems accessing child and maternity services. One woman, who went to hospital for the birth of her child, was rapid tested for HIV and was told she was HIV positive. However, she did not receive pre- or post-test counseling, wasn't offered any treatment, or advised on how she to prevent vertical transmission.

### **2.3.4 HIV TESTING ALGORITHM**

Those who test non-reactive in the screening process are given an HIV negative result. Those that test reactive are considered inconclusive and a blood sample is taken that is sent to Almaty for confirmation. PLHIV participants reported a waiting period of one week up to several weeks for their results. International standards are now available for the use of rapid HIV testing technology, for both screening and confirmation to ensure that reactive and non-reactive results and confirmatory testing are completed quickly and same-day test results are provided to all patients attending VCT.

### **2.3.5 INSUFFICIENT CD4 AND VIRAL LOAD TESTS CAN RESULT IN LONG WAITING TIMES**

NGO Shapagat clients described waiting long periods for CD4 and viral load testing services. At the time of visit, the Temirtau AIDS Centre can only provide five CD4 tests per week for PLHIV in the city. One client who received a CD4 result of 164 has been waiting five months for a follow up test to confirm her initiation of ARV treatment. She explained that she herself missed an appointment, but was then told she needed to wait another three months. It seemed that no triage system is in place that would allow PLHIV in urgent need of test results to receive them. This problem is reported to have been resolved since the consultants' visit.

## **2.4 CONCLUSIONS**

Temirtau HIV service system demonstrates that establishing local HIV health service systems is achievable in Kazakhstan and across Central Asia. Through well-considered planning, design, implementation and resourcing of HIV services, Karaganda has succeeded in forming a multiple entry point system for MARPS and PLHIV, although the system still has structural limitations.

Participants interviewed during the field visit believe that the HIV services in Karaganda are effective because HIV services work cooperatively: organizations and service providers create networks and regularly communicate, so can easily cross 'sector boundaries' to meet clients' needs. The use of multidisciplinary teams in cross-sector collaboration appears to be a core strength of the HIV service system, supporting both HIV testing and the retention of PLHIV within the health care service system.

The Karaganda AIDS Center reports that there has been an increased collaboration with tuberculosis centers and specialists. During the field visit, investigators observed that PLHIV clinical services are delivered in a polyclinic in Temirtau in collaboration with the local AIDS center, leading to a decrease in mortality amongst PLHIV who are co-infected with TB. Other strengths observed in Temirtau is a MAT service that reports positive results in improving patients' health, cessation of drug-use and their successful return to the workforce. In addition a small-scale 'expert patient' program operates through some AIDS centers and may be an effective strategy for the support of PLHIV in clinical settings.

As is the case in any health service system, there are areas that need to be strengthened. Participants described (and investigators observed) some systems in need of improvement in Karaganda and Temirtau. Discrimination, when PLHIV and MARPs seek health services outside the established HIV service system, appears to be common: including in child and maternity as well as emergency services. Logistics and the supply of surrogate market test kits are at present inadequate to meet the demand. Services targeting at-risk groups appear insufficient. Incorporating PLHIV and MARPs into mainstream clinical services is strongly promoted by the clinical practitioners interviewed during the field trip. Community-based organizations are under-utilized and their increased involvement in the clinic setting could dramatically decrease the workload of clinical staff, while simultaneously improving hospital-to-community support.

**Table 2: Strengths and weaknesses in the HIV service system in Temirtau**

No.	Key System strengths	No	Strengthening issues worth considering
1	Multiple clinical and community entry points into the HIV service system.	1.	Insufficient clinical staff to meet demand.
2.	Multidisciplinary teams and cross-sector collaborations.	2.	Lack of intensive targeted services for MARPs.
3.	Medically assisted treatment for opioid dependence.	3.	Discrimination in mainstream medical services outside the HIV service system.
4.	Strong involvement of communities at risk and PLHIV.	4.	Waiting times for confirmatory tests
		5.	Long waiting times for PLHIV seeking surrogate market testing.

Evaluation of services or of the HIV model was not available during the field visit. When asked, participants could not provide evaluation reports or client satisfaction reports. This is an important issue because the model is quite successful and is worth documenting and sharing with other regions in Kazakhstan and other countries in Central Asia. It is recommended that in-depth, qualitative research be undertaken in Temirtau in order to validate the observations of this field report and inform the development of models for testing by the Quality Health Care Project.

# IMPROVING HEALTH SERVICES FOR PLHIV: A PARTICIPATORY PLANNING MEETING WITH QUALITY HEALTH CARE PROJECT

## 3.1 INTRODUCTION

The Quality Health Care Project hosted a workshop in Almaty, Kazakhstan on May 19<sup>th</sup>-20<sup>th</sup>, 2011. The purpose of the forum was to increase the meaningful participation of people living with HIV across Central Asia the work of the project. The forum aimed to listen and learn from PLHIV and their community based organizations, and to document the lessons learnt by PLHIV groups as part of their efforts to engage the public health sector and governments in the provision of quality HIV services.

## 3.2 OBJECTIVES OF THE MEETING

Participants were asked to express their views in relation to their current challenges in accessing HIV prevention, treatment, care and support services in Central Asia. The workshop team documented successful strategies utilized by PLHIV community organizations to overcome these challenges. Of particular interest were the ways in which Quality Health Care Project can assist in empowering PLHIV community-based organizations to help contribute to the national response to HIV.

We identified four strategic areas we were seeking information on:

- Access to services
- Strategies used by PLHIV groups to improve quality and access
- Strategies for PLHIV involvement in improving HIV programming
- How to strengthen PLHIV community-based organizations.

## 3.3 SUMMARY: PLHIV PARTICIPATORY PLANNING WORKSHOP

### 3.3.1 SESSION ONE: OPENING REMARKS AND INTRODUCTIONS

**Christian Barratt, Health and Education Office Director for USAID Central Asia** welcomed participants to the meeting and spoke of his hope that the meeting would result in a clear sense of the ways in which USAID can work with people living with HIV in the region to improve health service delivery.

**Elena Kudussova, Kazakhstan HIV Director for Quality Health Care Project** welcomed participants to Kazakhstan and expressed her gratitude to those attending: explaining how it will assist the Quality Health Care Project in its upcoming planning for the coming twelve months.

Welcome statements were followed by a discussion about the purpose of the workshop. The facilitators asked participants to talk about why they had come to the workshop and what was motivating them to participate. A number of participants wept during this session and expressed their frustration about the high level of stigma that existed, and the problems they'd experienced in accessing quality HIV services.

### 3.3.2 SESSION TWO: 'WHAT'S ON YOUR MIND?'

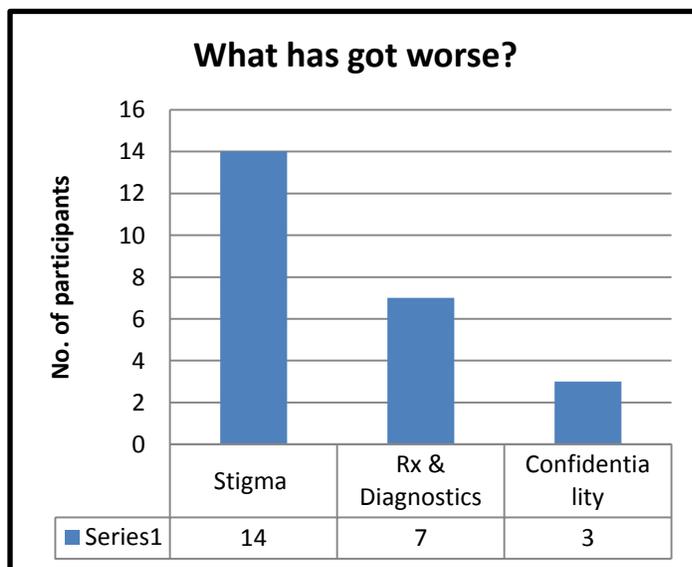
In Session Two, workshop facilitators asked participants to outline the key factors that have improved and worsened for PLHIV in relation to health care services in their contexts. The exercise was called 'Have Your Say' and underlined the diversity that exists from setting to setting. Issues raised included: illicit drug use, broader health needs including pre- and antenatal care, and access to treatment and diagnostics.

