



TECHNICAL REPORT



COMMUNITY ADVISORY BOARDS TO IMPROVE HIV SERVICES IN CENTRAL ASIA: THE FIRST YEAR OF IMPLEMENTATION EXPERIENCE

July 2014

This trip report was produced for review by the United States Agency for International Development. It was prepared by Danielle Parsons for the Quality Health Care Project in the Central Asian Republics.

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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BACKGROUND

The USAID Quality Health Care Project (“the Quality Project”), under the mandate of the United States President’s Emergency Response For AIDS Relief (PEPFAR) Regional Operational Plan, developed and introduced a model for Community Advisory Boards to contribute to the engagement of key populations and improvement of HIV prevention, care and treatment services. This work was initiated in Year 3 of the Quality Project.

This report summarizes findings previously reported in trip reports from technical advisory visits in January, May/June and September/October of 2013, and presents new findings from a regional workshop conducted to mark one year of active CAB implementation in May 2014. It is hoped that by presenting a continuum of process, interim progress and final results at the one-year mark, this report can be used by others to replicate the CAB model and understand that progress may occur at different rates and in different ways based on circumstances.

COMMUNITY ADVISORY BOARD MODELS

Variations of Community Advisory Boards (sometimes also referred to as Consumer Advisory Boards, Patient Councils, or by other names) exist in many industrialized countries. Though Community Advisory Boards (CABs) first became standard for clinical trials in the early 1980s, they have since expanded to the clinical care realm. In the United States, it is now considered common best practice for any HIV-related facility to have a CAB; many city health departments and even states have CABs, as well.

The purpose of CABs is to facilitate direct accountability of health care providers or researchers, care facilities, and sometimes even policy makers, to the patients who are receiving care – without jeopardizing an individual’s relationship with a care provider. In other words, if a patient feels uncomfortable or unable to speak directly to his/her health care provider about a concern, CABs provide a mechanism through which individuals may channel their complaints or concerns, and the CAB may address these as a community issue. Likewise, when health care providers notice trends that should be addressed on the community level, a CAB can reach out to the community communicate messages for behavior change, etc.

While many different definitions can be used for a CAB, the Quality Project offered the following common definition for consideration by Central Asian partners during the process of adaptation to local contexts¹:

A Community Advisory Board is a committee of clinic patients that meets on an ongoing basis to review services, provide recommendations, bring new issues to the attention of the health center or clinic, and address other tasks as necessary.

¹ Parsons, D and Burrows, D. 2013. *Forming Community Advisory Boards: A Guide for Expanding Patient Engagement in HIV and Drug Treatment in Central Asia*. USAID Quality Health Care Project in Central Asia. Abt Associates, Inc. [Unpublished draft]

QUALITY OF HIV TREATMENT AND CARE SERVICES

In exploring which areas of HIV prevention, care and treatment to target for this intervention, the Quality Project found that the experiences of people living with HIV (PLHIV) in accessing care at AIDS Centers were challenged by the quality of care and their ability to negotiate for better or more regular access to care. Many NGO partners regularly raised issues about quality of care, including lack of regular access to clinical monitoring services such as CD4 cell counts and viral load testing, lack of treatment for opportunistic infections, compromised confidentiality of patients, lack of treatment literacy (e.g. understanding which medications are being prescribed, how they work, how and why they should be taken), and regular support for adherence. The Quality Project's own assessments and experiences in implementation affirmed these gaps.^{2,3,4}

Most PLHIV still receive their HIV-related care at government AIDS Centers (not at integrated, primary care-level facilities). Therefore, given the importance of access to appropriate care and treatment for PLHIV, both to assure their own health outcomes and to provide a population-level preventative effect (e.g. "treatment as prevention"), improving the quality and accessibility of HIV care and treatment services at AIDS Centers was seen as a top priority for introduction of the CAB model.

QUALITY OF MEDICATION ASSISTED TREATMENT SERVICES FOR THE PREVENTION OF HIV

While Community Advisory Boards may be used for the improvement of a variety of services, both clinical and non-clinical. However, since the US models being drawn on for this intervention have been used most extensively in the clinical realm, the Quality Project felt it was appropriate to address a clinical HIV prevention service as a first point of introduction for CABs.

In the first two years of Quality Project implementation, the project focused a significant amount of energy on working with providers of medication assisted treatment for opioid dependency (MAT), in order to bring Central Asia's MAT practices closer to international standards. However, several of the Quality Project's own interventions⁵, as well as numerous outside reports^{6,7,8} and accounts from NGO and community-level partners,

² Berry, S; Kis, Z; Burrows, D and Parsons, D. June 2011. *Regional PLHIV Capacity Building*. Bethesda, MD. Quality Health Care Project in the Central Asian Republics, Abt Associates Inc.

³ Coughlan, M; Manukyan, A; Bolotbaeva, A; Parsons, D and Burrows, D. August 2011. *HIV Counseling and Testing in Kyrgyzstan, Kazakhstan and Tajikistan*. Bethesda, MD. Quality Health Care Project Central Asian Republics, Abt Associates Inc.

⁴ Thumath, M; Bolotbaeva, A; Parsons, D and Burrows, D. 2011. *Individual, Social and Structural Barriers to ARV Adherence in Kyrgyzstan and a Proposed Plan of Action* Bethesda, MD. Quality Health Care Project in the Central Asian Republics, Abt Associates Inc. [Unpublished draft]

⁵ van Beek, I; Williamson, P; Parsons, D, and Burrows, D. July 2011. *Medication-assisted treatment in Kazakhstan, Kyrgyzstan and Tajikistan*. Bethesda, MD. Quality Health Care Project in the Central Asian Republics, Abt Associates Inc.

