Rapid assessment of needs for services for children, affected by HIV/AIDS in the South Caucasus

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ACKNOWLEDGMENTS

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World Vision is a Christian humanitarian organization dedicated to working with children, families, and their communities worldwide to reach their full potential by tackling the causes of poverty and injustice. Middle East and Eastern Europe Regional Office of World Vision, national offices of World Vision Azerbaijan, Georgia and Armenia took part in rapid evaluation of needs in provision of services to children affected by HIV / AIDS in East Europe and Central Asia Union of PLWH - association of PLWH organizations, is an inspiring resource in Eastern Europe and Central Asia for PLHIV communities to promote them as leaders, professionals, equal and responsible partners in overcoming HIV/AIDS epidemic in the world. "Public Organization to Fight AIDS", Azerbaijan, the «Real World, Real People,» Armenia and NGO "Real People, Real Vision", Georgia also participated in rapid evaluation[1] of needs in provision of services to children affected by HIV/AIDS in the South Caucasus.

1 Rapid evaluation is an approach that uses intensive, team-based fieldwork, multi-method data collection, simultaneous data analysis and community participation.

LIST OF ABBREVIATIONS

ARV	Antiretroviral therapy
CF	Charitable Fund
HIV	Human Immune Deficiency Virus
ECUO	East Europe and Central Asia Union of PLWH
UNGASS	United Nations General Assembly
CLH	Children Living with HIV
CAH	Children affected by HIV
PLWH	People Living with HIV
MoH	Ministry of Health
NGO	Non-government organization
MoE	Ministry of Education
AIDS	Aquired Immune Defficiency Syndrome
SC	South Caucasus

DEFINITIONS

Children living with HIV: children diagnosed with HIV infection.

Children affected by HIV: children who have one or both parents have HIV or died of diseases associated with HIV infection.

Assessment or rapid assessment: «Rapid assessment of needs for provision of services to children affected by HIV/AIDS in the South Caucasus»

Social environment: family members living together, relatives, neighbors, friends and colleagues of the parents, teachers and classmates.

EXECUTIVE SUMMARY

ICO «East Europe and Central Asia Union of People Living with HIV» held «Rapid assessment of the needs in the provision of services to children affected by HIV/AIDS in the South Caucasus», with financial and technical support from World Vision, to identify the most important needs in the provision of services and prepare an action plan to address these needs. The main objective of a rapid assessment is to identify the most important needs of children affected by HIV/AIDS for their full growth and development as well as obstacles to the realization of children's rights in relation to HIV status of children or their parents.

Rapid evaluation considered such children's rights as the right to health and education, the right to upbringing in the family and the right to special care and assistance[2].

As a result of rapid assessment areas of a child's life and rights most vulnerable to HIV/AIDS were identified. Rights violations were primarily in health care and education. Parents and guardians of CLH and CAH involved in the rapid assessment mentioned cases of discrimination against children in the context of HIV status in medical institutions. In educational institutions, compared with medical, discrimination occurred less frequently, but it is explained by rare cases of the status disclose of the child or parent in schools or day care.

Access to antiretroviral therapy for children is adequate to the needs and all children in need of treatment receive it. The serious problem in the ARV treatment for children is the difficulty of adherence for various reasons, the most common of which is the reluctance of the child to take medication.

A third of children whose parents or guardians participated in rapid assessment are teenagers and most of them do not know their HIV-positive status or the status of the parents. According to the interviewed parents/guardians professional help in disclosing the status to a child is an important service for them and the need for it will increase as children get older.

Most of the respondents' families raising CLH and CAH noted difficult financial situation, which prevents provision of children with adequate food, clothing, school supplies, medical care and medicines. At the same time not all familisies use the social package provided by the state to the full extent. Often, this is due to the lack of information about what they are entitled to as CLH and the fear of breach of confidentiality. The difficult financial situation is one of the reasons why parents who do not live in regional centers are not able to bring the child to the AIDS center for the next check up or delivery of ARVs.

According to the rapid assessment the most favorable is the situation with the social environment of CLH and CAH. Of the 78 parents and guardians who participated in the rapid assessment only two noted the negative attitude of the relatives to the child because of the HIV status.

2 The Convention on the Rights of the Child, adopted by General Assembly resolution 44/25 of the General Assembly of November 20, 1989

As a result of the rapid assessment the following main recommendations were made:

- To develop and implement programmes on disclosure of HIV-positive status to a child, adherence to ARV therapy, overcoming stigma and protection of rights of families with children affected by HIV/AIDS;
- To conduct analysis of low number of children that receive social benefits in Armenia and develop steps on improvement of access to social benefits for Children affected by HIV/AIDS based on the identified needs. To consider the possibility of inclusion at legislative level of Children affected by HIV/AIDS into social group that requires state support in Georgia;
- To include rights advocacy of children affected by HIV/AIDS as a priority task into the work activity of NGOs.

BACKGROUND

The number of children under fifteen living with HIV in Eastern Europe and Central Asia (EE&CA) is still on rise. About one fifth more of children were newly infected with HIV in 2010 than in 2001: 2,200 [1,700–2,900] versus 1,800 [1,500–2,300]. The total estimated number of children living with HIV rose five-fold from 3,400 [2,800–4,700] to 17,000 [14,000–23,000] in the same period, and the number of children dying from AIDS-related causes more than doubled from fewer than 500 [<500 – <1000] to almost 1,200 [<1,000 – 1,800][3].

But these data mostly reflects situation in Russia & Ukraine, and there is no reliable data on the quantity of children affected by HIV/AIDS and quality of their lives in South Caucasus region. Moreover, most, if not all, existing HIV support programs in these countries do not take into account special needs of these children. As HIV-affected children grow into adulthood, it becomes necessary for them to transfer to adult care settings and take responsibility for their own health and disease management. Usually, financial support of such a support programs is not a priority for donors and governments as they are simple unaware of this problem; plus, children are not a critical group in the context of HIV/AIDS epidemics and implementation of children and adolescents-focused programs for teenagers are not always economically efficient. Hence, HIV-affected children usually stay alone with their problems, without opportunity to convene together and participate in the development of the national PLWH Networks' activities.

There are 142[4] registered cases of HIV infection in children in the South Caucasus as of September 2012. The relatively small number of children with HIV infection may be explained by a low prevalence of HIV in the SC countries, as well as by high coverage of pregnant women by HIV testing and access to prevention of HIV transmission from mother to child. For example: in the period from 2005 to June 2012 in Armenia, 67 children were born by HIV infected women, of those only one was diagnosed with HIV infection. In Georgia, from 2000 to September 2012, 174 HIV-infected women delivered babies, only a few children had a transmission of HIV from mother.

Due to the small number of children living with HIV, their problems do not take up any space on the agenda of reloevant stakeholders. But at the same time, children affected by HIV/AIDS not accounted for in the South Caucasus, face the same psychosocial problems as HIV-positive children. Therefore, this category of children must be taken into account when developing a plan of priority actions.

3 WHO/UNAIDS/UNICEF (2011) ,'Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access 2011'

4 As of August 31, 2012 24 cases of HIV infection in children were registered in Armenia. In Georgia - 77 cases of pediatric HIV infection were registered as of September 1, 2012. In Azerbaijan - 41 cases of HIV infection in children as of January 1, 2012.

REVIEW

This rapid assessment was initiated due to the urgent need to study the needs of CLH and CAH in the South Caucasus, determine the availability of health and social services, appropriate planning measures to improve the quality of life of children.

The HIV epidemic affects not only the individuals who have the infection, but also their families, and entire communities. For a long time programs for provision of treatment, care and support for HIV infection are based on a multi-component basis, and try to cover a wide range of needs of people living with HIV and their families. However, the problems of children living with HIV and children affected by HIV, remain «in the shadows» and of low priority.

In their activities the member organizations of ECUO came to understanding that there is an urgent need for a thorough study of the problems faced by the CLH and CAH and their families in child-rearing.

For the assessment, we took some domains of children's rights, as specified in the Declaration of Rights of the Child, adopted by the UN General Assembly resolution 1386 of November 20, 1959. The selection of these domains was made on the principle of «whether HIV would prevent the implementation of any rights.» In the end, the following domains of children's rights were selected: health, education, social security, family and social environment. Other aspects were not included for two main reasons:

1. Difficulty in determining the link between the violation of specific rights and HIV and
2. Not acceptable in the cultural context of the countries of the South Caucasus.

GOALS AND MAIN RESEARCH QUESTIONS

Conducting rapid assessment to analize the current situation of children affected by HIV/AIDS in Armenia, Azerbaijan and Georgia in order to identify the most important needs in the provision of services and prepare an action plan to address these needs.

Key questions posed to the evaluation is how HIV affects the quality of life of children, what aspects of quality of life are suffering the most, wether HIV influences the ability of family to raise a child?

SIGNIFICANCE

This rapid assessment is important for organizations whose mission is to support people living with HIV. Results of rapid assessment can be used by them for adequate planning of measures aimed at mitigating the impact of HIV on children. The need for such an activity is already there and will eventually increase.

The results of a rapid assessment will be disseminated as widely as possible among stakeholders from different sectors: the national civil society organizations, government and international organizations.