Access to treatment and diagnostics was rated as having worsened by seven participants and having improved by eleven people. While overall there have been improvements in treatment and diagnostic access in the region, there is clearly an urgent need for better access to substitution therapy and TB and hepatitis diagnostics and treatment. Another important issue that was highlighted was the inconsistent care offered to pregnant women with HIV.

On the whole, participants were critical of the lack of integration and cooperation across sectors, particularly within health care settings. Examples of areas needing further development include: increased peer counseling and care and support for PLHIV, better input by the community into health systems, and for medical practitioners to build partnerships with their patients.

#### 3.3.2.1 WHAT HAS GOTTEN WORSE IN THE HEALTH CARE SYSTEM FOR PLHIV?

Figure 2: Issues identified as having got worse



A total of 24 responses were collected: stigma (n=14) was identified as the biggest problem; the second was lack of access to treatment and diagnostics (n=7) and the third was breaches in confidentiality (n=3).

#### Stigma

Discrimination by the medical community was identified as being a factor in declining health service delivery for PLHIV. Medical staff (including psychologists) were described as having a "bad attitude" and "looking down upon" their HIV positive patients. They were described as "lacking the knowledge" to adequately meet the needs of PLHIV. An additional problem identified by participants was unwillingness of medical and state institutions to cooperate with PLHIV NGOs. Health care systems were described as "not paying attention" to HIV networks,

because of “negative and discriminatory attitudes.” One respondent explained that there is “resistance to interaction from the side of governmental structures with PLHIV community organizations.” Other themes that emerged in this category included corruption (user fees, bribes) and a lack of quality VCT, psychological support, and care for pregnant women at AIDS Centers.

### Treatment and Diagnostics

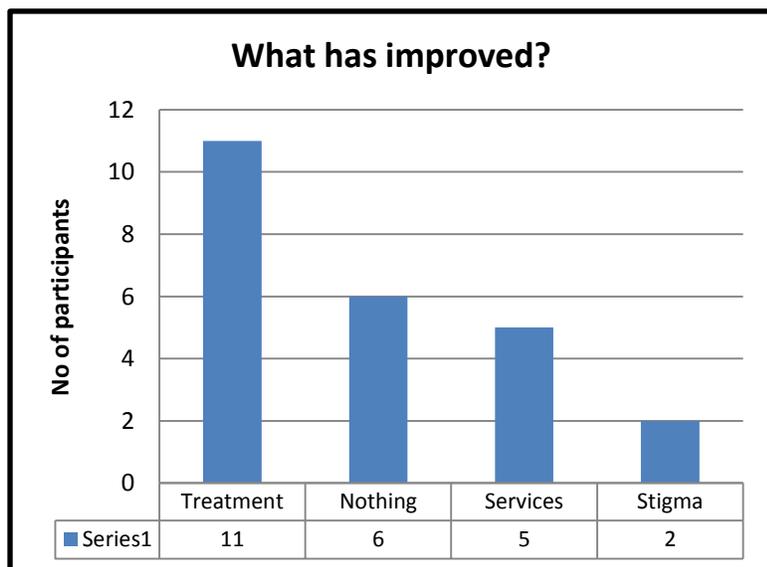
Access to HIV, hepatitis and TB treatment and diagnostics was described as declining by seven participants. Some respondents said “the medical system works badly” and that diagnostics, treatment and medical referral for TB, hepatitis and PMTCT “is bad.” ARV drug supplies were described as sometimes being inadequate to meet the need. “There are not enough hospitals”, one respondent said, while another stated “the problem is that the health system is still Soviet – it is neither state-owned nor a business.”

### Confidentiality

Three respondents reported that breaches in medical confidentiality had increased (see examples outlined in the personal stories section).

### 3.3.2.2 WHAT HAS IMPROVED IN THE HEALTH CARE SYSTEM FOR PLHIV?

Figure 3: issues identified as having improved



A total of 24 responses were collected: treatment (n=14) was identified as the issue most participants rated as having improved; six participants said nothing had improved in their context in relation to health care services for PLHIV; while two respondents cited stigma as decreasing.

### Treatment

While access to ARV treatment emerged as improving in the local health care settings of many respondents, a smaller number of respondents reported improvements in access to TB services

and MAT. Supply issues were said by some to have improved and as a consequence better ARV adherence was reported.

## Nothing has improved

Three responses were received that literally said one word ‘nothing.’ One response left the post-it note blank and stuck this note on the improvements flip chart. Still another said “Nothing! There is a lack of medical services for PLHIV.”

## Services

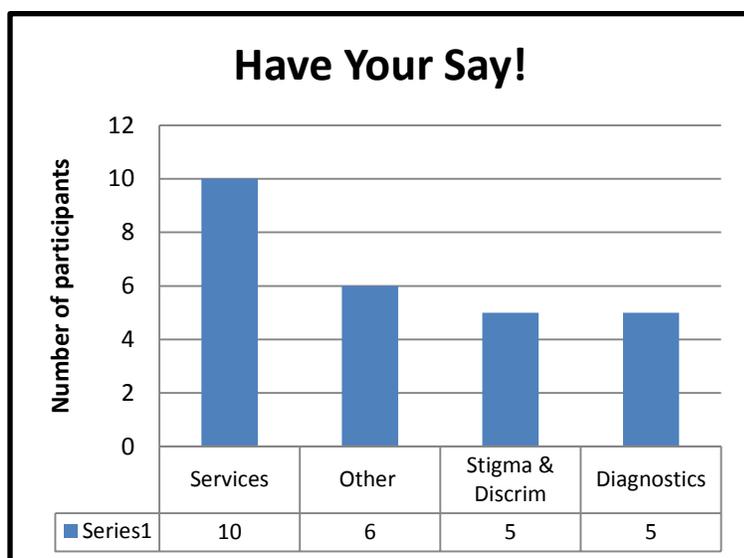
Three of the five responses cited improvements to HIV health care, in particular for women and children, including PMTCT. The other two responses in this category referred generally to improvements in service delivery.

## Stigma

Two respondents reported that medical service providers were less discriminatory that they had been in their local health care area.

### 3.3.2.3 HAVE YOUR SAY!

Figure 4: issues brought up in the ‘Have Your Say’ session



A total of 26 responses were collected: Services was the main issue people wanted to talk about; ‘other’ was a category covering a range of different issues; other topics commented on by participants were stigma and diagnostics.

## Services

A range of issues that fall into the HIV services category were brought up and they tended to be negative comments about the current situation being faced by PLHIV in Central Asia. Topics included: clinical care; financial support for PLHIV; concerns about children taking ARVs and the sustainability of taking ARV therapy as they grow up; access to diagnostics, the need to improve the doctor/patient relationship so that there was a “shared sense of responsibility for health”; better integration of community support and peer counseling and the poor quality of health servicing.