⁶ Subata E., Pkhakadze G., 2006. Evaluation of pilot methadone maintenance treatment in the Kyrgyz Republic, Bishkek (unpublished document)

METHODS

INTRODUCTION OF MODEL

The CAB model, based on international experience and adapted for Central Asian context, was presented to stakeholders in January 2013. In each country, a larger, roundtable-style meeting was held with a mixed group of stakeholders, including government health care partners, NGO representatives working with PLHIV and MAT clients and/or PWID, and a small subset of active community members from PLHIV and MAT client groups. These groups received a formal presentation on the guidance drafted by the Quality Project⁹, were invited to take part in an open question & answer session, and then took part in interactive small group work that explored the need for and feasibility of starting CABs in the HIV and MAT context in each country. At the conclusion of each session, the group was asked to develop consensus on whether the CAB model was feasible to try on at least a pilot (one-year) basis, with Quality Project support. While some individuals voiced concerns and skepticism about exact implementation details, the groups in each country came to the consensus that it was feasible to try.



During a roundtable session, a range of community stakeholders weighed in on feasibility of and likely needs for adaptation of the CAB model for various settings in Central Asia.

In small groups, using visual diagramming of current barriers to quality care, they brainstormed the ways in which CABs could be useful, and envisioned what improved quality of care would look like in terms of outcomes.

⁷ Subata E., Moller L, Karymbaeva S., 2008. Evaluation of opioid substitution therapy in the Kyrgyz Republic. World Health Organization, Regional Office for Europe. Copenhagen, Denmark. 2008.

⁸ Boltaev A, El-Bassel N, Deryabina AP, Terlikbaeva A, Gilbert L, Hunt T, Primbetova S, Strathdee SA. *Scaling up HIV prevention efforts targeting people who inject drugs in Central Asia: A review of key challenges and ways forward.* Drug and Alcohol Dependence. 2013 Aug 30. pii: S0376-8716(13)00298-6. doi: 10.1016/j.drugalcdep.2013.07.033. [Epub ahead of print]

⁹ Parsons D and Burrows D, *ibid.*

After these more formal presentations, smaller community groups were convened in comfortable settings to give community members a chance to voice opinions, hopes and concerns, without any undue influence from care providers or NGO partners. In each case, the lead consultant met with PLHIV and MAT client groups separately, recognizing the unique needs of each group and that, especially for PLHIV groups, confidentiality is a key issue in meeting and speaking freely. In these sessions, all community groups confirmed that they would like to pilot the CAB model, and discussed next steps for action planning, including how to recruit potential members, partnerships with NGOs (a sensitive issue in some cases, so that NGOs did not perceive the community as trying to ‘steal power’ from them), and the specifics of how often and where to meet. The Quality Project local staff helped to facilitate these sessions and agreed to follow-up with the clinical sites to ensure that clinical liaisons were in place and read to cooperate.

Full details on these sessions and their outcomes can be found in the lead consultants’ trip reports from January 2013^{10,11,12}.

SIX-MONTH PARTICIPATORY ASSESSMENT

Most CABs were able to start meeting in March or April, after having held open calls for membership and utilizing a multi-sectoral stakeholder panel to choose a group of eligible inaugural CAB members. Therefore, a six-month participatory assessment of progress to date was scheduled for late September/early October, to allow for a full six months of active work before assessing early progress and outcomes.

The design of this assessment drew heavily from Rossman’s participatory assessment methods, and prioritized the inclusion and active participation of CABs to assure productive reflection instead of a purely top-down, objective assessment of progress-to-date. The primary questions to be addressed during this assessment were:

- Are the Community Advisory Boards (CABs) on track to meet the indicator elements prescribed by USAID to measure their success? If not, what can be done to support them meeting the requirements of this indicator? (See table below)

USAID Indicator for Community Advisory Boards

Criterion	Description
1	CAB established through transparent process (e.g. application forms and selection board), with due consideration of diverse membership.
2	CAB meets at least quarterly, with minutes documenting the meeting.

¹⁰ Parsons, D. HIV Brief Trip Report – Kazakhstan, February 2013.

¹¹ Parsons, D. HIV Brief Trip Report – Kyrgyzstan, February 2013.

¹² Parsons, D. HIV Brief Trip Report – Tajikistan, February 2013.

3	CAB has an established contact at the medical facility with whom it interfaces.
4	Number of efforts undertaken by CAB to solicit community feedback on needed improvements in the medical facility's services (specify the number and type of effort undertaken – e.g., community meeting, outreach visit).
5	Number of medical facility responses to CAB requests, leading to the improvement of a particular service (specify the type of responses received – e.g., meeting with CAB, community meeting – and outcome – e.g., increased availability of service).
6	Number of documented instances of increased access to services or quality of services in response to actions by the CAB (specify the number and type of changes or instances of increased access and quality).

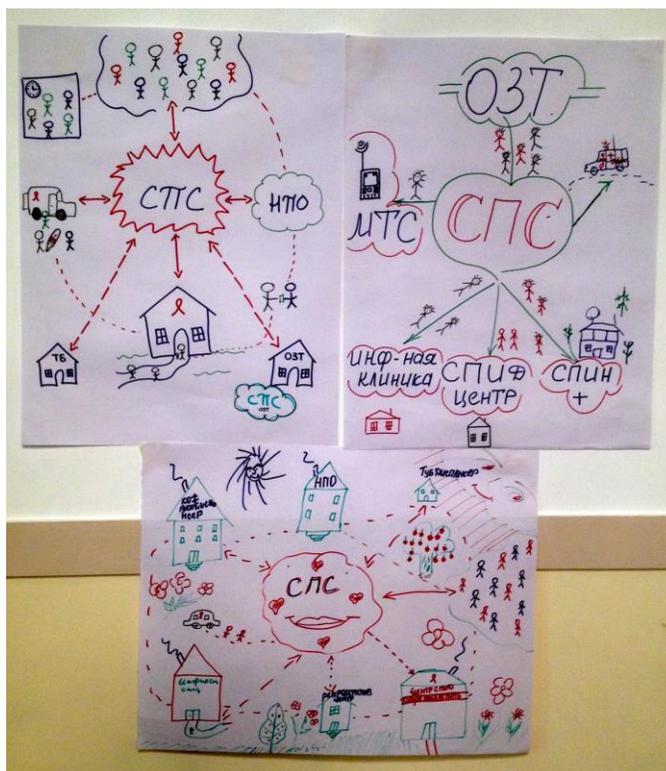
- Have CABs demonstrated effectiveness captured outside of the indicator? What/how?
- In addition to serving the wider community, has the CAB model been beneficial to CAB members themselves? How?
- How has the CAB model been adapted differently in different contexts? What are the critical relationships that sustain the CAB at each site?
- Has the CAB model achieved sufficient local ownership to assure stability?