We hope that the results of this evaluation will be used not only by organizations working in the field of HIV/AIDS, but also by other organizations working with children and protecting their rights.

Assessment results will be presented at the regional and national workshops for stakeholders, distributed via Internet mailing lists, posted free access online.

ASSESSMENT METHODOLOGY

39 in-depth interviews with key informed persons (31 women and 8 men) were conducted **within the rapid assessment:**

- 14 representatives of international organizations (14 women);
- 8 representatives of state organizations (3 women and 5 men);
- 5 representatives of national NGOs (4 women and 1 man);
- 9 representatives of educational institutions (7 women and 2 men);
- 3 - physicians (pediatricians of AIDS Centers) (3 women).

Also a survey of 78 parents and guardians of children living with and affected by HIV/AIDS (41 women and 37 men) was conducted - 26 respondents in each country. Interviewed people raise 43 children affected by HIV/AIDS, and 35 children living with HIV/AIDS.

To obtain a complete analysis of the needs of children living with and affected by HIV/AIDS, rapid assessment was based on the views of the two sides. Therefore, in the report every problem is covered with at least two points of view, that is, from the perspective of parents and guardians of children living with and affected by HIV/AIDS, and the positions of the stakeholders involved in the response to HIV/AIDS and lowering its impact.

The following methods were used for rapid assessment:

1. **Review of publicly available reports and studies:** aimed to meet the needs of children living with and affected by HIV/AIDS.
2. **In-depth interviews with key stakeholders:** in-depth interviews were conducted with representatives of the national, international and non-government organizations. The questionnaire consisted of three main components:
   a. The main problems faced by children living with and affected by HIV/AIDS;
   b. What is being done by an organization to address the problems faced by children living with and affected by HIV/AIDS;
   c. What can organizations do to address the problems faced by children living with and affected by HIV/AIDS.

During the field work 3 pilot interviews were conducted in each country. The purpose of the pilot interviews was to determine the acceptability of the interview questionnaire. After receiving positive feedback on the content and structure of the questionnaire majority of the field work was carried out.

Interviews were also conducted with representatives of educational and medical institutions.

Three doctors from the medical institutions were interviewed (pediatricians of AIDS Centers). The purpose of these interviews was to identify the main problems in the treatment of HIV infection and the need for additional assistance to maintain the adherence to antiretroviral therapy in children living with HIV/AIDS.

Nine representatives of educational institutions were interviewed. The main purpose of these interviews was to assess the readiness of schools and pre-schools to accept children living with HIV/AIDS, and to maintain the confidentiality of their status to prevent stigma and discrimination.

3. **Interviewing the parents and guardians of children living with and affected by HIV/AIDS:** Developed questionnaire for parents and carers has been tested in focus groups with staff of Public organizaiton “Real World, Real People”, Armenia, which provides services to people living with HIV, including children.

Based on the results of the panel discussion the core set of questions that cover the most common problems of children living with and affected by HIV/AIDS were identified:

a. Medical services;

b. Secondary and pre-school education;

c. Social Services;

d. The social environment of children.

Also 5 pilot interviews were conducted during the field work in each country. The purpose of the pilot survey was to determine the acceptability of the questionnaires. After receiving positive feedback on the content and structure of the questionnaire most of the field work was carried out.

LIMITATIONS

Rapid assessment had limitations for appropriate sampling of parents/guardians. Each country has estimated data of officially registered HIV infected children but the number of children affected by HIV has never been calculated. We made assumption based on rough estimate of the total number of children affected by HIV in Armenia (300)

And in Azerbaijan and Georgia this number reaches 700. . Within framework of this rapid assessment we selected 26 respondents in each country – parent/guardians of 43 children affected by HIV/AIDS and 35 children living with HIV.

The other limitation is that we were not able to conduct in-depth interviews with parents and guardians before development of the questionnaire. Since this was a regional assessment and interviews should have been conducted in 3 different languages because parents spoke mostly local languages and due to limited recources, we chose semi-structured questionnaire as a tool for questioning parents and guardians, after that all results of the interviews were translated into Russian or English.

Due to limited resources, it was not possible to provide an adequate geographical coverage. In Armenia it was impossible to ensure the participation of 13 parents and guardians of children living with HIV in the assessment. As a result, in Armenia only 7 parents of CLH took part in the assessment, and the remaining 19 were parents of CAH, although the planned ratio was 13/13. Since the analysis of the answers to most of the questions in the questionnaire was made for all the countries of the South Caucasus, we assume that this limitation should not have any impact on the overall picture of the situation concerning CLH and CAH.

This assessment doesn't contain information given by CLH and CAH due to lack of such children, who know about their HIV-positive status of status of their parent or guardian in South Caucasus. It's obvious that in future when services of HIV-status disclosure will be implemented, it'd be necessary to include adolescents as direct respondents of data gathering.

MAIN FINDINGS

Overview of Publicly Available Reports and Studies

In examining the documents, previous studies and assessments aimed at meeting the needs of children living with and affected by HIV/AIDS, the overall picture was found for all the countries of the South Caucasus. Unfortunately, in the South Caucasus there has not been previously conducted any studies or assessments of this kind. In the reviewed documents issues relating to social problems of children affected by HIV/AIDS are not a priority.

All countries of South Caucasus see provision of ARV therapy for children and prevention of mother to child transmission of HIV as priorities.

The reason for poor attention to the issues of children affected by HIV/AIDS is a small number of these children the South Caucasus, as well as the absence of any research on this topic.

List of reviewed documents

Armenia

1. Rolling Continuation Chanel Programme proposal "Support to the National Programme on the Response to HIV Epidemic in the Republic of Armenia".
2. The law of the Republic of Armenia on "Prevention of the disease caused by human immunodeficiency virus", adopted on 03.02.1997
3. Amendments on the law of the Republic of Armenia on "Prevention of the disease caused by human immunodeficiency virus", adopted on 03.02.1997
4. National Strategic Plan on HIV&AIDS, the Republic of Armenia, 2012-2016
5. UNGASS Country Progress Report 2008-2009

Azerbaijan

1. Action Program on prevention and control of HIV/AIDS in the Republic of Azerbaijan for 2009 – 2013 years.
2. The law of the Republic of Azerbaijan "On Control of the Disease Caused by the Human Immunodeficiency Virus", adopted on 11.05.2009
3. Decision No. 62 of Cabinet of Ministers of the Azerbaijan Republic on Approval of certain legal acts associated with application of the Law of the Azerbaijan Republic "On control of Disease Caused by the Human Immunodeficiency Virus".
4. UNGASS Country Progress Report 2008-2009

Georgia

1. UNGASS Country Progress Report 2008-2009.
2. Georgia National HIV/AIDS Strategic Plan for 2011-2016.

Demographic profile of the respondents

1.1. Sex of the respondents

Table 1: Sex of the respondents

	Armenia	Azerbaijan	Georgia
Male	7	16	14
Female	19	10	12

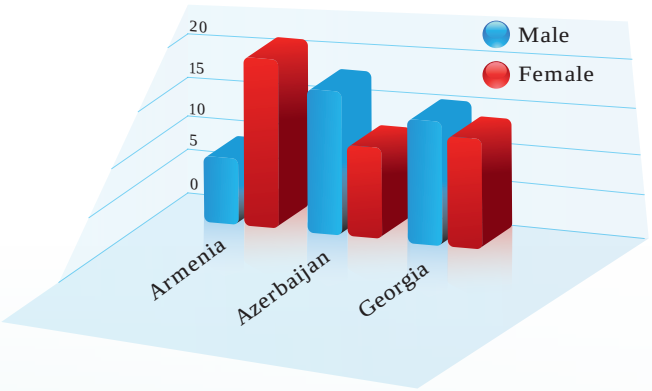

Chart 1

1.2. HIV status of children whose parents or guardians participated in the assessment.

The survey was conducted among the parents and guardians of children both living with HIV and affected by HIV. The chart below shows the correlation between the parents of CLH and CAH:

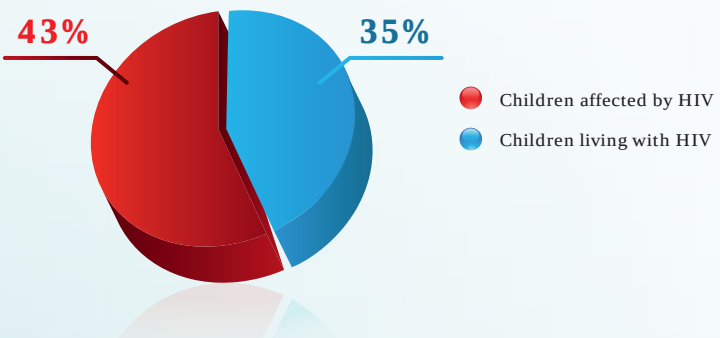

Chart 2: Correlation of parents of CLH and CAH

1.3. Respondent's relationship to the child.

Of all respondents, only two were guardians of children.

1.4. The average number of children per family

The average number of children in families who participated in the survey by country is: in Armenia - 1.8, in Azerbaijan - 1.38, in Georgia - 1.23. Overall, for the three countries of the South Caucasus, the figure was 1.47 children per family.