## Other

A range of personal issues were discussed: “How do I tell my sexual partner I have HIV”, “self stigmatization” and “shall I get married?” hint at the fears that PLHIV have around the disclosure of their HIV status in their personal lives. Two others spoke of migration issues and their right to access pensions in other countries. One person spoke about the impact of the pill burden; of having to take pills twice a day with her son. She explained how administering treatment to her son was often very difficult and her desire to reduce the number of pills they take to “one a day, or even once a month”.

## Stigma and Discrimination

Three respondents spoke about disclosure issues, of wanting to be open about their HIV status, but being unable to do so because of perceived and/or actual discrimination and stigma. And one spoke of wanting to be respected: regardless HIV status. See the personal stories section for more detail on this.

## Diagnostics

Access to diagnostics was an important topic for PLHIV participating in this workshop. Better access to diagnostics for HIV, TB and hepatitis was identified as an issue of concern. One person wrote: “I doubt that I am HIV positive” highlighting the fact that some participants have little faith in the quality of the ARV testing in their local contexts.

### Recommendations

Three priorities emerge from the ‘what’s on your mind’ session:

4. **Stigma and Discrimination** – the attitudes of health care service providers toward PLHIV needs attention; in particular, respecting medical confidentiality.
5. **Treatment and Logistics** – ARV and OI treatment and diagnostics, substitution therapy, TB and hepatitis diagnostics and treatment.
6. **Improving the quality of health care services** – pre- and antenatal care, medical services and support for children and mothers and the integration of a wide range of clinical and community services into HIV health care systems.

### 3.3.3 SESSION THREE – WHAT IS THE USAID QUALITY HEALTH CARE PROJECT?

Session Three provided an overview of the USAID Quality Health Care Project and described the project’s focus on health system strengthening for tuberculosis, HIV, and maternal and child care.

### 3.3.4 SESSION FOUR – STRATEGIES OF THE QUALITY HEALTH CARE PROJECT FOR IMPROVING SERVICES FOR PLHIV

Session Four provided a detailed presentation on the strategies that the Quality Health Project aimed to utilize to improve HIV services, including services for PLHIV.

### 3.3.5 SESSION FIVE – THE PERSONAL STORIES OF PLHIV

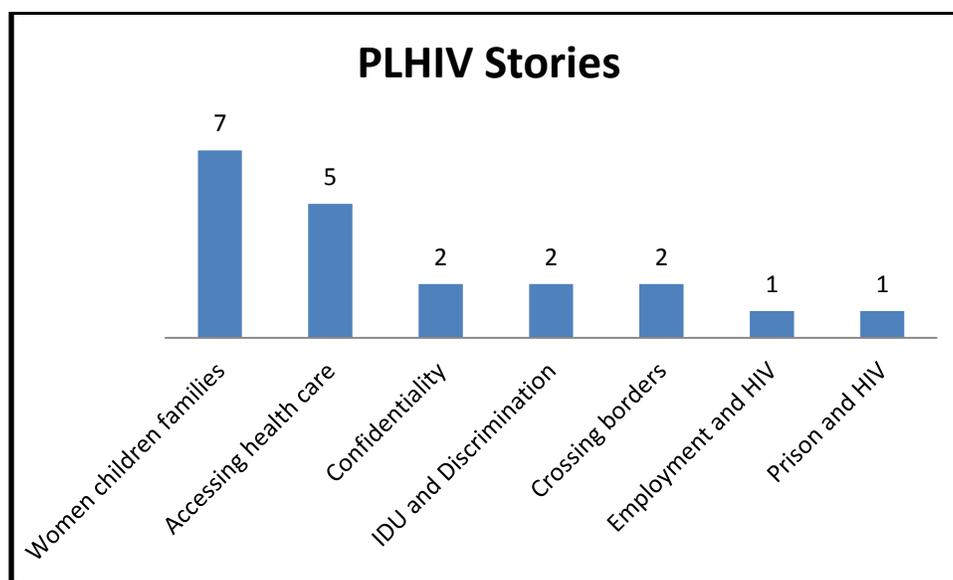
In Session Five, the workshop facilitators asked participants to write down a personal story about living with HIV. Facilitators invited participants to tell positive and negative stories from their experience of accessing the health system.

Seven themes emerged from the story telling session:

1. Children, pregnant women and families affected by HIV.
2. Confidentiality in the health care system.
3. Prison and cross-border experiences of HIV health care.
4. Experiences of the health care system in Central Asia.
5. HIV and injecting drug use – stories of discrimination.
6. Employment and HIV.

Almost all of the stories highlight the stigma and discrimination experienced by HIV positive patients from within the Central Asian Region's health care systems. The stories provide a 'lived reality' of what it means to experience stigma and discrimination. They are reproduced in their entirety as a means of informing HIV policymakers working across the Central Asia region.

**Figure 5: key themes from PLHIV stories**



#### 3.3.5.1 CHILDREN, PREGNANT WOMEN AND FAMILIES AFFECTED BY HIV

**STORY 1:** (Tajikistan) 8 years ago, when I was pregnant, I was diagnosed with HIV. I didn't know what that meant at that moment. The director of the AIDS center was a friend of my father-in-laws and my father's, so he told them I was positive. Before I gave birth to my son, I was told I was HIV-positive, but I received no proper counseling. I thought that was the end of the world for me. I wasn't told I shouldn't breastfeed my baby: I was given no information on that, so I breastfed him for the first month. Then, the chief doctor called me in to the local children's polyclinic. He told me that they had discussed my case at a meeting and that I couldn't breastfeed my baby anymore. That was very hard for me. I wasn't given any information at that time, so I didn't understand what was going on. I started looking for information myself. When my baby was 18 months old I was able to find out what my son's HIV-status was. When

my son was a year old, I took part in training and the local AIDS center chief doctor took part in it too. After she found out who I was: the first HIV-positive woman in the oblast to have a child, she told me “your baby should have been killed at the maternity house.” I was shocked by what she said. I have met her many times since then, but I can’t listen to her. All I hear are those words... I didn’t experience any stigmatization from my parents or relatives at all.

**STORY 2:** (Tajikistan) A year ago my friend was tested for HIV at a maternity house. She turned out to be HIV-positive. After she left the hospital, the people from the local AIDS center came to her house to counsel her. She was so upset after that she had suicidal thoughts. She called me on the phone and said she didn’t want to live. She also said her child was very sick. I went to her house and found out she didn’t have any idea what HIV was. I told her no one is 100% able to prevent getting HIV, and that there are many NGOs who will help her. I gave her several examples of people living full lives with HIV, I provided her with information on adherence and baby-formula. Now her child is one year old. Before that, the mother was getting 100 *somani* allowance. She now visits us at on a regular basis, and I’m very happy I was able to help her. She is now planning to have a second baby.

**STORY 3:** (Kazakhstan) On May 12, 2011, my younger son (3 months old) had a high temperature, and my elder son, who is six years old and HIV-positive also had a high temperature. I rang the local medical center and the doctor arrived within 15 minutes and began examining my children. A local examination was done and it was decided to call for an ambulance and to check my younger son and his mother into an infectious disease ward and our elder HIV-positive son into a ‘Mother and Child’ hospital. I stayed at home with my two daughters (six and two and a half years old). Over the next 6 days, while my sons were in hospital, doctors visited us from the local hospital. Every day, morning and evening, they came to our home and examined my daughters and gave them medical care. On May 18, my children were discharged and all our family was together again. I am glad that the doctors and medical staff treated us professionally and without any financial cost to us. The multidisciplinary team worked very well. This is my positive story about receiving quality medical services for my family.