The methods employed to answer these questions included the following:

- Key informant interviews with clinical liaisons, clinic Directors, and other key contacts.
- Participatory meetings with CABs to:
 - Establish progress to date,
 - Map nature and quality of relationships with partners (an important aspect of meeting criteria 3-5 on the USAID indicator),
 - Capture unexpected benefits of the CAB, or those that lie outside of
 - Assess how the CAB model has been adapted for each

As part of this participatory assessment of CAB progress, CABs visually mapped their relationships with other entities, including their designated clinics, other government health care services, NGOs, their broader community, and others. They were then asked to identify which relationships needed strengthening, and brainstorm means for making these improvements.

A similar visual exercise was conducted to visualize specific results and progress so far, and plans – both organizational and result-oriented – for the next six months of implementation.



ONE-YEAR REGIONAL WORKSHOP

The one-year regional workshop aimed to revisit the main assessment questions from the six-month assessment:

- Are the Community Advisory Boards (CABs) on track to meet the indicator elements prescribed by USAID to measure their success? If not, what can be done to support them meeting the requirements of this indicator?
- Have CABs demonstrated effectiveness captured outside of the indicator? What/how?
- Has the CAB model been beneficial to CAB members? How?
- Has the CAB model been beneficial to clinic patients/clients who are not CAB members? How?
- How has the CAB model been adapted differently in different contexts? What are the critical relationships that sustain the CAB at each site?
- Has the CAB model achieved sufficient local ownership to assure stability?

However, while presenting an opportunity for revisiting self-assessment procedures, the workshop also aimed to be capacity-building in nature. Therefore, building off of the participatory methods used in the six-month assessment, and responding to needs and weaknesses identified at that point, the agendas for two regional workshops (one for HIV CABs and one for MAT CABs) were developed with the following basic principles in mind:

- It was most appropriate to hold the regional exchanges for PLHIV and MAT clients separately. Not only had their roles and functions as CABs diverged quite significantly by 6 months, attempts to combine the two groups for a day of in-country experience exchange in Tajikistan had led to some degree of discomfort and suspicion surrounding confidentiality of HIV status, etc, despite facilitator efforts to actively create a friendly, trusting environment.
- Content of the workshops should be balanced between facilitated self-assessment that could double as experience sharing, and direct capacity-building activities on specific topics.

- Varying levels of education and expertise in advocacy and self-organization needed to be considered, allowing more advanced individuals and groups to be challenged while not leaving behind individuals or groups who struggled with more basic concepts.
- Building the capacity and commitment of clinical liaisons should also be a priority, and they should be included in the workshop if possible. They should have a chance to work alongside CABs in some portions of the workshop, while working separately to exchange experiences with their counterparts from other countries during other portions.

Full agendas for these workshops can be found in Appendix 1 and Appendix 2 of this report.

KEY FINDINGS

PROGRESS AT SIX MONTHS

Are the Community Advisory Boards (CABs) on track to meet the indicator elements prescribed by USAID to measure their success? If not, what can be done to support them meeting the requirements of this indicator?

All six CABs were on track to meet criteria 1-3 of the indicator; CABs in Kazakhstan and Tajikistan had already successfully fulfilled these criteria. CABs in Kyrgyzstan had struggled in their first attempt at formation, and were re-forming at the time of the six-month assessment, with necessary adjustments to the model to meet local circumstances.

The four well-established CABs in Kazakhstan and Tajikistan were working towards reportable results for criteria 4-6. Reasonable methods of data collections were not yet clear, and the Quality Project staff were encouraged to explore options for how these data would be collected when the time comes.

Have CABs demonstrated effectiveness captured outside of the indicator? What/how?

The primary outcome captured outside of the parameters of the indicator was the benefit to clinical administration, which noted in Kazakhstan (for the MAT CAB) and Tajikistan (for the MAT and HIV CABs), that having the CABs as a mechanism for the clinic to communicate with the broader patient population was of significant benefit to the clinic's function. The Quality Project praised this two-way, mutually-beneficial relationship, and encouraged all parties to continue to cultivate these roles. These lessons were also shared with the Kyrgyzstan CABs as they began to re-establish themselves.

In addition to serving the wider community, has the CAB model been beneficial to CAB members themselves? How?

The results of this question were mixed. In two cases, CAB members expressed – and the assessor observed – they were clearly benefiting from the empowerment of being part of an official body representing the community:

- The Dushanbe MAT CAB expressed that their role has given them purpose and a sense of empowerment. Especially after transitioning from regular drug use to a steady program of methadone, clients often feel that they have a lot of free time available in their day (time that used to be spent looking for money or procuring drugs, or under the influence of

drugs). Being part of the CAB gives them a positive outlet, and having the responsibility of working with the rest of the client community allows them to find productive ways to use their time – collecting feedback from other clients, or working to educate clients or pass along messages from clinic administration.

- The Almaty HIV CAB expressed a similar level of empowerment, and noted that many of the problems that they have been able to address as a group had long plagued them as individuals, but they did not have an opportunity or mechanism to get them addressed. This group expressed that they were particularly fulfilled by helping others, and felt a great sense of motivation to improve services for the sake of their own lives as well as for less empowered clients.