1.5. Type of settlement in which respondents live

The majority of respondents (51 persons or 65%) live in urban areas with a population of over 300,000 inhabitants. 23 respondents live in towns with lower population and only 4 respondents were from rural areas.

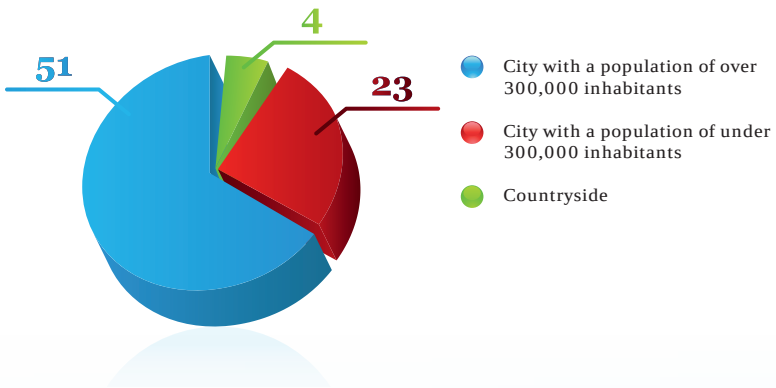

Chart 3: Type of settlement, with a population of respondents

1.6. The average monthly income per family

According to the responses to the question of the average monthly income per family, no family in the South Caucasus has the income exceeding $ 600 per month. Only 5 respondents indicated that their family income per month is in the range of 400 to 600 U.S. dollars. The general picture of the income of families involved in the rapid assessment is shown in Chart 4[5]

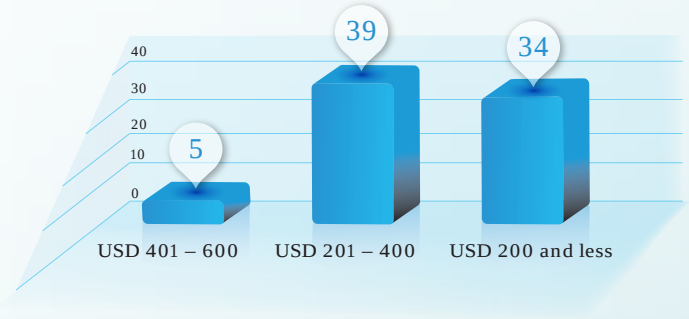

Chart 4: Average monthly income per family in USD

5 Minimum consumer basket in Azerbaijan equals 216 dollars (www.abc.az/eng/news/64696.html), and in Armenia U.S. $ 130 (news.am/eng/news/115442.html)

Income figures per family for each country in relation to minimal living subsistance are reflected in Chart 5.

Chart 5: Average monthly income per family in USD for each country

	Armenia	Azerbaijan	Georgia
Subsistance minimum (USD)	125[6]	138[7]	79.5[8]
TOTAL number of respondents	26	26	26
INCOME, USD:			
less than 200	23	7	4
201-400	3	16	20
401-600	0	3	2

Interview results with key informants

During the interview low level of material security proved to be the most important problem for families with children affected by HIV/AIDS. For children, who lost one of their parents this problem is especially critical: "Material problems occur because parents usually don't work or have temporary or non-demanding jobs. At the same time, a child should be provided with good nutrition and organised therapeutic resort on the regular basis".

1.7. Children and HIV status

From 35 families that participated in the questionnaire survey and that raise an HIV-infected child, only one family had two children, who were both HIV-infected.

1.8. Age of children

An average age of children with HIV-infection was 6 years old. Mid-point age range of children living with HIV coincides with an average age and totals 6. The eldest child was 13 years old and the youngest was less than a year old. The average age of all children is 7.85, mid-point age range totals 8. The eldest child was 18 years old. The number of children over 10[9] years in families, whose members took part in the survey amounts to 37 and this makes up a third (32%) from the total number of all children.

6 Average cost of the minimal consumer goods basker per capita for the third quarter 2012 is used: http://www.armstat.am/file/article/sv_09_12a_6300.pdf page 187

7 Average cost of the minimal consumer goods basket per 1 person for 2012 is used: http://www.president.az/articles/3814

8 Average cost of the minimal consumer goods basket per 1 person for September 2012: http://geostat.ge/cms/site_images/_files/english/households/Subsistence-minimum.xls

9 According the resource guide for World bank operations staff and government counterparts «ADOLESCENT HEALTH AND DEVELOPMENT» adolescent age begins from 10 years old http://siteresources.worldbank.org/HEALTHNUTRITIONANDPOPULATION/Resources/281627-1095698140167/Rosen-AHDFinal.pdf

Children and knowledge of HIV status

2.1. Child's awareness about their status or status of their parent

According to results of the assessment, the abslute majority of children are not aware neither of their HIV status nor their parent(s). Among children living with HIV, only one five-year old boy knew about his HIV-positive status. Since the question of informing a child about their status or the status of their parent(s) is related to the age of a child, data about child's awareness of the parents HIV status are given in two age groups: under 10 years and older. Due to small number of children, who know about HIV-positive status of their parent(s) and due to large response dispercsion [10]to the question about psychological impact of this news, analysis of this question is of no value.

Interview results with key inormants

Among 39 key informants, who participated in the rapid assessment, two representatives of PLWH organisations reported the problem of telling a child about their HIV-positive status or the status of their parent(s). At the same time, two representatives of AIDS Centres stated the importance of provision of psychological assistance to a child, which is related to growing up, including telling a child about their HIV status: "We need professional personnel both in NGOs and non-government organisations to provide quality assistance to children".

2.2. Reasons due to which parents didn't tell their child about his/her and their own HIV-positive status.

Table 2: Reasons for not telling a child about HIV status

	Own status	Parent's status
Young age	26	55
Confidentiality concerns	4	5
Don't know how to tell	3	6
Don't want to hurt child	0	1
Other	1	1
No answer	1	1

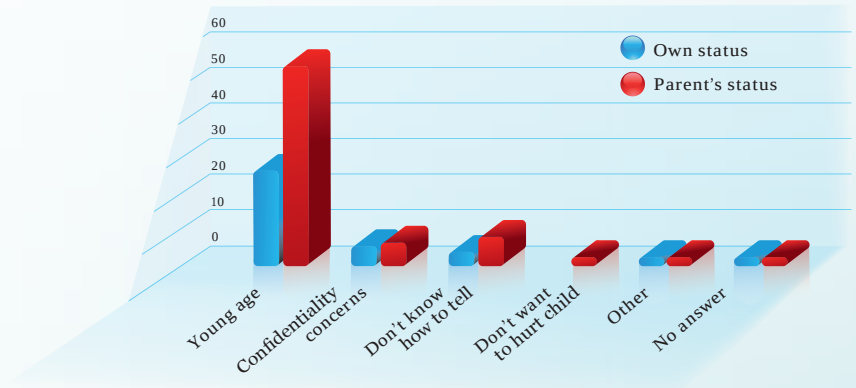

Chart 6

10 The highest score is 10, the lowest score is 1, average score is 4.88, median is 5

2.3. Willingness of parent(s) to tell their child about his/her and their own HIV-positive status.

Number of parents of HIV-positive children, whose children do not know about their status and who want to tell their children about it, increasingly outnumbers those parents that are not going to inform their children about their HIV-infection. Rate ratios are 28:5. Two parents didn't answer the question. Similar situation is with the question of informing a child about HIV status of their parent(s).

Rate ratios between parents, who want to inform a child about their status and parents, who don't want to do this is 50:19. Eight parents and one guardian did not answer the question.

2.4. Need of assistance for parents while informing child about his/her and their HIV-positive status.

Parents that participated in the rapid assessment were offered to evaluate the need in assistance of qualified professional (psychologist, peer consultant, doctor) to tell their child about his/her HIV status or status of parent(s). Surveyed were offered to evaluate the need for such assistance. The following results were received: average evaluation of importance for assistance of telling a child his/her status amounts to 2.41.

Similar results are with the question of informing a child about their parent's HIV-positive status. In this case, the average assessment amounts to 2.52. It is important to note that only one parent reported that they "don't need any assistance at all" to tell their child about his/her status. Also, from 50 respondents, who stated that they want to inform child about their HIV status, five said that they "don't need it at all".

Question A.3.2. *Please indicate whether you and your child need assistance of qualified professional (psychologist, peer consultant, doctor) to tell your child about their HIV status?*

I need it very much	5
It's necessary for me	11
It would be helpful	10
I likely don't need it	2
I don't need it at all	1

From 29 respondents, who answered the question about the need in assistance to inform their child about his/her status over half (16 people) answered that they need it, other 10 people said it would have been useful for them. Only 3 think that they don't need such assistance. Therefore, 90% of parents, whose children are living with HIV are ready to accept such assistane.

Regarding assistance in disclosing the status of parents, we received similar rate ratios. From 50 answers to this question 27 (over half) stated that they need such assistance, another 14 would accept it as useful for them. Every fifth (9 people) believe that they don't need it, while every tenth (5 people) said that they "don't need it at all". I.e. 80% of parents are ready to receive assistance to disclose their status to a child.