**STORY 4:** (Kazakhstan) I lived in a small town of South Kazakhstan region. I have really struggled with the fact that my child is HIV-positive. He was infected in the maternity house and I got infected there also while breastfeeding him. My husband is HIV-negative. I have been discriminated against in the women’s clinic, when I have sought treatment. All the staff at this time knew about my status. The gynecologist refused to treat me saying "I'm not sure, if I will be able to correctly sterilize the equipment after you. You can go to a special hospital, ‘Mother and Child’ in Chimkent, you can go there.”

During this time I was frightened by my diagnosis, I experienced self-stigmatization and fear. I was afraid to seek help, afraid that someone would find out about my and my child’s HIV status. At one point I wanted to make a big scandal about the doctors and their treatment of us, to make sure that they would be fired. But my fear that everything would be revealed - has stopped me. And I haven’t done anything about it.

Two months passed, we were called to the children's clinic for routine tests. We waited in a long queue. My child was terribly tired. Finally our turn came, he saw a nurse in a white coat, my son got very upset. While I was comforting him, the nurse took blood from his finger. Only after the process, did I notice that the nurse’s gloves were covered in blood, that is, the nurse had not changed gloves. My concern, fear and resentment at that moment forced me to reveal my child’s HIV status, I told them all I thought!

I said: "Why didn't you change your gloves? After all, you have enough of them. What will happen if a child before us had hepatitis or other viruses? And you didn't even know that my child has HIV and next you'll be taking blood from other children in the same gloves you're using now that are covered with blood". The nurse replied: "What? Your child has AIDS" and quickly ran to change her gloves. I said: "Not AIDS, but HIV!"

I immediately contacted the chief doctor and my pediatrician about this. The chief physician did not believe me, denying that it would have happened because they had enough gloves. These events were an impetus for me to change my life. I left my town for Chimkent, leaving behind my husband, who was not supporting us at this time. We started a new life and we are now struggling to inform everyone! I was able to get rid of my self-stigmatization. And now nobody can discriminate against us.

**STORY 5:** (Kyrgyzstan) When I was 4 months pregnant, as part of routine testing, my gynecologist told me I should get tested for all infectious diseases. I was referred to a local polyclinic, and there I had to pay 120 *soms* (approx. 3 USD). After 4 or 5 days I was told to come to the polyclinic, where I met the doctor. I don't remember exactly what I was told, but I can remember she told me I should have an abortion before it was too late. Six months before this I had miscarried my baby, which was very hard for me, so I refused to have an abortion and I decided to keep my baby, although I was told the baby could be born sick. They stopped arguing with me because they saw I had already made up my mind. On the same day the infectious diseases doctor asked me if she could inform my gynecologist about my diagnosis. I believe that a doctor needs to know everything about their patient, so I agreed. I was very anxious when I went to my next appointment with the gynecologist. I was surprised by her understanding and support. She did not condemn me: we were just trying to figure out who could have infected me. I remember she told me no one is 100% protected from getting the virus and that doctors have a high risk too and that they get tested on a regular basis.

She also told me that she had helped deliver a baby from a woman who was HIV positive, and that the child was born healthy. She told me that if I followed her advice, I would be fine. She also told me she would make sure she delivered my baby no matter what her work schedule was. When it was time, I called her and she came and performed the delivery. I didn't have a caesarian. That was 4 years ago. Now my daughter is healthy and very clever. I think everything is up to the people and their consciousness. I don't think I was discriminated against in this case and the doctors supported me.

**STORY 6:** (Kyrgyzstan) my story began 9 years ago when I came back from Russia and got married. Of course, I was very happy to have children and a husband. After a year I had my first baby, who was delivered at home. After 2-3 years I started getting very sick, and I had some reproductive health problems. I was told that could be treated in Bishkek. I went to a center in Bishkek, where I was asked to have all the tests, including for HIV. I was waiting for my results for a week, and then I had to have another test. I wasn't told anything. I was shocked. I waited for another week and when I came back, everyone there was looking at me with compassion. I felt something was wrong. They gave me some information, they were smiling so I didn't feel too bad, and they told me I was HIV-positive. I began crying and asking how I could be cured. They told me there is medication that could help me. They asked if I breast-fed my son. Of course, I had. So, this is my second grief. My son was very weak at that time, and he turned out to be positive as well. Now my daughter is growing up, and I don't know what her HIV-status will be. I'm now pregnant with my third child. I think I'm a very strong woman. My advice is "give birth to children on time, take medication – we are just the same people".

**STORY 7:** (Kyrgyzstan) A 28 years old pregnant girl, who was registered as HIV-positive, decided to have an HIV-negative child, and went to the local AIDS center for counseling. She was prescribed Zidovudine from her 23rd week of pregnancy and one pill of Nevirapine 4 hours prior to delivery. She was provided with Zidovudine, but wasn't given the pill of Nevirapine, because they said they were out of Nevirapine. They asked her to call back in a week. When she did so, someone at the other end of the phone told her that they always had Nevirapine and that there were no stock outs ever. When she asked if she could come and get her pill, the doctor asked for her surname. After the doctor realized that it was her patient calling, she said "we have no Nevirapine". The girl then called an NGO and told her story. Two NGOs brought this story to a higher level. As a result, she was provided with Nevirapine and delivered a healthy baby. She now works with one of the NGOs.

### **3.3.5.2 CONFIDENTIALITY**

**STORY 1:** (Tajikistan) My husband and I went to a local polyclinic to get tested for TB. He turned out to have TB. He was injecting drugs. He spent 8 years in a prison, where he got very sick. After he tested positive for TB we were referred to the AIDS center for a confirmatory HIV test. They didn't provide us with any information, and we didn't know anything. As my husband was unwell, we decided we would go to the AIDS center the next day, because he wasn't able to walk. After we came home, my sisters-in-law were looking at us in a very strange way. It turned out that the nurse who tested us for HIV, was a friend of my sister-in-laws and she called her and told her both I, and my husband were HIV-positive. Because of our mentality, my relatives were sure I had been "having fun" while my husband was in the prison, and I had later infected him. As I had no information about the ways in which HIV is transmitted, I could not have protected myself. But I told them I never left the house on my own.

Next morning we went to the AIDS center and got our tests done. We were tested with rapid tests first, and then they drew our blood. They told me I could get my result in a week. I had my post-test counseling, where I learnt it wasn't my fault. They explained to us how HIV is transmitted. They told me that my husband had probably infected me: who was a drug user. A week later I found out I was HIV-positive as well, and I had a meeting with a psychologist. Before that, my family said I wasn't allowed in to the kitchen and I couldn't use common dishes. Thanks to 'GuliSurkh' I'm with you today, they have supported me a lot.

**STORY 2:** (Kazakhstan) At my regular day at the NGO, a 50-year-old woman came into the office. She wanted to talk to our psychologist. I told her that was me and invited her to my little office. She was very anxious, and she told immediately "I came here to talk to you personally, because I know you will understand me, as you are just the same as me". Then she told her story in detail. A TB dispensary, where she had been told she was HIV-positive, referred her to me personally. She was shocked to learn she had TB and HIV, as she never used drugs and she had a normal, healthy lifestyle. When she was told she could get psychological support at our NGO, she refused, because she didn't want to disclose her status to anyone. She was afraid her elderly parents would find out, or her sister and her son.

But the staff of the TB dispensary assured her that PLHIV work at our NGO, and they understand this problem and they would never disclose her status. She refused to seek support anyway but then she was recommended to talk to me personally. They told her my name and surname, and told her I was also HIV-positive. In our little town I'm not living openly with HIV. I'm not even registered with the local AIDS center. Even at work only two employees are aware of my HIV-status. I don't know what motivated the doctors to do what they've done. I still don't understand how those TB doctors would have known about my HIV-status.

Although I was shocked myself, I was able to support the lady. Now we are good friends, we meet on a regular basis, and support each other.