In two other cases, the results were less clear:

- While the Dushanbe HIV CAB expressed their pleasure with the opportunity to be part of the CAB and reaffirmed that the model was necessary, they lamented their lack of capacity and difficulty finding a way that they could make a difference. While their desired mission and goals were clear, their confidence in their capacity to meet these goals is so far severely limited, which limits their own ability to benefit from the experience as an exercise in empowerment. Continued team building and capacity building were highly recommended for this group in order to instill a greater sense of confidence and work through detrimental feelings of guilt and self-stigmatization associated with HIV infection.
- Somewhat similarly, the Ust-Kamenogorsk MAT CAB affirmed the need for their group, and felt considerably more confident in their capacity to address local problems than their Dushanbe HIV CAB peers, but felt that the challenges facing their program were largely external – e.g. anti-MAT propaganda campaigns that were playing out at the national level. As such, their largest identified role would be in serving as an advocacy body that could work to counteract anti-MAT propaganda on their local stage. It was recommended that this team receive additional technical assistance from Quality Project's local experts to build their capacity to plan and conduct advocacy activities, and that ongoing technical assistance help them to continue thinking through local quality of care issues that can be addressed even in the currently challenging environment. This would not only help the CAB to function more effectively, but is anticipated to give CAB members the confidence boost needed to make their experience more empowering.

In the cases of the Kyrgyzstan CABs, because the model needed further adaptation to account for the saturated NGO environment and large number of MAT facilities in a single city, CABs were unstable at the time of the six-month assessment and this question was agreed to be revisited in another six months time.

How has the CAB model been adapted differently in different contexts? What are the critical relationships that sustain the CAB at each site?

Adaptations of the CAB model have been significant between sites, which is seen as a positive indicator that the model is responsive to a variety of settings, and local ownership is strong enough to find creative solutions when adaptations are needed. The most distinct pattern observed at six months was that MAT CABs focused more heavily on critical enablers such as police presence on site (or lack thereof), political will for MAT, and community perceptions of MAT. HIV CABs, on the other hand, focused more on clinical care issues. The single most

notable adaptation at six-months was the city-wide model of the Bishkek MAT CAB, which is being explored after a single-site MAT CAB did not appear viable under the current circumstances.

Has the CAB model achieved sufficient local ownership to assure stability?

At six months, no CAB had achieved complete local ownership in terms of management capacity to assure stability. Specifically:

- The Dushanbe MAT CAB showed great progress, but remained heavily dependent on the support of their clinical liaison, and was still seeking a physical space to hold meetings (outside of their clinical liaison's office). They also struggled at times to maintain a reasonable number of goals and keep their activities within the scope of their stated mission.
- The Dushanbe HIV CAB still struggled with confidence and crippling confidentiality issues, which made it challenging for the CAB to interface with the wider patient population. The relationship with their facility appeared to be cordial and the AIDS Center Director was clearly interested in working with the CAB, though all parties were still struggling to find the appropriate level of engagement for facility-level improvement, expressing frustration that some national and policy level issues made it difficult to improve circumstances at the facility level.
- At six months, the Bishkek MAT CAB had never fully formed at a single MAT site, due to a number of factors including perceived competition from NGOs and lack of agreement within the community about the most appropriate pilot site. At the six-month check-in, community members had agreed to try a re-launch of the CAB using a city-wide model, which would draw a representative from each of Bishkek's 6 MAT sites. The Quality Project encouraged this adaptation, based on the stronger community support enjoyed by this option.
- The Bishkek HIV CAB had struggled in its first iteration due in part to the weak and fractured community of PLHIV that are generally mobilized under two rival PLHIV organizations in Bishkek. At six months, the CAB was only starting to re-form under new leadership with a stronger emphasis on linking to the facility's functions rather than community politics. Though the new CAB, led by a feldsher (mid-level medical professional) and counselor based at the AIDS Center who is himself a PLHIV, maintained a relationship that was uniquely intertwined with the clinical staff, it was supported by Quality Project staff as the most viable option, and encouraged to continue growth.
- The Ust-Kamenogorsk MAT CAB had developed a small core of dedicated executives, but struggled with basic capacity issues and was still working to identify an appropriate role for the CAB to contribute to the community in a situation where the clinical leadership was already quite responsive to patient needs, but the larger environmental threat to MAT program stability presents a large challenge.
- The Almaty HIV CAB enjoyed the most stability and local ownership, with members self-managing the functions of the CAB quite independently of their clinical liaison. The primary concern with this group was an expressed desire to consider incorporating as an organization, to assure the ability to raise funds; the Quality Project has advised against this, noting that this will effectively shift the group from a CAB to another NGO, and they will lose their inherent authority with the facility as an advisory board.

PROGRESS AT ONE YEAR

By the one-year mark, the CABs showed considerable improvement both in terms of organization and outcomes. Each CAB had a clearly articulated mission and vision, which they diligently presented to their other-country peers with explanations of why their priorities were what they were.

Are the Community Advisory Boards (CABs) on track to meet the indicator elements prescribed by USAID to measure their success? If not, what can be done to support them meeting the requirements of this indicator?

Yes. By one year of implementation, all six CABs had met all six criteria set out in the indicator matrix. Note that criteria 4-6 call for specific numbers of results to be documented; those numbers were not collected as part of this assessment, but it is expected that they will be readily available for the Quality Project HIV and M&E teams during regular project monitoring.

Have CABs demonstrated effectiveness captured outside of the indicator? What/how?

While most CAB effectiveness is technically captured within the indicator matrix assigned by USAID (with the possible exception of benefit to the clinic administration, as noted in the six-month assessment), the short-hand notation allowed by the current indicator is not sufficient to reflect the full depth and quality of results achieved by CABs. Therefore, it is suggested that at least annually CABs reflect on their successes using the participatory methods employed during the one-year workshop, and that USAID or other funders seeking results take care to explore the qualitative results of CABs in depth. Some of these results are presented in brief in **Specific Outcomes**, below.

Additionally, as CABs become more established, USAID, other funders, or even government institutions themselves, such as the Republican AIDS Center or Republican Narcology Center, may wish to collect additional indicators that could reflect the impact that CABs have on facilities. Such indicators may include HIV-related morbidity and mortality rates, adherence to and/or retention on treatment, and level of new enrollment on treatment at facilities with CABs versus those without.