Question A.6.2. *Please indicate whether you and your child need assistance of qualified professional (psychologist, peer consultant, doctor) to tell your child about your HIV status?*

I need it very much	11
It's necessary for me	16
It would be helpful	14
I likely don't need it	4
I don't need it at all	5

Access of child to medical institutions, including ARV therapy

In this module we tried to assess how HIV diagnosis in a child or their parent can be perceived as an obstacle to receive necessary medical services by a child.

3.1. Cases of unadequate treatment (discrimination) towards a child because their HIV status and status of parents.

From 35 parents 12 stated that their child experienced discrimination in medical institutions because of HIV infection. Meanwhile, from 43 parents, whose children are not infected, 3 pointed out that their child was treated unfairly in medical institutions because of their parents' HIV status. Frequency of discrimination cases did not have any correlation with the place of residency of respondents. Disciminatory cases were expressed by scornful or offensive treatment. There were 4 cases of refusal in medical services provision.

Table 3: Types of discrimination

Type of violation	# of responses
Refusal to provide medical services	4
Scornful or insulting attitude	11
Breach of confidentiality	5
Demand of additional payment	2
Other	2

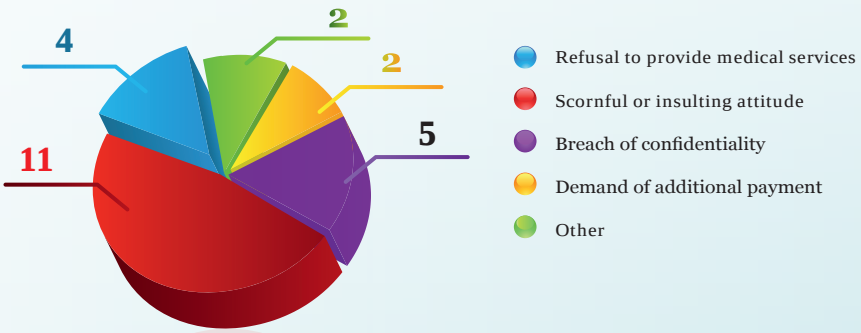

Chart 7

Total number of answers to the question about types of discrimination exceeds the number of respondents, whose children experienced unfair treatment in medical institutions, because respondents could choose several answers.

Substantially better is situation with access of children to ARV therapy. Out of 35 children, 24 receive ARV therapy. Out of 11 children, who don't receive therapy, 10 don't have indication for therapy initiation and one child shoud start therapy soon. Half of parents, whose children receive ARV therapy, said that they experienced difficulties with adherence to ARV treatment regimen. According to 9 respondents the most frequent reason of this difficulty is unwillingness of a child to take medicines. Table below shows all reasons for difficulties with regimen adherence that respondents stated. Often social environment can complicate regimen adherence because it's uncomfortable to give medicines with other people around – in school, child care centre, in family or in the street. In families with other children apart from HIV-positive child, the latter starts asking question why their sibling(s) don't take medicines. Parents say that this is very difficult question for them and it hinders adherence to ARV treatment regimen.

Table 4: Reasons of non-adherence tp ART regimen

Reason of non-adherence	# of responses
Pharmaceutical form is not convenient to take	2
Child refuses to take medicines	9
Social circle prevents	4
Other	2

Total number of answers is bigger than the number of respondents, who stated difficulties with therapy adherence because respondents could choose several answers.

Results of interview with qualified professionals, who provide ARV treatment to children.

Questionnaires results of parents and guardians of CLH coincide with information given by doctors that provide ARV treatment to children: there are cases of ARV treatment regimen violation. However, according to the survey the main reasons of ARV treatment regimen violations differ. Doctors from all countries of South Caucasus believe that regimen violations are caused by unresponsible attitude of parents towards ARV treatment adherence and financial expenses on visits to AIDS centres to receive medicines. "There was a case when treatment of a child was interrupted because their mother denied that her child had HIV infection".

After doctors find out about ARV treatment regimen violations, they carry out explanatory work with parents, involve social workers and peer consultants from public organisations. In cases when parents have financial difficulties because of commute to AIDS centres, mobile groups organise treatment delivery.

Social support for children and their families

4.1. Access to social benefits envisioned for children living with HIV

In tables below you can see the number of families that receive disability pension and other types of social assistance.

Table 5: Access of CLH to social benefits

	Armenia	Azerbaijan	Georgia
Receive any social support	1	13	0
Do not receive social support	6	1	13

Table 6: Benefits available to CLH

Disability pension due to HIV	13
Other type of social assistance	2

As you can see from Table 6, the majority of respondents selected disability pensions out of all benefits available to CLH and their parents. It's noteworthy that Azerbaijan is the only country where almost all CLH receive disability pensions. Only one child receives it in Armenia. In Georgia there is no legal framework for provision of social benefits to children living with HIV, whereas Armenia[11] and Azernaijan[12] have such benefits envisioned for disabled children under 16 years old.

In Table 7 below you can find reasons for not receiving social benefits that were indicated by respondents:

Table 7: Reasons of not receiving social benefits

I don't know the rights I'm entitled to	5
It's difficult to collect all documents necessary to receive assistance	1
I'm afraid of confidentiality breach	5
Other	2
No answer	9

Insufficient level of knowledge about social benefits of parents and guardians is confirmed by the fact that 9 respondents didn't answer this question.

4.2. Support in raising a child from different organisations

Table 8 below shows answers of respondents to the question: «Do you receive assistance or support on issues relevant to care and child's upbringing from below mentioned persons or organizations?". Respondent had an opportunity to assess the support they receive from their immediate circle (relatives, friends), government and non-government organisations.

11 The law of the Republic of Armenia on "Prevention of the disease caused by human immunodeficiency virus", Article 15.

12 The law of the Republic of Azerbaijan on "Control of the disease caused by human immunodeficiency virus", Article 27.

Table 8: Sources of family support

PLEASE CHECK ONE ANSWER IN EACH LINE	Yes, to full extent	More likely	Less likely	Don't receive
1. Relatives	14	11	10	43
2.Friends	2	2	3	71
3. State guardianship agencies	0	4	18	56
4. Public organizations and charitable funds	12	19	18	29

As you can see from the table, most respondents chose public organisations and charitable funds as organisations from which they received or still receive childcare services or help in their upringing.

We used the following formula to determine the level of help received:

$$M = N1*1+N2*0,5+N3*0,25,$$

where M is the overall score, N1 is the number of statements in the category «Yes, to the full extent», N2 is the number of statements in the category «More likely» and N3 is the number of statements in the category «Less likely». As a result of using this formula the list of people and organisations that provide assistance to CLH and CAH looks like this:

I Public organisations with 26 points
II Relatives with 22 points
III State guardianship agencies with 6.5 points
IV Frinds with 3.75 points

4.3. Service demand for childcare and upringing for children living with and affected by HIV/AIDS

Table 9 below shows the analysis of different types of sought-after support by parents of CLH and CAH, who participated in the assessment. These figures reflect the number of mentionings of particular type of support since respondents had an opportunity to choose several types of assistance for each organization or person. Different types of assistance chosen by respondents were clustered together the following way: such assistance services as food, clothes, living conditions, heating and financial aid were joined into one category entitled "welfare assistance". The category "medical assistance" includes medicines. "Psychosocial assistance" was called "moral support" by respondents and it was included into relevant category.

As you can see from Table 9 financial and psychological assistance is the most sought-after.

Table 9: The most sought-after types of assistance

	Material	Employment	Education	Medical	Legal	Psychosocial	Care for child	Any kind of support
Relatives	8	1	0	0	0	28	3	0
Friends	2	1	0	0	0	15	1	0
State	45	4	11	9	1	0	1	2
NGOs	23	2	2	2	5	28	1	2

Chart 8 shows priorities in types of services, which are important for respondents, who participated in the assessment. If you look at requests of respondents, it becomes obvious that they expect support from government and NGOs. They expect material help, as well as help with education and treatment of children mostly from the government, whereas from NGOs they expect psychosocial and financial assistance.

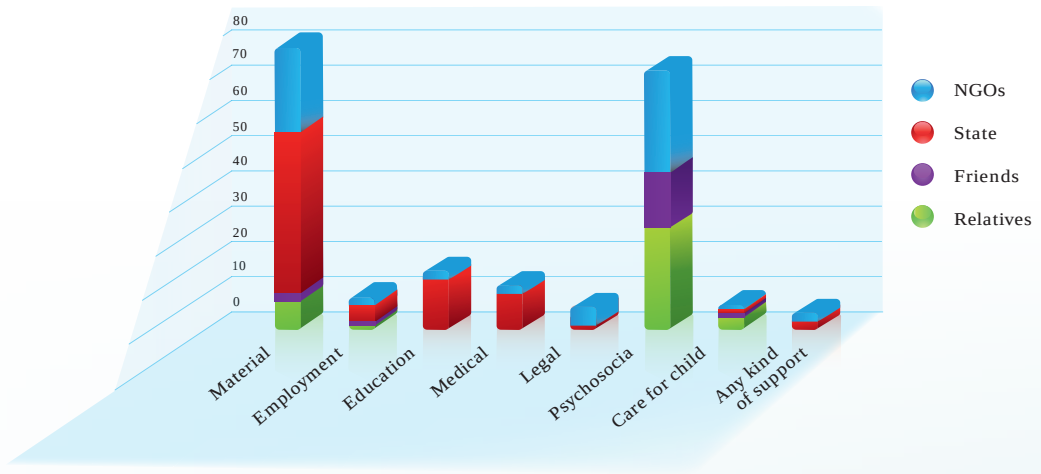

Chart 8: Priorities in types of assistance

Apart from the question about types of assistance required by parents from persons and organisations, there was question where respondents were offered to choose from the list three the most important services for their child. Table 10 below shows results of questionnaires on these issues. Results below are given both - per each country and generalized.