### **3.3.5.3 PRISON AND HIV**

**STORY 1:** (Kazakhstan) I found out I was HIV-positive in 2001, when I was in prison. There was no information about HIV at all and there was no advice provided either before or after the testing. After I left prison, I went to the AIDS center and I was put on their records. I have never experienced stigma and discrimination by doctors, or when I have been in hospital. But I have experienced some 'lack of professionalism' because the AIDS center was still in its early days of operation. I receive my ART therapy without any problems. One should respect oneself and demand respect from the doctors. Self-stigmatization is one of the problems. Eliminating this and knowing one's rights will help to solve some problems. Knowledge is power!

### **3.3.5.4 CROSS-BORDER EXPERIENCES OF HIV HEALTH CARE**

**STORY 1:** (Kazakhstan/Russia) In 2004 I lived in Russia, and one day I was visited by a health care worker at home. He brought me a summons stating that I had had contact with an HIV positive person through injecting drug use and I had to get tested for HIV. I was very surprised, I went to the AIDS center, they drew my blood, and I waited for my results for two weeks. When two weeks passed, I was called to the AIDS center. From the doctor's expression, I realized that I had a positive result. The doctor said that I had tested positive for HIV but he didn't give me any advice on what to do. When I asked him what I should do he just said that I had two weeks to leave the country because they have enough of their own HIV-positive people to deal with already. He said if I didn't leave the country they would report me to the police and I would be deported to my homeland, since I was a citizen of Kazakhstan. I was very upset by the doctor's attitude towards me and I wanted to commit suicide. I didn't want to live after that, knowing how doctors view HIV positive people. I am still alive now, thanks to my friends and relatives who supported me at that time.

**STORY 2:** (Kazakhstan) Three years ago I was tested for HIV. To be honest I did not know what it was. Next day they called me at home and told to come to the clinic. After this I began to suspect something. When I came to the clinic with my husband, they told me that I had a positive result. My eyes just went dark, I started screaming and crying, saying that it was untrue. I was asking myself "Why me?" and "What can I do?" For me it was a death sentence. The doctor told me not to worry and that I did not have AIDS, but just HIV. I asked, "Will I die soon then?" "What about my little daughter who I am breastfeeding, what will happen to her?" It was a shock to me, a terrible grief.

I was lucky the man I lived with was with me. We checked him as well, and he was healthy. He took me home. I was feeling really unwell. On my way home I met my dear mother and I told her I had AIDS. We cried together, I fell to the floor and sobbed, and I thought that was my death. Then my mother continued praying for me. I took my daughter to get tested. The day the result was due, I prayed all the time and cried a lot and prayed to God that he spare my child. God heard my prayers; my daughter was a healthy, intelligent child. After that, I became depressed and no one could understand what I was going through. I left my home, I drank, wandered around and sought death. I spent a whole year like this. I began to get weaker, I was in pain, I struggled to walk. Around me was emptiness, a tomb.

I started looking for some medical support from the doctors. At this time my husband left me. I asked the doctors to introduce me to someone I could simply talk to. But I could not find anyone; all doors were closed to me. But despite that, my mother and my little daughter prayed for me

every night. They were waiting for me. Then I came home and I was all right for a month or two and then I left home again. Eventually, I was invited to work for an NGO. I made some new friends, I met a new boyfriend, but still I was very frustrated. Now I have ARV therapy and my condition has improved. I support my family, I want to live and my daughter gives my life a purpose. And I thank God for my mom, family and my husband who all support me. I try not to go to the hospital; I only pick up my ARV therapy there.

### **3.3.5.5 EXPERIENCES WITH THE HEALTH CARE SYSTEM**

**STORY 1:** (Kazakhstan) Three years ago my husband was taken by ambulance to the gastroenterology unit with pains in his stomach. The diagnosis was two ulcers - one opposite another. He was treated for 10 days, while his attending physician said that an urgent surgery was needed to treat the ulcers. My husband and I thought for a long time about whether or not to reveal his HIV status. We decided to tell the doctor and at that moment he refused to arrange the surgery, explaining that we'd have to wait. He added that as the bleeding had stopped, there was no need for the surgery anymore.

By the way, before we told the doctor about my husband's HIV, we even talked about the price of the surgery. It was going to cost \$500. But when he found out about his status, he didn't want this money anymore! What lesson can we learn here? Either not to tell anyone about one's HIV-status, or to reveal it as soon as one gets into hospital.

**STORY 2:** (Kyrgyzstan) a man, who lives with HIV, comes to the clinic for his regular clinical tests. The doctor put a "B-20" code in the referral coupon. A laboratory assistant who was about to perform some procedures looks fearfully and contemptuously at the man, as he puts his gloves on. The laboratory technician does not care what the patient feels at that moment. He doesn't care what that man might do to himself afterwards; he simply does not understand how difficult it is for the patient to live with HIV. And all this is happening due to a lack of awareness from nurses. Conclusion: nurses must be trained and cooperation between the community and medical institutions should be established.

**STORY 3:** (Tajikistan) this is the story of my client from Tajikistan. When I told my teacher about where and with whom I work, she asked me to accompany her friend to the regional AIDS center for an HIV test. When we got there, it turned out that after a long illness, this young man was examined thoroughly and was given the diagnosis. However when he was in the capital of our country he had also taken HIV tests but he was never informed of the results. On the same day after the test in the evening he returned home. On the next day someone called his older sister, and reported his positive diagnosis. All these things I learned at the AIDS Centre. He did not know anything at that moment. In the same place his blood samples for CD4 and viral load were taken. According to the test results, he was prescribed ARV therapy. He started taking the drugs but still without knowing about his HIV-status. The doctors at the regional AIDS center simply told his relatives that he had hepatitis. At an earlier time he had wrongly been diagnosed as having hepatitis when he didn't. So, he still thinks his HIV diagnosis will soon turn out to be wrong.

**STORY 4:** (Kazakhstan) About 5 months ago a 40 year old man was lying at home with a high temperature of 38 - 39 degrees Celsius. This lasted for 2 weeks. When his mother and his wife called an ambulance, the doctors refused to hospitalize him, after they saw HIV drugs next to his bed. The physician's first question was "Is he a drug addict? Does he have AIDS?" And then he hurried off. After 2-3 hours the mother called an ambulance again and another team arrived

already saying that the patient might have HIV, although the relatives hadn't said anything about his illness. The second team also refused to hospitalize him saying that there wasn't no obvious reason to do so.

Then relatives called a social worker from an NGO. They asked her to call for ambulance. The third time the same team who had come the first time came back. The social worker asked the doctor on what basis they had asked if the sick man had AIDS, if he knew what confidentiality was, and what law allowed them to refuse treatment for HIV positive people? The social worker also said that he would go to the media with the story. Only after that conversation, was the patient hospitalized. The most terrible thing was that the man died after 6 days. He had meningitis. The ambulance crew said that there were no indications for hospitalization, although the man was practically unconscious.

The lessons are:

- The ambulance had no right to refuse him care on the basis of their assumptions of the patient's HIV-status.
- People living with HIV are eligible for hospitalization.
- The ambulance does not make a diagnosis.
- The time has been lost.

**STORY 5:** (Tajikistan) many years ago, I had to leave my home because I owed a large sum of money. My family left the country for work. It lasted three and a half years. Once I was seriously ill and I needed surgery. I was hospitalized when I was in a very serious condition and they began to prepare me for surgery. My blood was taken, and they prepared the surgery room. My body was covered with blue spots and they said I had a blood infection.