In addition to serving the wider community, has the CAB model been beneficial to CAB members themselves? How?

In contrast to lack of confidence observed during the six-month assessment, the one-year workshop presented six CABs that represented their constituencies with pride and a marked level of empowerment.

In particular, while a high degree of self-stigma was noted amongst the Dushanbe HIV CAB at the six-month assessment, the difference at one-year workshop was remarkable. CAB members no longer displayed concerns about confidentiality and stated that they were serving their communities as proud, openly HIV-positive individuals. They welcomed having their picture taken as part of the workshop activities, and discussed their newfound purpose in their community with great enthusiasm. This was a

marked departure from the six-month sessions where preservation of anonymity was a prominent concern, and members perceived themselves as lacking the ability to help others.



Members of the Tajikistan HIV CAB joke and laugh while posing next to the results of an art therapy-inspired identity-building activity at the regional workshop. While this group was tearful while discussing prospects for improving care in January 2013, and still highly concerned about confidentiality (including photographic documentation of CAB work) in September 2013, they openly embraced being photographed and publicly sharing their experiences in May 2014.

How has the CAB model been adapted differently in different contexts? What are the critical relationships that sustain the CAB at each site?

Similarly to trends noted at six months, MAT CABs tended to focus more on advocacy and critical enablers, while HIV CABs focused more heavily on improvement in clinical services. In addition, after a year of implementation it was noted that in relatively resource poor settings, such as Dushanbe, CABs focused on utilizing their own man-power to provide services to community members, as exemplified by the CAB-run counseling hotline of the Dushanbe HIV CAB. In relatively richer settings, such as Almaty, CABs focused on mobilizing existing resources and be more conscious of fundraising possibilities, as demonstrated by the Almaty HIV CAB, which has negotiated for added clinical services using the existing budget. These are considered by the assessor to be appropriate differentiations in response to local circumstances, and CABs should be encouraged to continue to focus their resources on functions that will have the most impact within their specific environment.

Has the CAB model achieved sufficient local ownership to assure stability?

Local ownership of CABs was noted to have increased significantly, with both clinical liaisons and CAB members functioning at a higher level of confidence in their roles and responsibilities related to the CAB, indicating higher degrees of ownership and ability to function independently without outside technical assistance. Specifically:

- The Dushanbe MAT CAB showed marked improvement towards heavy dependence on their clinical liaison, with members able to clearly articulate successes, targeted upcoming goals and activities, and current and anticipated challenges. The establishment of a designated meeting/work space for the CAB seems to have encouraged a positive sense

of independence. While financial sustainability is always a question in Tajikistan, where many CAB members may face food insecurity and/or transportation hardships, the capacity and commitment of this CAB was impressive and indicated strong local ownership to assure continuation over the course of the next year.

- The Dushanbe HIV CAB made perhaps the most marked progress of any group, transitioning 180 degrees from self-stigmatizing and lacking confidence, to an open and creative problem-solving group. One concern for this group during the one-year workshop was that some members expressed concern that the multi-lingual and multi-ethnic make-up of the CAB, including varying levels of education and literacy, may create a 'bad impression' when the CAB members were not able to participate fully in Russian discussions (translation was provided to/from Tajik and Uzbek, as needed). It should be noted that the diverse nature of the this group is **not** a weakness, and rather should be considered a strength that allows the group to represent their constituency. The group, including clinical liaisons, are strongly urged to support the democratic nature of the group and allow its own self-determination, rather than considering 'changing out' members for those who are better Russian speakers or have higher levels of education.
- The Bishkek MAT CAB, as the single model of a multi-facility CAB representing all MAT sites across the city, has made progress but seems to still struggle at times to find a sustainable role in the community. This may be because of the saturation of harm reduction-related NGOs in Bishkek, and may also be because the group necessarily has less cohesion, as a group representing multiple programs across the city. While the group's early work on common issues of polysubstance use and basic MAT treatment literacy are commendable, as a step towards stability and long-term purpose, it is recommended that the group continue to look for discrete clinical care issues that can be addressed at the facility level, since this is a function not served by other city-wide groups, such as NGOs.
- After an effective six months of function (having re-formed at the initial six-month mark), the Bishkek HIV CAB has achieved a very respectable degree of cohesiveness and progress. The group has established a physical 'home' within the AIDS Center and works closely with clinical administration due to one of the members being dually a community member and AIDS Center health care worker. The most significant caution for this group to assure long-term stability is to be sure that all members are actively involved and empowered equally in decision-making, so that the group does not depend on the involvement of one enthusiastic or knowledgeable individual.
- The Ust-Kamenogorsk MAT CAB has developed an increased sense of organization and purpose, with more sophisticated advocacy plans in place. At the same time, the external factors that hinder this CAB's work have increased, as enrollment in the program has dropped precipitously amidst rumors of funding reductions for MAT. The group is encouraged to continue working on patient outreach and education to fight inaccurate perceptions of program stability (in fact, Kazakhstan has been expanding their MAT programs nationally, not shrinking them), but it is anticipated that continued technical assistance will be needed for this group for some time before it can be considered stable and independent.
- As previously noted, the Almaty HIV CAB exhibits a high degree of stability and local ownership, with members self-managing the functions of the CAB quite independently of their clinical liaison. The primary concern for this group remains its plans for self-incorporation outside of the AIDS Center, which could be problematic in terms of the relationship of the CAB to the facility itself. As an alternative to the CAB incorporating as

an organization, it is recommended that options for receiving institutional funding be explored in this relatively well-funded setting, as discussed in more detail in **Suggested Next Steps**.