Table 10: priorities in types of assistance

	All countries			Armenia			Azerbaijan			Georgia		
	1st	2nd	3rd	1st	2nd	3rd	1st	2nd	3rd	1st	2nd	3rd
1. Food support	42	1	5	9	0	5	25	0	0	8	1	0
2. School education	15	34	3	2	3	1	1	24	1	12	7	1
3. Sport activities	0	7	5	0	7	2	0	0	1	0	0	2
4. Clothes	2	4	9	2	2	2	0	1	0	0	1	7
5. Art-hobby group	2	2	2	2	2	2	0	0	0	0	0	0
6. Participation in support groups	2	2	11	1	0	1	0	0	8	1	2	2
7. Summer vacation	5	9	16	3	4	5	0	0	8	2	5	3
8. Out-of-school education	7	12	17	5	5	6	0	1	5	2	6	6
9. Psychotherapeutic consultations	1	4	5	1	2	2	0	0	2	0	2	1
10. Consultations on status disclosure to a child	0	0	2	0	0	0	0	0	1	0	0	1
11. Other, please specify	2	3	3	1	1	0	0	0	0	1	2	3

For better understanding of these priorities, we used formula that enabled us to assess the importance of each service for respodents participating in the assessment. This formula looks like this:

$$M = N1*1+N2*0,75+N3*0,5$$

where M is the overall score of service, N1 is the number of mentioning as the top-priority service, N2 is the number of mentioning as second-priority service and N3 is the number of mentioning as third-priority service.

Total number of priorities for all countries are shown in Chart 9:

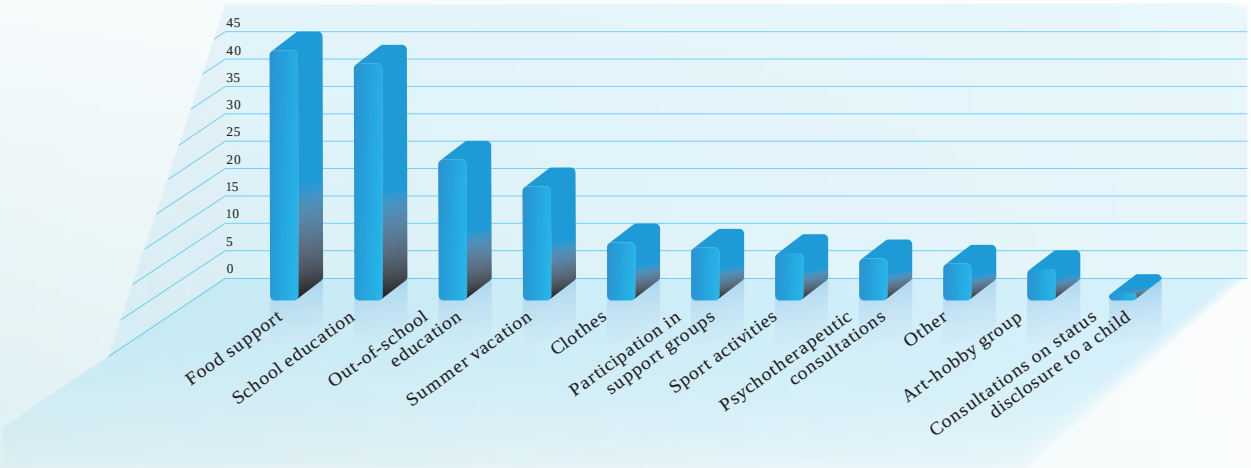

Chart 9

Access to school and pre-school education

5.1. Children, who do not visit educational institutions and reasons for non-visit.

Out of 78 respondents participating in the rapid assessment, 26 children do not visit educational institutions (Table 11).

Table 11: Visit of educational institutions

Visit school or kindergarten	52
Do not visit school or kindergarten	26

Chart 10 shows reasons children do not visit school or pre-school institutions. As it turned out during the assessment, there was only one case of admission refusal to educational institution because of HIV-positive status of a child. Respondents, who chose the answer "Other" explained that they want to raise their children themselves instead of letting their children to pre-school institutions, and they also mentioned expenses related to kindergartens. Children of five respondents do not visit pre-school institutions because of perceived or anticipated discrimination.

Results of interview with key informants

28 key informants stated that stigma and discrimination in general and in educational institutions in particular is viewed as the most critical problem for CLH or CAH. «First of all, stigma is caused by ignorance of HIV transmission and basic prevention methods».

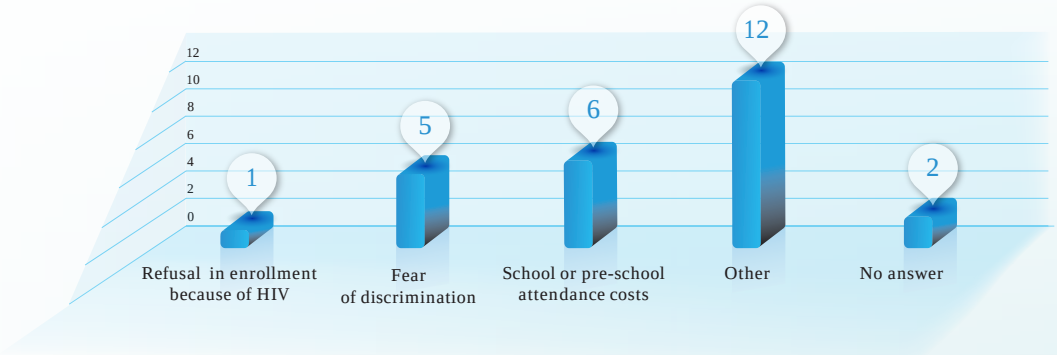

Chart 10: Reasons why children do not visit school or pre-school institutions

5.2. Questions of confidentiality and discrimination of children living with and affected by HIV/AIDS in educational institutions.

25 respondents did not answer the question whether educational institution knew about their own HIV status or status of their child, positive answer was received from 4 respondents. None of the respondents informed pre-school institutions or school about HIV status of their child. Source of information (when educational institution found out about child's status) was specified only by one parent: confidentiality was breached by a relative. In all cases, treatment of a child was very

negative or there was some degree of discrimination from administration, teachers and parents of other children and one child was eventually forced to leave their educational institution. In most cases, educational institutions are not aware of HIV status of their pupils therefore it's impossible to assess their real attitude towards HIV-positive children or their parents.

To identify the level of perceived or anticipated discrimination, participants were asked to answer the question about readiness of educational institution to admit an HIV-positive child. Results we received demonstrate that none of the interviewed parents and guardians believe that school and pre-school institutions are ready to admit children, living with HIV.

Interview results with representatives of school and pre-school institutions

30 interviewed individuals reported that educational institutions are not ready to admit CLH but should informational and educational events for personnel of educational institutions and parents of other children are carried out then it is possible to reach adequate attitude towards children. 9 representatives of educational institutions said that CLH do not visit their institutions or they do not know about such cases. That is why interview results are based on assumptions and opinions on this problem of those interviewed.

«When an HIV-positve child enrolls to school or pre-school institution, we are obliged to inform relevant healthcare authorities about this».

«Children with HIV should be isolated from other children».

Such answers indicate low awareness level about HIV transmission and intolerant attitude towards PLWH from representatives of educational insitutions.

Children, HIV and social environment

The assessment showed that family members or relatives are mainly aware of HIV-positive status of a child. Significantly rarely friends of parents know about child's status. In all cases when representatives of social environment knew about child's status or status of their parents, attitude towards them did not differ or it became more caring and attentive. Only in two cases attitude of grandmother and uncle to HIV-positive child got worse compared to other children. Neighbours, colleagues of parents, teachers and classmates don't know about HIV infection of a child or his/her parents and, consequently, their attitude cannot be correlated with HIV.

CONCLUSIONS AND RECOMMENDATIONS

Conclusion 1

Out of all children, whose parents were interviewed, 37 were in their adolescent years and comprised the third of all children. We can assume that for families of these children the question of informing their child about his/her HIV-positive status or or parents' status will be of crucial importance. This point is confirmed by the results of the survey conducted with parents and guardians. Most parents of CLH and CAH are willing to disclose their status and status of a child. The majority of respondents (9 out of 10) are in need of some assistance from qualified professional (psychologist, peer consultant, doctor) to inform a child about their HIV status. Fewer but still the majority of those interviewed (8 out of 10) reported that they need help from qualified proffesional to tell their child about status of his/her parent(s). This means that organisations that provide services to PLWH and their families must be ready to ever-increasing demand for such service.