Later, a nurse entered my ward. She looked at me with such pathetic eyes, and I could not understand why I hadn't been taken to the surgery room. After 6 hours of my agonizing patience I was told to get dressed. They took my passport and put me in a car. I was taken to another hospital, which was separate from the others and all the windows were latticed (it was in Iran). I was placed in one of the wards with an armed security guard at the door. I was scared and did not understand what was going on.

I was operated on and kept in such conditions for 20 days. I was well looked after, fed well too. But they came to me masked in protective gowns and shoe covers, and always interested in who I was, if I had children, what my marital status was and what I was doing in their country.

After two weeks when they visited my apartment and they met with the director of the organization where I worked and they started treating me a bit better. When I recovered, I bought a ticket from my work and asked to leave the country. But they deported me and said my blood had a virus and that it could not be cured and it was called HIV. At that time I did not know anything about it and what it was (this was 2003).

I returned to my country and did not know what to do or where to go, so no one could find out who I was. Several times I was tested under a false name, and each time the diagnosis was confirmed. I knew it was the end. It was very hard and I wanted to commit suicide, but failed. Finally I came to the AIDS center and gave my name and showed them my results. To my surprise, I was helped and reassured by a doctor. She asked me what my profession was. A few days later I started working at the AIDS center.

For the past 7 years I live and help my peers, because I learned a lot and now I understand that life goes on. I want to wish all the people who are affected by this problem self-confidence and good health. I realize that our lives are in our own hands and everything is up to us.

### **3.3.5.6 HIV AND INJECTING DRUG USE – STORIES OF DISCRIMINATION**

**STORY 1:** (Kyrgyzstan) I'd like to tell a story of a man, who has been HIV-positive since 2005. He got infected through injecting drugs. He's now on ARVs and hasn't taken any drugs for 5 years. His mother once called me; she was very worried and asked for help. It turned out that he was depressed which led to a suicide attempt. We called an ambulance and took him to a psycho-neurological dispensary. They gave him a sedative injection. As he was on ARVs, I decided to inform the chief doctor about that. Immediately after the chief doctor found out the patient was HIV-positive, he demanded we take the patient away, and he referred us to the narcology dispensary. But as my friend had been clean for 5 years, we couldn't put him into a narcology unit because it increased the risk that he might start taking drugs again. It is very easy to access drugs in narcology clinics and there is a lot of temptation around. He didn't want to get back to using drugs.

Essentially, I had to bribe the doctor and he agreed to allow our friend to stay for 3 more days. Thank god, he got better quickly and he was very happy to have avoided the narcology. Now he's doing fine and is not using any drugs.

**STORY 2:** (Tajikistan) this story happened to my friend, who had taken ARVs for three years. Later his doctor quit his job and was replaced by another doctor. The new doctor treated my friend as someone who does not deserve respect because he was a drug addict. My friend lost all hope for his treatment and future life and therefore stopped taking his ARVs. He's now not been taking drugs for eight months and recently his condition has deteriorated. Trying to persuade him to start taking his drugs again hasn't worked. He wrote a letter in which he accused the doctor of taking away his hope. I do not know what to say to such people, because while there are doctors who get their jobs via nepotism and don't care for their patients, many people will lose hope for their future.

### **3.3.5.7 EMPLOYMENT AND HIV**

**STORY 1:** (Kazakhstan) my name is [name deleted]. I learned about my diagnosis, by accident, when I applied for a job in a large organization. My post was directly connected with leaving the country and before I left, I was sent to an HIV clinic for testing. I was sent to a clinic that belonged to the organization I worked for. By the time I returned to the clinic to receive my test results all the doctors already knew about my diagnosis and all our staff working in the organization.

The doctors broke the law about revealing confidential medical information. After visiting the doctor at the clinic, I returned to work and I noticed that no one wanted to socialize with me at my table for dinner. I wasn't fired, but there was a tense situation among the staff, so I didn't want that job anymore. One of the positive aspects was that I was first sent to the AIDS center, and then to an NGO, where I was able to learn and continue to be employed. Today I help others, I work in the NGO sector, helping PLHIV to accept their diagnosis.

### 3.3.6 SESSION SIX – REGIONAL SUCCESS STORIES

In Session Six, the workshop facilitators asked participants to separate into groups. The groups were asked to describe some examples of regional successes for improving HIV health care service delivery. Participants separated into regional, national and city/oblast groups to describe successes at each of these levels.

**Table 3: Success stories identified by participants**

Regional	National	City/Oblast
<p><b>1. Central Asia Network of PLHIV.</b></p>	<p><b>Kyrgyzstan</b></p> <ol style="list-style-type: none"> <li>1. Inclusion of Tenofovir in Global Fund Round 10.</li> <li>2. Two PLHIV community representatives and two alternates elected to the CCM.</li> </ol> <p><b>Kazakhstan</b></p> <ol style="list-style-type: none"> <li>3. Setting up the Kazakhstan Union of PHIV.</li> </ol> <p><b>Tajikistan</b></p> <ol style="list-style-type: none"> <li>4. Improved access to health care for PLHIV.</li> <li>5. Advocacy to provide an allowance for HIV positive children.</li> </ol>	<p><b>1. Shymkent, Kazakhstan</b> – Improvement in the quality of medical care for HIV positive children.</p>

#### 3.3.6.1 REGIONAL LEVEL SUCCESS STORIES

##### **Establishing the Central Asia Network of People Living With HIV**

###### *Description*

This initiative aimed to establish a Central Asia Network of People Living with HIV. The founding group mobilized PLHIV through national networks and worked with the leadership that already existed, drawing upon their experience and knowledge. Their first strategy was to call a meeting of Global Fund Country Coordinating Mechanisms and to build a regional dialogue through these committees with the governments. Their initial goals are to unify care protocols for HIV and to improve the integration of HIV treatment into primary health care systems and services.

###### *Learning*

The founding group learned that legislative differences at the country and oblast levels represent a barrier to the standardization and integration of HIV treatment and care in to primary health care systems. Countries vary in their standards for HIV treatment, care and support as well as in their logistical and procurement systems. ARV registration systems are not well developed across the region. A particular barrier is that each country has a different approach to illicit drug use and substitution treatment policies. There is no continuity between social and medical service responses to PLHIV in the region.

### *Goals for the future*

This group focused on the need to increase policies and services that target most-at-risk populations (MARP) for HIV: FSW, people who use drugs, MSM and transgender people. This included:

- Awareness raising for MARPs was identified as a key priority and this included producing and providing information material, developing actions/activities, educating the mass media on HIV issues/encouraging their coverage of these issues and conducting training programs for MARPs.
- The increased involvement of MARPs groups and organizations in treatment, care, support and prevention programming and service delivery.
- Improved referral systems between clinical services and social services across the region.

### **3.3.6.2 NATIONAL-LEVEL SUCCESS STORIES**

#### Kyrgyzstan

#### **Inclusion of Tenofovir procurement in to Global Fund Round 10 Proposal**

##### *Description*

People living with HIV lobbied to include Tenofovir in the drug procurements for Round 10 GFATM along with allies within the government and the medical sector. PLHIV played a central part in developing the GFATM proposal. PLHIV community representatives were active at the CCM level; their involvement in the process helped to improve access to information and ultimately influenced the decision making to improve access to treatment and other services. PLHIV representatives engaged in work meetings, roundtables and consultations with local and international experts. The likelihood of success for this initiative was rated as low, but community activism and interest in the issue helped to facilitate its success.

##### *Learning*

The group of PLHIV involved in this initiative discovered that the doctors who are responsible for prescribing ARV treatment are not well trained. Often procurement forecasting is wrong and PLHIV face barriers accessing procurement policies and understanding procurement procedures.