SPECIFIC OUTCOMES

For HIV CABs, the most notable outcomes reported were as follows:

- **Lipid profile testing introduced using existing funds** for PLHIV on ART. This is the first time that this service has been available regularly in Central Asia, and allows patients to track their hepatic function while on medications that can potentially cause liver damage. This request was funded by using existing funds at the AIDS Center that had not yet been allocated for any other purpose. (Almaty)
- **VL testing and OI medications made available regularly** through better forecasting. While both services had been intermittently available at the AIDS Center, patients regularly reported lack of access, despite no obvious budgetary shortfalls to pay for these services. Increased attention to them as a stated priority for patients spurred more attention to consistent forecasting. (Almaty)
- **Confidentiality for HIV testing and counseling (HTC) improved** by requesting improved supervision of HTC staff. Both the layout of the anonymous testing room and the practices of particular staff members had regularly put confidentiality in jeopardy. With help from the clinic administration, these issues were successfully addressed to improve confidentiality. (Dushanbe)
- **Peer-run hotline created** for newly-diagnosed women. This hotline, staffed by CAB members with minimal financial support (for phone cards and minutes/airtime for calls) receives approximately 50 calls per month. CAB members and clinical staff note that it has led to marked **increases in enrollment for pediatric HIV treatment**, as mothers who call the hotline speak to other mothers who have put their HIV+ children on ARVs and can assure them that it is a healthy and responsible choice for their children. (Dushanbe)
- **Daily peer-to-peer counseling made available** for new diagnoses. This allows for a supportive environment for all new diagnoses, and is expected to contribute to lowered loss-to-follow-up among newly diagnosed patients, which will bolster the treatment cascade and assure that more PLHIV are successfully enrolled on ART. (Bishkek)

For MAT CABs, the most notable reported outcomes at one year were as follows:

- **Police harassment successfully addressed** onsite at MAT clinics by documenting and reporting violations to clinic management. Management then worked with local law enforcement to assure that there is no undue pressure or investigation of clients simply for showing up to receive MAT. This reduces a major barrier to long-term MAT adherence for clients. (Dushanbe)
- **Daytime space for productive gathering** of MAT clients established on-site at the MAT clinic. This space provides clients a place to go after receiving morning doses, reducing loitering that was threatening program stability due to complaints of nearby neighbors. In addition, this space allows for

productive, educational activities to take place, further support adherence to the program and better social reintegration. (Dushanbe)

- **Articles successfully published** in local papers in support of MAT programs, in response to Russian-support anti-OST campaigns. Providing pro-MAT information gives both the general public and PWID a more accurate perspective on the benefits of MAT and helps to build local support for the program – an important issue in a country heavily influenced by Russian drug treatment policies under the new Customs Union. (Ust-Kamenogorsk)
- **Outreach and information sessions conducted** for people who use drugs and their families, helping to maintain enrollment in a program that is perceived to have an unstable future due to political threats (as described above). (Ust-Kamenogorsk)
- **Creation of a network of MAT clients from different sites** creates the first representative platform of MAT clients to engage on issues that affect not just a particular site, but sites all throughout Bishkek. This also allows the multiple sites to share their experiences and solve problems together, as needed. (Bishkek)

All CABs have created some form of patient feedback mechanism, most in the form of a **patient complaint log** where issues can be recorded (anonymously, if desired) for redress by the CAB.

EXTERNAL BARRIERS AND CHALLENGES

In addition to the inherent organizational and capacity challenges of forming a new group such as a CAB, many of the CABs noted external barriers or challenges affecting their ability to operate. Specifically:

- The primary barrier facing CABs in Kazakhstan and Tajikistan is the stability of political will to maintain OST programs in the face of Russian anti-MAT pressure. While CABs continue to counter negative propaganda locally, national-level advocacy efforts threaten the continuation of programs from month to month, and the lack of progress on scale-up and expansion to new sites undermines confidence for would-be new enrollees. To counter this, the CABs continue to partner with larger advocacy movements nationally, but are often hampered by inability to travel for advocacy purposes (e.g. no MAT is available in Kazakhstan's capital or second major city, where many political discussions are had and deals are brokered).
- HIV CABs faced issues with national level procurement of ARVs, including access to 2nd and 3rd line regimens of ARVs, and legal/policy-based access to ARVs for undocumented immigrants and migrant laborers.
- HIV CABs also noted integration of TB services (for improved regularity of screening and for treatment of co-infection) and expansion of HCV testing and treatment services as priorities that needed to be addressed in the context of the broader health system.

In response to these challenges, it is suggested that countries consider forming national CAB networks that provide an opportunity for advocacy beyond specific facilities; this recommendation is discussed in greater detail below under **Suggested Next Steps**.

LESSONS LEARNED AND SUGGESTIONS FOR OTHERS

In keeping with the spirit of empowering communities to share and empower each other, recording the first-hand experience of these start-up CABs was seen as a priority for the one-year workshop. Overall, the six CABs had the following advice to offer to new CABs that are started in the future:

- **Be patient.** It may take some time for your CAB to learn how to work together productively, and you may lose or change some members in the first months. You will figure out the right balance eventually.
- **Be confident.** At first, you will not be sure what you are doing, or whether you have the experience or skills to improve anything. But, quickly, you will realize that you are experts on your own experiences, and no one can voice your problems like you can.
- **Address your own self-stigma.** You are now a representative for your community, and you will be able to help more people if you let go of your own negative feelings about yourself.
- **Partnerships are important.** Working not only with your clinical liaison onsite, but also with local politicians and mass media might be necessary to make sure you have political support. Invite these people to do site visits with your CAB if possible.
- **Involve family members** of OST clients and people who use drugs. Some clients may not be able to engage yet, but their families can be great allies and can reach other families who are not supportive of their relatives who are on or in need of OST.
- This is a **chance to lead by example.** Being a member of the CAB gives a voice to people whose lives have been changed by access to OST. You don't have to argue about whether OST is good or bad, you simply have to show people your example.

CONCLUSIONS

The introduction of the CAB model has been a significant success for USAID and the Quality Project implementers, leveraging limited financial investments through direct support and technical assistance, to create an opportunity for meaningful empowerment of communities affected by HIV. The results of both the six-month participatory assessment and the one-year regional workshop show that CABs have not only formed successfully – the ‘output’ stage – but have moved rapidly to producing outcomes that make a real difference for both CAB members themselves and the wider constituencies they serve.