Recommendation 1.1

To prepare relevant personnel in NGOs and government organisations that provide psychosocial assistance to PLWH and their families for assistance of parents and guardians of CLH and CAH during the process of informing child about his/her HIV status or status of their parent(s) and regarding other issues, such as sexual and reproductive health.

By using experience of other countries, develop methodological guide for social workers,parents and adolescents on the status disclosure, sexual and reproductive health. It is necessary to foresee social-psychological assistance of children and parents at all stages of status disclosure.

Conclusion 2

Half of all parents interviewed during the assessment reported difficulties in adherence to ARV therapy regimen. This is mainly caused by unwillingness of children to take medicines because they are not aware of their HIV status and because parents don't know the importance of adherence to ARV therapy. These two aspects can contribute to violation of treatment regimen and resistency development in children.

Recommendation 2.1

Prepare relevant personnel in NGOs and in government organisations on issues of achieving adherence to ARV therapy for children and adolescents.

Recommendation 2.2

Study and implement available tools that would help parents and children in adherence to ARV therapy regimen. For instance: materials "Story of Vitaminka Fairy".

Conclusion 3

In medical institutions, children experience discrimination and this issue should be addressed regardless of incidence od such cases. Discrimination against CLH and CAH in medical institutions is violation of both – human rights and patient righs.

Cases of refusal to provide medical services because of HIV infection is the utmost manifestation of discrimination. Facts of discrimination that were highlighted during the rapid assessment show the need to conduct events dedicated to protection of rights of CLH and CAH and raising willingness of medical institutions to work with HIV-positive patients.

Recommendation 3.1

Public orgnisations should take steps to train parents, guardians of CLH and CAH on the issues of human rights, in particular, patient rights.

Recommendation 3.2

Relevant healthcare administration authorities should develop the mechanism that will prohibit discrimination of children and especially refusal in provision of medical assistance due to their HIV status or status of their parents.

Recommendation 3.3

Include protection of children rights during delivery of medical services into the activity of non-governmental organisations.

Recommendation 3.4

It is advisable to analyse the content of trainings and additional trainings of medical personnel of relevant profiles and directors of healthcare institutions on such issues as HIV transmission, HIV prevention methods and other aspects of medical and social services for CLH. Special focus should be placed on availability of information about human rights and children rights.

It is important to approach an issue of focused informational and educational campaign in healthcare institutions based on the analysis of the trainings and additional trainings for medical personnel at the level of particular countries and with consideration of their specifics.

Conclusion 4

Respondents receive only disability pension out of all types of social support and benefits related to HIV-positive status of a child. The fact that implementation of this social support differs drastically in different countries of South Caucasus could be explained by different legislation in each country. In Georgia, for example, CLH are not equated to disabled children as they are in Azerbaijan and Armenia according to “the law on AIDS”.

Recommendation 4.1

To analyse the reason of low number of children, who receive social benefits in Armenia. To develop steps on improving access to social benefits for CLH based on the findings of the analysis.

Recommendation 4.2

To consider possible steps of including CLH into social group that needs state support at legislative level in Georgia.

Recommendation 4.3

To conduct mapping of all services and benefits available to CLH and CAH in each country to create effective referral system.

Conclusion 5

Out of all types that respondents chose as priority for them, the most sought-after is financial support and other types of welfare assistance in different manifestations. Respondents expect welfare assistance mostly from the state. But at the same time, significant part of those interviewed in Armenia do not use even those benefits they are entitled to according to the current legislation (for example, disability pensions). The category "welfare assistance" included such humanitarian aid as clothes, food supplies, medicines and school supplies.

Recommendation 5.1

Access to these types of assistance could be ensured through government organization, international and private charitable foundations.

Conclusion 6

NGOs are viewed as bodies that assist the most in upbringing of a child and its care by participants of the assessment. Activity of NGOs in this area is assessed higher compared even to the role of relatives. This is crucial indicator for the countries of SC, where family relationships and kinship are very strong. Yet 29 out of 78 individuals reported that they never received services from NGOs and CF, which amounts to the third of all survey participants. Considering the fact that parents and guardians, who are clients of NGOs or to whom such organistions have access, participated in the assessment this result should be viewed as a wake-up call for NGOs and CF to put focus on service provision for PLWH and children affected by HIV/AIDS.

Recommendation 6.1

To implement of proactive approaches in the work with families with CLH and CAH to identify and solve difficulties in upbringing of children and to ensure necessary care for children affected by HIV/AIDS.

Conclusion 7

Low involvement of state guardianship agencies in assistance of parents of CLH and CAH could be explained by absence of proactive approach of government organisations and therefore problems are solved only when they appear.

Recommendation 7.1

It is necessary to conduct advocacy activities in each country of SC to attract attention of government and ensure availability of programmes for children affected by HIV/AIDS. NGOs should act as proxies between parents of CLH and CAH and relevant state bodies that can provide assistance in upbringing and care for children.

Recommendation 7.2

To conduct mapping of organisations and services that can assist parents and guardians of CLH and CAH. To create effective referral system of clients.

Conclusion 8

Psychosocial assistance was second sought-after service for CLH and CAH according the questionnaires' analysis. Provision of this type of service is expected more from NGOs and CFs. Psychologists and social workers are employed in state institutions, such as AIDS centres but usually they are not trained to provide psychosocial assistance to children affected by HIV/AIDS.

Recommendation 8.1

To train psychologists and social workers from NGOs and government organisations that work with CLH and CAH considering the process of HIV status disclosure.

Recommendation 8.2

Mapping and establishment of partnership realtions with government, non-governmnet and charitable organisations that can provide professional psychosocial support to children or technical assistance to PLWH organisations and other AIDS service NGOs.

Conclusion 9

The other scope of sought-after services for CLH and CAH is recreation and out-of-school education. It includes art-hobby groups, sports extracurricular activities, summer camps, etc. By creating proper recreation activities and out-of-school education for CLH and CAH one can conduct a work for self-stigma reduction, integration of children into society and giving them an opportunity to use their own potential and express themselves.

Recommendation 9.1

Mapping and and establishment of partnership realtions with government, non-governmnet and charitable organisations that can provide financial and technical assistance to organize such services for CLH and CAH.

Conclusion 10

Access to school and pre-school education for CLH and CAH does not differ from access of children, who are not affected by HIV/AIDS as long as these institutions don't know about HIV-positive status of a child or parent(s). In all cases when educational institution publicly disloses HIV status, children usually experience discrimination. Perceived stigma and fear of perceived discrimination is strongly expressed among parents of CLH and CAH, which in some cases led to refusal of pre-school institution visits of their child.

Parents and representatives of educational institutions reported that educational institutions are not ready or hardly ready to admit CLH and CAH.

Recommendation 10.1

To conduct trainings for parents of CLH and CAH aimed at self-stigma reduction and skills of human rights protection.

Recommendation 10.2

Relevant state educational agencies should develop mechanism that will prohibit discrimination against children because their or their parents' HIV status. It is advised to analyse the content of training and advanced training of educational professionals and directors of educational institutions on such issues as HIV transmission, HIV prevention methods, human rights and children's rights. To consider the necessity of the focused informational and educational campaign for educational professionals of pre-school and school institutions at the level of particular countries and with consideration of their specifics based on the analysis of the training and advanced training programmes.

Recommendation 10.3

International charitable organisations, state and faith-based organisations should implement programmes, which aim to shape tolerant attitude towards HIV –positive children and adolescents in educational institutions.

ANNEX 1

Question guide for interview with key informants

Dear _____,

ICO «East Europe and Central Asia Union of PLWH» with support of the World Vision is conducting the Rapid assessment of the service needs for children affected by HIV/AIDS in South Caucasus.

We are striving to identify the most important needs in service provision and prepare the action plan to satisfy those needs. The objective of the rapid assessment is to improve life quality of children. However, to secure an effective action plan we need your help to develop it, so that later we could address the real and high-priority issues of children affected by HIV/AIDS.

We are grateful for your readiness to help and for consent to take part in this rapid assessment. This questionnaire is anonymous and confidential. It will take 30-40 minutes of your time to complete it.

Question guide

1. What are the main problems faced by children affected by HIV/AIDS in the country _____?
2. What are the peculiarities of the problems for different age groups of children affected by HIV?
5. How services available in the country for children affected by HIV/AIDS match their needs?
6. Is there enough data (evidential basis) in the country about needs of different groups of children affected by HIV/AIDS and their families?
7. What data and information is missing?
8. Please describe the work areas of your organization for children affected by HIV/AIDS and/or their families?
9. Are there any plans for additional activities aimed at children affected by HIV and their families for the next 1-2 years?
10. What should and what can state institutions do for children affected by HIV/AIDS?
11. How state institutions are ready for service provision for children affected by HIV/AIDS?
12. How do activities of state institutions match the needs of children affected by HIV/AIDS?