#### **Two PLHIV community representatives and two alternates elected to the CCM**

##### *Description*

Community leaders activated a group to lobby for the inclusion of PLHIV in the CCM. Their policy position included advocating for the equal and fair representation of all those with a stake in HIV, including two community representatives. MPs and government officials were not ready to accept and understand the problem. Key to success was that the community was well informed about the structure of the CCM and they organized a PLHIV forum to lobby for change (the forum included local and international observers). As a result, two agreed candidates were delegated to the CCM.

#### Kazakhstan

#### **Setting up the Kazakhstan Union of PLHIV**

##### *Description*

The Kazakhstan Union of PLHIV was created to provide services and improve the quality of life for PLHIV. Fourteen organizations came together to form the Union and partnership agreements and MoUs were signed with government and international organizations. The Union held roundtables, meetings and negotiations as part of its development process. Key goals are the scaling up of services and improving the quality as well as the reach of regional services, in particular for most at-risk populations. The President and community representatives are represented on the CCM and can influence decision-making. A key success was that the Union attracted funding through GFATM Round 10 as a sub-recipient for the Republic AIDS Center.

### *Learning*

Stigma remains a serious obstacle for improving the health care of PLHIV in Kazakhstan. It remains very difficult to implement programs because of government bureaucracy. There is insufficient leadership and skills capacity for service delivery among PLHIV and funding is insufficient.

### *Goals for the future*

The group focused upon the need for increased PLHIV advocacy including:

- PLHIV activists – there is a need to develop more PLHIV activists in Kazakhstan.
- Funding and resources – are insufficient to meet the needs.
- Legislative barriers – there are a range of legal barriers which need advocacy for change.

## Tajikistan

### **Improving access to health care services for PLHIV**

#### *Description*

This advocacy initiative focused upon improving access to health care services for PLHIV by increasing donor funding. The goal was to improve the accessibility of ARV stock and to ensure an effective referral system to TB, hepatitis and STI diagnosis and treatment services and to other health care specialists. The initiative aimed to improve diagnostics, inpatient care for PLHIV and the way that doctors and outreach workers cooperate to improve ARV treatment adherence. Activities involved meeting with service providers, signing agreements to work together, the development of referral systems and the provision of services to PLHIV, in cooperation with medical services.

#### *Learning*

Stigma remains a key barrier to accessing health care services. Waiting times and queues at service points are too long. User fees represent the main barrier to consistent health care seeking amongst PLHIV. Services should be free-of-charge. Demand for services increased in the regions where the advocacy initiative was most active; evidence for this came from service indicators and reports from the self-help PLHIV support groups in these regions.

### **Advocacy for a financial allowance for HIV positive children**

#### *Description*

A taskforce was created by parents of children with HIV and also included senior government members from the Ministries of Justice, Health, Labor and Finance. The likelihood that this initiative would succeed was rated as very low, because it was very difficult to bring the five ministries together and the parliament wanted compelling evidence to support the bill. But the evidence was collected and UNICEF provided a letter of support to parliament. Through these strategies, cross-government support was gained and an official bill was drafted and submitted

to parliament. The adoption of the bill took three months and was supported by UNICEF. At present 64 children with HIV receive US\$60 per month.

#### *Learning*

This was a very difficult advocacy task because there was no precedent for such financial awards and no legislation to support it – therefore, no mechanism for implementation. There was also no immediate demand from the parents for such an allowance and awareness had to be generated as the initiative got underway.

### **3.3.6.3 OBLAST/CITY-LEVEL SUCCESS STORIES**

#### **Improving quality of medical care to children with HIV**

##### *Description*

In Shymkent, Kazakhstan, this advocacy initiative aimed to improve the quality of medical and community care for children living with HIV. A mother and child rehabilitation center was set up to provide prevention and treatment services. A charitable foundation called 'Protect Children from AIDS' was established. Access to social benefits including pensions and other allowances was secured. NGOs were also established to provide care and support to adults living with HIV, including parents. The *2007-2011 AIDS Plan* which was approved at the oblast level, included cooperation with parents' communities

##### *Learning*

Stigma and discrimination remain significant barriers for HIV positive children and their parents to fully participate in society. Parents often experience self-stigmatization and censor themselves as a way of protecting themselves and their families. Medical personnel are described as "quite ignorant" and not well trained

### **3.3.7 SESSION SEVEN: WHAT CAN THE QUALITY HEALTH CARE PROJECT DO TO SUPPORT EXISTING INITIATIVES?**

In Session Seven, facilitators asked participants to discuss and document in their regional, national or oblast/city level groups how the Quality Health Care Project can contribute to supporting and working with PLHIV in the region and building on the already existing PLHIV initiatives (see Table 4).

Common issues that emerged were: the need for increasing financial resources, human resources training for health care providers, and skills-building training (including communication skills) for PLHIV. Other emerging themes were the desire to learn and share experiences from PLHIV in the region and across Europe, related to PLHIV advocacy and leadership. At the regional level, activities that are required include: better analysis of existing legislation; a regional PLHIV needs assessment and advocacy initiatives targeted at governments and key politicians.

At the national level, advocacy is needed to call for the adoption of international standards of treatment and care and technical assistance across the spectrum of HIV prevention, treatment, care and support services. At the oblast/city level, facilitation is required to help increase cooperation between the medical and community (including PLHIV) sectors.

### **3.3.8 SESSION EIGHT: CLOSING REMARKS**

Elena Kudussova, Kazakhstan's HIV Director for the Quality Health Care Project thanked participants for attending the meeting and for their generous contribution to the workshop. Ms.

Kudussova explained that their input would inform the development of the Quality Health Care Project's upcoming annual planning process.

**Table 4: key issues identified as needing support from Quality Health Care Project**

Regional	National	Oblast/City
<ul style="list-style-type: none"> <li>• Financial and human resources.</li> <li>• Technical leadership and support.</li> <li>• An analysis of legislation across the region.</li> <li>• A regional PLHIV needs assessment.</li> <li>• A regional HIV services analysis.</li> <li>• Share experiences from regional PLHIV networks in Western and Eastern Europe.</li> <li>• Advocacy and diplomacy for increased support from political leaders and government.</li> </ul>	<p><b>Kyrgyzstan</b></p> <ul style="list-style-type: none"> <li>• Regular cooperation between PLHIV community leaders and the project.</li> <li>• The regular adoption of new international standards of treatment.</li> <li>• Capacity building and training of HIV specialists.</li> <li>• Technical support from the international community.</li> <li>• Training.</li> <li>• Experience exchange.</li> <li>• Consultants with expertise in PLHIV leadership and participation.</li> </ul> <p><b>Kazakhstan</b></p> <ul style="list-style-type: none"> <li>• Training regional activities and involvement of activists in projects.</li> <li>• Technical support and human resources.</li> <li>• Funding for annual PLHIV meeting, summer camps and seminars.</li> <li>• Scaling up of service provision within primary</li> </ul>	<ul style="list-style-type: none"> <li>• Training of medical personnel.</li> <li>• Technical support, including support for office and organizational management.</li> <li>• Funding for the training of psychologists, counselors, for roundtables, work meetings and seminars.</li> <li>• Facilitation of coordination and cooperation between PLHIV and the health care sector.</li> <li>• Active involvement of PLHIV.</li> <li>• Coordination with the Ministry of Health.</li> </ul>

	<p>health care settings (training of doctors).</p> <ul style="list-style-type: none"><li>• Setting up special clinics to provide a range of services to PLHIV.</li><li>• Setting up an inpatient care unit for PLHIV.</li></ul> <p><b>Tajikistan</b></p> <ul style="list-style-type: none"><li>• Analysis and monitoring of the health care system in the region.</li><li>• Capacity building for PLHIV including shared activities for PLHIV NGOs and active involvement of PLHIV in the project.</li></ul>	
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## NEXT STEPS

In Central Asia at present, certain populations are identified as at particular risk of HIV infection and transmission (most-at-risk populations or MARPs, including PLHIV). These populations are marginalized from health services due to stigma and discrimination and isolation caused by the illegality of their behavior. This access gap is filled to some extent by donor interventions that provide outreach to isolated populations, however the geographic reach and breath of services offered by these programs has been limited and is not at a scale that is likely to significantly reduce HIV incidence and impact in the long-term. The health system has not generally been an active partner in these outreach programs and there is often a significant difference in the quality of services that MARPs receive from donor interventions compared with that received once in the health system.