Perhaps most interestingly, from the perspective of an implementer or donor organization, is the successful adaptation and differentiation of the CAB model in each setting, and the degree to which local ownership has developed over a short period of time. The diverging but largely successful results of six unique CABs in the course of a year provide encouragement that this model may be successfully expanded to other settings in Central Asia with confidence that, under most circumstances, the flexibility of the model and the dedication of the community will find the most appropriate iteration to achieve positive results.

SUGGESTED NEXT STEPS

CONTINUED SUPPORT OF EXISTING CABS

Given the impressive progress made by CABS in just a single year of implementation, it is highly recommended that the Quality Project continue to support existing CABS through the remainder of Year 4 and all of Year 5 of the project.

Depending on USAID's intentions for future funding cycles, it is also recommended that the Quality Project and/or USAID help the CABS to explore sustainability options. While this is a high-value, low-investment intervention that USAID may choose to continue supporting through future projects, there are also possibilities for alternative funding through either Global Fund grants or state budgets. If the latter (non-USAID) options are pursued, the following principles are recommended to guide the transition to these sources of funding:

- CABS are not designed to be stand-alone organizations. Just as a company's Board of Directors would not decide to 'form their own company,' a Community Advisory Board would not be well positioned to form its own organization and still retain its original purpose, which is as an advisory mechanism for an existing facility.
- With this in mind, the most logical way to support the continued existence or start-up of CABS is to provide funding directly to (or assure that there is state funding for) the institutions that are advised by the CABS. This funding can then be used for any incentive stipends for both CAB members and clinical liaisons, just as they may be provided to the CABS through the Quality Project now, as well as for small discretionary funds that allow CAB activities such as patient education sessions, regular community meetings, etc.
 - In some cases, CABS may also benefit from having a separate physical space within a facility to conduct their work, so an in-kind contribution may be made from the facility and small funds for renovation may be required. However, in any case that a space is set aside for CAB use, it is preferable if it is a multi-functional space that can serve the wider community (e.g. for community education sessions or for peer-counseling), and not solely members of the CAB.
- In the situation outlined above, providing CAB funding directly through the institution may create more motivation and ownership on the part of the institution to maintain a CAB. However, there may also be perverse incentives to misuse funds set aside for the CAB, either by inappropriately interfering in the selection process for the CAB members, by threatening to withhold funds for CABS who raise issues that are problematic, etc. For this reason, it is ideal if funding is provided with a high degree of oversight and accountability for at least the first few years. This may be, for instance, through USAID or the Global Fund providing funds directly to the institution with the condition that independent monitoring can still be conducted and that funding can be removed from the institution if the CAB is not judged to be functioning freely.

INTRODUCTION OF CABS TO NEW REGIONS

As many HIV and MAT service facilities in the region face similar challenges, and the initial pilot sites for CABS were chosen in part based on geographical convenience for project implementation, it is recommended that CABS be introduced more widely throughout each country to facilities in need. Specifically:

- Tajikistan has already expressed desire to expand the model to Vahdat and Khujand, where the Quality Project is active, during late Year 4 and throughout Year 5. Further

expansion to other HIV service sites and any new MAT sites is also recommended, either under the scope of the Quality Project or during future USAID HIV interventions.

- Kazakhstan has expressed interest in expanding to Uralsk and Karaganda HIV facilities during late Year 4 and throughout Year 5. Eventually, all HIV service sites should be presented with the option of forming CABs; the availability of government resources in Kazakhstan should permit funding of these bodies with very little problem, though technical assistance (and oversight of fund use for a period of time, as noted above) are likely to be needed.
- Additional opportunities may be available to form CABs at MAT sites in Kazakhstan as the country continues to expand its MAT program. CABs could be critical to assuring quality of programming at new site, which may be helpful in warding off politically-motivated anti-MAT campaigns that prey on lackluster treatment outcomes of poor quality programming.
- Kyrgyzstan should explore expanding both HIV and MAT CABs to Southern regions to start, keeping in mind that cultural norms in Kyrgyzstan differ significantly and, while it is still expected that the model will be useful in this region of the country, adaptation of the model may be necessary to fit circumstances. In particular, given the large number of HIV+ children in the region, a separate CAB or subcommittee of the CAB may need to be established for pediatric HIV services at some sites.

Ultimately, scale up should ideally see a CAB in every HIV treatment site (including primary care facilities that integrate HIV treatment services for a significant number of clients), and every MAT site throughout Kazakhstan, Kyrgyzstan and Tajikistan. Existing CABs should be able to provide a large portion of the technical expertise that would make this expansion possible, with some coordination and limited technical support from USAID (or other) project implementers.

If USAID does not envision direct financial support for the above-described CAB activities in the future, it may consider working with decision-making bodies (e.g. the CCM, Concept Note writing teams, etc) to assure that CABs are included as part of Concept Notes for future Global Fund funding in the country.

FORMING NATIONAL OR REGIONAL NETWORKS

Regardless of the future source of funding for additional CABs, it is recommended that, as CABs are replicated across each country, each country consider forming a national network of CABs. This does not mean that there needs to be a National CAB or that the CAB structure needs to be recreated on the national level in any way; rather, it means that all existing CABs should have mechanisms for sharing experience regularly – whether through remote communication (an online platform, conference calls) or through semi-annual or annual meetings. Likewise, the experience of the one-year workshop in May 2014 has show that there would be value to supporting periodic regional meetings for experience exchange, as well. Funding such connections may provide USAID with low-cost, high-impact results as the funding pool continues to shrink in the Central Asian region.