13. What should and what can international organisations do for children affected by HIV/AIDS?

14. How are international organisations ready to provide services for children affected by HIV/AIDS?

15. How do activities of international organisations match the needs of children affected by HIV/AIDS?

16. What should and what can public organisations do for children affected by HIV/AIDS?

17. How are public organisations ready to provide services for children affected by HIV/AIDS?

18. How do activities of public organisations match the needs of children affected by HIV/AIDS?

19. Is service provision for children affected by HIV/AIDS and their families one of the priorities of state response to epidemic?

20. Please specify your suggestions for improvement of services for children affected by HIV/AIDS and their quality improvement in the country _____

_____?

21. Are changes in legislation necessary?

22. Is there any problems of preparation/advance training of personnel that provides services for children affected by HIV/AIDS?

23. Is universal access to necessary services in the country secured for all children affected by HIV/AIDS?

ANNEX 2

Question guide for representatives of medical institutions

№_____(leave empty)

Dear _____,

ICO «East Europe and Central Asia Union of PLWH» with support of the World Vision is conducting the Rapid assessment of the service needs for children affected by HIV/AIDS in South Caucasus.

We are striving to identify the most important needs in service provision and prepare the action plan to satisfy those needs. The objective of the rapid assessment is to improve life quality of children. However, to secure an effective action plan we need your help to develop it, so that later we could address the real and high-priority issues of children affected by HIV/AIDS.

We are grateful for your readiness to help and for consent to take part in this rapid assessment. This questionnaire is anonymous and confidential. It will take 15 minutes of your time to complete it.

Question 1.1. Do you know cases when parent(s) or guardian of a child violated ARV-therapy regimen of their child?

Question 1.2. How often do such cases occur? (Please specify: what is the portion of such "violators" and "persistent violators" (hints: half, one third, few, etc.)

Question 1.3. What grounding do you have to assume that ARV regimen is violated? (Hints: subjective opinion of doctor, opinion of other professionals, objective indicators – missed doctor's appointments, missing or weak virologic response to therapy, resistance development, considering the number of medicines "on hands" of a patient, etc).

Question 1.3. How do(es) parent(s) / guardian explain ARV regimen violation of their child?

Question 1.4. In your opinion, what are the real reasons of ARV regimen violation of a child?

Question 1.5. What steps do you make when ARV regimen of a child is violated because of parent(s) / guardian?

Question 1.6. What other professionals and organisations can help you with in providing necessary ARV-therapy regimen and regular medical check-up of a child? Please specify, how exactly these professionals and organisations can help you?

Question 1.7. Do you have enough knowledge, information and methodological support on medical services provision for HIV-infected children (not only ARV treatment but other opportunistic infections)?

Question 1.8. What can help you in providing more full medical services to children living with HIV?

ANNEX 3

Question guide for representatives of educational institutions

№_____(leave empty)

Dear _____,

ICO «East Europe and Central Asia Union of PLWH» with support of the World Vision is conducting the Rapid assessment of the service needs for children affected by HIV/AIDS in South Caucasus.

We are striving to identify the most important needs in service provision and prepare the action plan to satisfy those needs. The objective of the rapid assessment is to improve life quality of children. However, to secure an effective action plan we need your help to develop it, so that later we could address the real and high-priority issues of children affected by HIV/AIDS.

We are grateful for your readiness to help and for consent to take part in this rapid assessment. This questionnaire is anonymous and confidential. It will take 15 minutes of your time to complete it.

Question 2.1. Do children living with HIV go to your school/ your kindergarten?

Question 2.2. What are your actions if you find out that there is a child living with HIV in your school / kindergarten? (ONE ANSWER ONLY)

Question 2.3. In your opinion, how school / kindergarten (personnel, other children, parents of other children) are ready to accept an HIV-positive child?

Question 2.4. In your opinion, what should be done to secure equal conditions for education of children living with or affected by HIV/AIDS?

Question 2.5. Do you have enough knowledge and information about HIV infection, ways of its transmission, prevention methods and other relevant questions?

Question 2.6. What knowledge, information do you lack?

ANNEX 4

Questionnaire for parents or guardians

№_____(leave empty)

Dear _____,

ICO «East Europe and Central Asia Union of PLWH» with support of the World Vision is conducting the Rapid assessment of the service needs for children affected by HIV/AIDS in South Caucasus.

We are striving to identify the most important needs in service provision and prepare the action plan to satisfy those needs. The objective of the rapid assessment is to improve life quality of children. However, to secure an effective action plan we need your help to develop it, so that later we could address the real and high-priority issues of children affected by HIV/AIDS. It will take 30 minutes of your time to complete it.

This questionnaire consists of 4 modules and focuses on the needs of children that correlate with the following themes: HIV+ status disclosure, accessibility of children to medical, social, educational services and condition of family in general.

General information

1. Sex:

◯1 Male

◯2 Female

2. Relation to child:

◯1 Parent

◯2 Guardian

3. Information about children under 18 years old in your family:

	Child 1	Child 2	Child 3	Child 4	Child 5
1. Age (years)					
2. Sex (M/F)					
3. HIV status (positive, negative, don't know)					

4. Place of residence:

◯1 City with population over 300.000

◯2 City with population under 300.000

◯3 Countryside

5. Average monthly income of your family:

◯1 Over USD 1000

◯2 USD 801 - 1000

◯3 USD 601 - 800

◯4 USD 401 - 600

◯5 USD 201 - 400

◯6 USD 200 and less

MODULE A

In this module we will review questions related to child's awareness of their HIV status or their parents' status.

Question A1. Does your child know about their HIV status?

◯1 Yes (*go to* **question A2**)

◯2 No (*go to* **question A3**)

Question A2. Please assess on a scale from 1 to 10 the severity of impact on psychological state[13] of a child when they found out about their HIV-positive status, where 10 means very strong impact and 1 means that it didn't affect them. (It is recommended for parent /guardian to assess the severity of impact themselves).

1	2	3	4	5	6	7	8	9	10
						Go to **question A4**			

13 Aggression, reticence, fears, passive behavior and other.

Question A3. Why didn't you tell your child about their HIV-positive status?

◯1 Age is not appropriate

◯2 I'm afraid that they won't be able to adequately perceive the information/ keep confidentiality

◯3 I don't know the right way to tell

◯4 I don't want to hurt my child

◯5 Pre- and post-exposure support is not available for me and my child (group support, peer-to-peer consultation, psychologist, psychotherapist)

◯6 Other. Please specify: _____

_____

Question A3.1. Do you want to tell your child about their HIV status?

◯1 Yes

◯2 No

Question A3.2. Please indicate how necessary is it for you and your child to get assistance of qualified professional (psychologist, peer consultant, doctor) to tell your child about their HIV status?

◯1 I need it very much

◯2 It's necessary for me

◯3 It would be helpful

◯4 I likely don't need it

◯5 I don't need it at all

Question A4. Does your child know about your HIV status?

◯1 Yes (*go to* **question A5**)

◯2 No (*go to* **question A6**)

Question A5. Please assess on a scale from 1 to 10 the severity of impact on psychological state[14] of a child when they found out about their parent(s) HIV infection, where where 10 means very strong impact and 1 means that it didn't affect them. (It is recommended for parent /guardian to assess the severity of impact themselves).

1	2	3	4	5	6	7	8	9	10
						Go to **Module B**			

Question A6. Why didn't you tell your child that you are HIV-positive?

○1 Age is not appropriate

○2 I'm afraid that they won't be able to adequately perceive the information/ keep confidentiality

○3 I don't know the right way to tell

○4 I don't want to hurt my child

○5 Pre- and post-exposure support is not available for me and my child (group support, peer-to-peer consultation, psychologist, psychotherapist)

○6 Other. Please specify: _____

_____

Question A6.1. Do you want to tell your child about your HIV status?

○1 Yes

○2 No

Question A6.2. Please indicate how necessary is it for you and your child to get assistance of qualified professional (psychologist, peer consultant, doctor) to tell your child about your HIV status?

○1 I need it very much

○2 It's necessary for me

○3 It would be helpful

○4 I likely don't need it

○5 I don't need it at all

14 Aggression, reticence, fears, passive behavior and other.

MODULE B

In this module we will review question related to access of child to medical and social services.

Question B1. Have you ever experienced unfair treatment of your child by personnel of any medical institution?

○1 Yes (*go to* **question B2**)

○2 No (*go to* **question B3**)

Question B2. How was this unfair treatment expressed?

(MULTIPLE ANSWERS ARE APPLICABLE)

○1 Refusal to provide medical services

○2 Scornful or insulting attitude (rude comments, insults, unreasoned placement into isolation ward or quarantine)

○3 Breach of confidentiality

○4 Demand of additional payment for medical assistance

○5 Other. Specify: _____
_____

QUESTIONS B3 – B8:
related to children that are HIV infected.
For others – please go to ***MODULE C.***

Question B3. Does your child receive ARV therapy?

○1 Yes (*go to* **question B5**)

○2 No (*go to* **question B4**)

Question B4. Why they don't receive it?