The demand created by these outreach programs is not generally met by an increase in high-quality supply. Referral is often a passive exercise of notifying MARPs of the location of services, rather than an active exercise of assisting services to better provide care for MARPs and assisting MARPs to gain entry and maintain contact with these services.

Few of these programs focus on achieving long-term change in the relationship between MARPs and the health system. This is often brought about by the empowerment of MARPs so that they can more effectively participate in health system reform and health service planning, delivery and evaluation. There has also been inadequate focus on removing the barriers to access that exist – going beyond stigma and discrimination to look at issues of task allocation, core competencies and health financing.

Pockets of access exist – some primary health care or family medical care centers (PHC/FMCs) gain a reputation for being particularly friendly towards a certain MARP group, such as PLHIV. This may be because of the motivation of the Director or other personnel within the service or because of the work of a neighboring civil society organization (NGO). This PHC/FMC acts as an entry point for other services but it is not clear how wide this improved access or quality spreads or how it can be replicated in other geographical areas.

The USAID Quality Health Care Project will work in target localities to examine and support these pockets of improved access and work with communities, NGOs and services to further open entry points to care, so that MARPs can access the full range of services they need when they need them. It will work with the key staff in these entry points to determine the factors that led to this increased access and take the lessons from this to other services in the same locality. It will work with NGOs involved in outreach programs, through the USAID Dialogue on HIV and TB, Global Fund to fight AIDS, TB and Malaria (GF) projects and other initiatives, to develop more effective referral strategies, brokering systems and other initiatives to ensure that MARPs reach these services and develop long-term health-seeking relationships with them.

The needs of PLHIV are being taken into account in the work by the Quality Project in these localities. This work will concentrate on facilitating increased cooperation between the medical and PLHIV sectors, including replication and improvement of the model used in Temirtau. A training process will be initiated toward the end of Year 1 to ensure that PLHIV groups are well-trained in the core activity of running PLHIV support groups, and capacity building to address other issues identified at the regional workshop will be carried out in Years 2-5 of the project.

## ANNEX A: LIST OF PARTICIPANTS

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# ANNEX B: PLHIV PARTICIPATORY PLANNING WORKSHOP

Regional Workshop  
**Improving Health Services for People Living with HIV:  
 A Participatory Planning Meeting with the Quality Health Care Project**  
 19 – 20 May 2011 – Hotel Kazzhol, Almaty, Kazakhstan  
 Agenda

<b>Day 1</b>	
<b>Time</b>	<b>Session Theme</b>
09:00 – 10:00	Introduction <ul style="list-style-type: none"> <li>• Welcome</li> <li>• Introduction to the USAID Quality Health Care Project</li> <li>• Purpose of the workshop</li> <li>• Introductory activities</li> </ul>
10:00 – 10:30	Exercise: «What's on your mind?» <ul style="list-style-type: none"> <li>• Exercise to determine key concerns for PLHIV and interactions with the health system</li> </ul>
10:30 – 11:00	Coffee Break
11:00 – 12:30	Group Discussion
12:30 – 13:30	Lunch
13:30 – 14:00	Presentation: «What is the USAID Quality Health Care Project?»
14:00 – 15:30	Small Group Work: «What are the issues that you're advocating for right now?»
15:30 – 16:00	Presentations of Small Group Work
16:00 – 16:30	Conclusion of Day 1
16:30	Coffee Break and Social Networking
<b>Day 2</b>	
09:00 – 9:30	Morning Welcome <ul style="list-style-type: none"> <li>• Housekeeping</li> <li>• Thoughts and feedback on Day 1</li> </ul>
9:30 – 10:00	Presentation: «Strategies of the Quality Health Care Project for Improving Services for PLHIV»
10:00 – 10:30	Group Discussion
10:30 – 11:00	Coffee Break

11:00 -12:00	<p>Small Group Work: «Successes So Far»</p> <ul style="list-style-type: none"> <li>• Group work by country to consolidate successes that have been experienced so far in connecting PLHIV and the primary health care setting</li> </ul>
12:00 – 13:00	Presentations of Small Group Work
13:00 – 14:00	Lunch
14:00 – 15:00	Large Group Discussion: Determining Priorities For the Upcoming Year
15:00 – 16:30	Small Group Work: Operational Planning for Priority Areas of Work
16:30 – 17:00	Presentations of Group Work & Determination of Emerging Themes
17:00 – 17:30	Workshop Conclusion

## ANNEX C: BIBLIOGRAPHY

NAC National AIDS Center. 2010. *National UNGASS Report 2008-2009*. Almaty, Kazakhstan.

RoK Republic of Kazakhstan. The Republican Centre for Prophylactics and Control of AIDS. 2007. *The Third Annual Report on the Implementation of the Grant provided by the Global Fund to Fight AIDS, Tuberculosis and Malaria KAZ-202-G01-H-00*. Almaty, Kazakhstan.

Thorne, Claire. Ferencic, Nina. Malyuta, Ruslan, Mimica, Jakrank, Niemiec, Tomasz. 2010. 'Central Asia: hotspot in the worldwide HIV epidemic'. In *The Lancet Infectious Diseases*, Volume 10, Issue 7, pp479-488.

Tokbaeva, Dina. Sadyrkulov, Beksutlan, Manzarshoea, Aslibegim. 2010. 'HIV Alarm in Central Asia: Large-scale population movement contributes to virus spreading across broad cross-sections of society'. In Institute for War and Peace Reporting. RCA Issue 613, 21 May 2010.

UNAIDS. 2010. *UNAIDS Report on the Global AIDS Epidemic 2010*. Available at: [http://www.unaids.org/documents/20101123\\_GlobalReport\\_em.pdf](http://www.unaids.org/documents/20101123_GlobalReport_em.pdf)

USAID. 2010. 'USAID Launches Quality Health Care Project'. Available at: <http://centralasia.usaid.gov/page.php?page=article-899>

USAID. 2011. *Quality Health Care Project HIV Strategy*. Unpublished draft 26 04 2011.

USAID Measure Evaluation Project. 2003. *PLACE Assessment*. Center for Study of Public Opinion, Almaty, Kazakhstan. Principal Investigator: BaurzhanShusupov.

USAID Aidstar Two. 2011. *Mapping of Key HIV/AIDS Services, Assessment of their Quality, and Analysis of Gaps and Needs in Most-at-Risk Populations in Selected Sites of Kazakhstan*. Authors: Deryabina A, Osipov, K and Surdian T.

Viktorovich, A. 2011. *Inventory to compare legislation, policies, regulations, guidelines/protocols with international best practice*. Kazakhstan. Available at: [http://www.eematkb.com/PDF\\_KAZInventory-final-Kazakhstan\\_ENG.pdf](http://www.eematkb.com/PDF_KAZInventory-final-Kazakhstan_ENG.pdf)