APPENDIX 1 – REGIONAL MAT CAB WORKSHOP AGENDA

Regional Workshop: Experience Exchange for MAT Client Community Advisory Boards

Description: Community Advisory Boards (CABs) have been operating in Kazakhstan, Kyrgyzstan and Tajikistan since Spring 2013. The MAT CABs, operating under Narcology Centers in Almaty, Bishkek and Dushanbe, have had a wide range of successes, and faced an array of challenges. This workshop offers an opportunity to discuss the progress and barriers so far, and exchange experiences in an empowering environment, supportive of constructive problem-solving and skills building.

Workshop Objectives:

1. Share experiences, including successes and challenges, experienced by Community Advisory Boards in the first year of implementation.
2. Build skills in critical areas identified as valuable by Community Advisory Boards: advocacy for MAT, assessment of services, and reaching special populations
3. Achieve consensus on key lessons learned and messages to be shared to help new community advisory boards start their work.
4. Plan next steps for Community Advisory Board work in each country.

Day 1: Introductions and Situational Review

Time	Item	Facilitator
9:00-10:15	Welcome, Introductions & Goal Setting	Danielle Parsons
10:15-10:45	<i>Coffee Break</i>	---
10:45-12:30	Review of CABs in Kazakhstan, Kyrgyzstan, Tajikistan, including Q&A	Aisuluu Bolotbaeva, CAB Representatives
12:30-13:30	<i>Lunch</i>	---
13:30-14:30	Reflections: Success & Barriers	Group Activity
14:30-15:00	Regional Update: other CAB work throughout the rest of the region (Ukraine, EATG)	A. Bolotbaeva
15:00-15:30	<i>Coffee Break</i>	---
15:30-17:00	Advocacy Workshop: skills & tools for effective community-led advocacy	A. Bolotbaeva
17:00-17:30	Daily Feedback & Wrap-up	D. Parsons

Day 2: Lessons Learned & Building Vision

Time	Item	Facilitator
9:00-9:30	Welcome, Review of Day 1	D. Parsons
9:30-10:30	Workshop: skills & tools for assessing client satisfaction with MAT services	A. Bolotbaeva
10:30-11:00	<i>Coffee Break</i>	
11:00-13:00	Site Visit: Bishkek Family Medicine Center #6 MAT Clinic	A. Bolotbaeva
13:00-14:00	<i>Lunch</i>	
14:00-15:30	Identity Building: Breaking down stigma & building a positive identity for better MAT outreach, enrollment and retention	D. Parsons
15:30-16:00	<i>Coffee Break</i>	
16:00-17:30	Spreading the Word: what needs to be shared with others about our experience? How do we share it?	D. Parsons, A. Bolotbaeva
17:30	Workshop Feedback & Wrap-up	D. Parsons

APPENDIX 2 – REGIONAL HIV CAB WORKSHOP AGENDA

Regional Workshop: Experience Exchange for PLHIV Community Advisory Boards

Description: Community Advisory Boards (CABs) have been operating in Kazakhstan, Kyrgyzstan and Tajikistan since Spring 2013. The PLHIV CABs, operating under AIDS Centers in Almaty, Bishkek and Dushanbe, have had a wide range of successes, and faced an array of challenges. This workshop offers an opportunity to discuss the progress and barriers so far, and exchange experiences in an empowering environment, supportive of constructive problem-solving and skills building.

Workshop Objectives:

1. Share experiences, including successes and challenges, experienced by Community Advisory Boards in the first year of implementation.
2. Build skills in critical areas identified as valuable by Community Advisory Boards: assessing quality of treatment & support services, effective advocacy, and how to reach more community members.
3. Achieve consensus on key lessons learned and messages to be shared to help new community advisory boards start their work.
4. Plan next steps for Community Advisory Board work in each country.

Day 1: Introductions and Situational Review

Time	Item	Facilitator
9:00-10:15	Welcome, Introductions & Goal Setting	Danielle Parsons
10:15-10:45	<i>Coffee Break</i>	---
10:45-12:30	Review of CABs in Kazakhstan, Kyrgyzstan, Tajikistan, including Q&A	Aisuluu Bolotbaeva, CAB Representatives
12:30-13:30	<i>Lunch</i>	---
13:30-14:30	Reflections: Success & Barriers	Group Activity
14:30-15:00	Regional Update: other CAB work throughout the rest of the region (Ukraine, EATG)	A. Bolotbaeva
15:00-15:30	<i>Coffee Break</i>	---
15:30-17:00	Advocacy Workshop: skills & tools for effective community-led advocacy	A. Bolotbaeva
17:00-17:30	Daily Feedback & Wrap-up	D. Parsons

Day 2: Lessons Learned & Environment Strengthening

Time	Item	Facilitator
9:00-9:30	Welcome, Review of Day 1	D. Parsons
9:30-10:30	Treatment Workshop: skills & tools for assessing client satisfaction with treatment	D. Parsons
10:30-11:00	<i>Coffee Break</i>	
11:00-12:30	Support Services Workshop: skills & tools for assessing client satisfaction with support services	A. Bolotbaeva
12:30-13:30	<i>Lunch</i>	
13:30-15:00	Linkages Workshop: creating a plan for reaching and helping more community members	D. Parsons, A. Bolotbaeva
15:00-15:30	<i>Coffee Break</i>	A. Bolotbaeva
15:30-16:30	Site Visit: Almaty City AIDS Center	D. Parsons, A. Bolotbaeva
16:30	Daily Feedback & Wrap-up	A. Bolotbaeva

Day 3: Skills Building & Vision

Time	Item	Facilitator
9:00-9:30	Welcome, Review of Day 2	A. Bolotbaeva
9:30-10:30	Identity Building: Breaking down stigma & building a positive identity	D. Parsons
10:30-11:00	<i>Coffee Break</i>	
11:00-12:30	Identity Building, continued	D. Parsons
12:30-13:30	<i>Lunch</i>	
13:30-15:00	Spreading the Word: what needs to be shared with others about our experience? How do we share it? And with whom?	A. Bolotbaeva
15:00-15:30	<i>Coffee Break</i>	
15:30-17:00	Next steps	D. Parsons

17:00

Workshop Feedback & Wrap-up

D. Parsons