○1 No indications (please specify CD4 level+ cells_____ , if unknown, please put X)

○2 Doctors / AIDS centres refuse treatment. Please specify, how refusal is reasoned:

- ○1 Absence of pediatric dosage forms of ARV medicines
- ○2 There are contraindications

Go to **question B 6**

○3 Resistance developed to all existing medicines

○4 Other. Please specify: _____
_____

○3 We refuse to begin treatment. Please specify the reason: _____
_____

○4 Should begin treatment soon

○5 Other. Please specify: _____
_____

Question B5. Question B5. Do you experience difficulties in adherence to ARV treatment regimen?

○1 Yes (*go to* **question B5.1**)

○2 No (*go to* **question B6**)

Question B5.1. What these difficulties in adherence to ARV treatment caused by?
(MULTIPLE ANSWERS ARE APPLICABLE)

○1 Pharmaceutical dosage form is not convenient to take

○2 Child refuses to take medicines

○3 We forget about it

○4 Social circle prevents (For example: it's not convenient to give medicines while other people are present, at school, in child care centres, in family, on the street)

○5 Other. Please specify: _____
_____

Question B6. Do you receive any social benefits due to HIV infection of your child?

○1 Yes (*go to* **question B7**)

○2 No (*go to* **question B8**)

Question B7. What social benefits do you and your child use?
(MULTIPLE ANSWERS ARE APPLICABLE)

○1. Disability pension due to HIV

○2 Additional days of holidays for working parents

} *Go to* **module C**

○3 Paid sick leaves due to child's disease

○4 Other type of social assistance. Please specify: _____
_____

Question B8. Please specify the reasons why you don't receive social benefits due to HIV infection of your child?

(MULTIPLE ANSWERS ARE APPLICABLE)

○1 I don't know the rights I'm entitled to

○2 It's difficult to collect all documents necessary to receive it

○3 I'm afraid of confidentiality breach

○4 I asked for it but was denied. Please specify how denial was reasoned: _____
_____

○5 I didn't ask for it because I don't need it

○6 Other. Please specify: _____
_____

MODULE C

In this module we will review questions related to domestic surrounding where you child is living.

Question C1. Please assess attitude of different members of your family towards your child, who is living with HIV:

PLEASE CHECK ONE ANSWER IN EACH LINE	Same as to other children	More attentive, caring than to other children	Worse than to other children	I don't have this family member
1.My husband/my wife	1	2	3	4
2. Other guardian	1	2	3	4
3. Grandfather	1	2	3	4
4. Grandmother	1	2	3	4
5. Elder brothers	1	2	3	4
6. Elder sisters	1	2	3	4
7. Uncles	1	2	3	4
8. Aunts	1	2	3	4
9.Other family members	1	2	3	4

Question C2. Who knows from your immediate circle about HIV status of: you and / or your child?

PLEASE CHECK ONE ANSWER IN EACH LINE	Know	Know but not all	Don't know	Not applicable
1. Family members that live in the same house as you	1	2	3	4
2. Friends	1	2	3	4
3. Parents that don't live with you	1	2	3	4
4. Neighbours	1	2	3	4
5. At workplace	1	2	3	4
6. Classmates of your child	1	2	3	4
7. Teachers of your child	1	2	3	4

Question C3. Have you noticed any special (unfriendly or, vice versa, too caring, one that differs from normal) attitude from your and your child's immediate circle that you can attribute to HIV status?

PLEASE CHECK ONE ANSWER IN EACH LINE	Always	Sometimes	Never	Not applicable
1. Family members that live in the same house as you	1	2	3	4
2. Friends	1	2	3	4
3. Relatives that don't live with you	1	2	3	4
4. Neighbours	1	2	3	4
5. At workplace	1	2	3	4
6. Classmates of your child	1	2	3	4
7. Teachers of your child	1	2	3	4

Question C4. Do you receive assistance or support on issues relevant to care and child's upbringing from below mentioned persons or organisations?

PLEASE CHECK ONE ANSWER IN EACH LINE	Yes, to full extent	More likely	Less likely	I don't receive
1. Relatives	1	2	3	4
2.Friends	1	2	3	4
3. State guardianship agencies	1	2	3	4
4. Public organisations and charitable funds	1	2	3	4
5. Other	1	2	3	4

Question C5. What type of assistance do you need from:

PLEASE CHECK ONE ANSWER IN EACH LINE	Please specify what kind of assistance do you need	I don't need assistance
1. Relatives		1
2. Friends		1
3. State guardianship agencies		1
4. Public organisations and charitable funds		1

MODULE D

In this module, we will review questions related to access of child to educational services.

Question D1. Does your child attend school or preschool institution?

○1 Yes (*go to* **question D3**)

○2 No (*go to* **question D2**)

Question D2. What is the reason that you child doesn't attend school or preschool institution?

(MULTIPLE ANSWERS ARE APPLICABLE)

○1 School /preschool institution refuses to enroll my child because of HIV infection

○2 School /preschool institution refuses to enroll my child because their parents have HIV

} *Go to* **question D6**

○3 We are afraid to let child to school/preschool institution because of fear that there will be bad attitude towards them because of their or our HIV status

○4 School or preschool attendance is related to material costs that our family can't afford to cover

○5 Other. Please specify: _____

_____

Question D3. Does anyone at school / kindergarten know about your status or status of your child?

○1 Yes (*go to* **question D4**)

○2 No (*go to* **question D6**)

Question D4. How did school/ kindergarten find out about this:

◯1 We told them

◯2 Someone told them (please specify _____)

◯3 We don't know how they found out

Question D5. How did different persons at school/kindergarten treat your child because of HIV status?

PLEASE CHECK ONE ANSWER IN EACH LINE	Extremely negative, demanded expulsion	Kept child in institution but there were everyday cases of discrimination	Accepted but sometimes there were cases of discrimination	Accepted, rarely there were cases of discrimination	Adequately
1. Administration of institution	1	2	3	4	5
2. Teachers / instructors /nursemaids	1	2	3	4	5
3. Technical personnel	1	2	3	4	5
4. Other pupils	1	2	3	4	5
5. Parents of other pupils	1	2	3	4	5

Question D6. In your opinion, how comfortable (convenient) school / kindergarten for your child is? How are personnel, other children, parents of other children ready* to accept HIV-positive child to their group?

PLEASE CHECK ONE ANSWER IN EACH LINE	Ready	Partially ready	Not ready
1. Administration of institution	1	2	3
2. Teachers / instructors /nursemaids	1	2	3
3. Technical personnel	1	2	3
4. Other pupils	1	2	3
5. Parents of other pupils	1	2	3

* "Ready" means how tolerant and non-discriminatory attitude towards child will be.

Question D7. Please, check THREE the most important services / possibilities for child that you would like to provide to or improve for your child:

(In column 1 put the most important, major service/possibility,
in column 2 – the second most important,
in column 3 – the third the most important)

PLEASE CHECK ONE ANSWER IN EACH LINE	1st service/ possibility	2nd service/ possibility	3rd service/ possibility
1. Food	1	1	1
2. School education	2	2	2
3. Sport extracurricular activities	3	3	3
4. Clothes	4	4	4
5. Art-hobby group	5	5	5
6. Participation in support groups	6	6	6
7. Summer vacation	7	7	7
8. Out-of-school education (computer class, foreign languages, groups for studying school subjects, etc.)	8	8	8
9. Psychotherapeutic consultations	9	9	9
10. Consultations on status disclosure to a child	10	10	10
11. Other, please specify	11-_____ _____	11-_____ _____	11-_____ _____

Question D8. What else worries you about your child's upbringing? What additional issues do you want to touch upon?

_____

_____

_____

_____

_____

_____

THANK YOU FOR YOUR PARTICIPATION!

ANNEX 5

List of key informants

Armenia

№	Organisation	Respondent	Position
Representatives of international organisations			
1	UNAIDS	Naira Sargsyan	Social Mobilization Adviser
2	UNICEF	Lianna Hovakimyan	Health and Nutrition Officer at UNICEF
3	UNFPA	Aida Ghazaryan	National Programme Officer
4	World Vision Armenia	Shaghik Mahrokhian	Operations manager
5	Mission East, GFATM NGO Principal Recipient	Yelena Amirkhanyan	NGO PR Team Leader
Representatives of government organisations			
6	Ministry of Health - GFATM Gov PR	Hasmik Harutyunyan	Gov PR Team Leader
7	Ministry of Education	Anahit Muradyan	Senior Specialist of Special Education Unit
8	AIDS Centre	Arshak Asmarian	Deputy, Department of medical assistance services
Representatives of non-governmental organisations			
9	Positive People Armenian Network	Anahit Harutyunyan	President
10	Real world, real people	Elina Azaryan	Co-president
Representatives of educational facilities			
11	High school 183	Anahit Torosyan	Teacher
12	High school 183	Mariet Simonyan	Director
13	Kindergarten	Adjapkhanyan Astghik	Caregiver
Representatives of medical facilities			
14	AIDS Center	Zhaklin Hakobyan	Family doctor

Azerbaijan

№	Organisation	Respondent	Title
Representatives of international organisations			
1	UNAIDS	Dzhamilia Dzharahova	Country office manager
2	UNICEF	Aida Aimarova	Programme manager. UNİCEF Youth programme
3	OSI	Leyla Imanova	Public Health Program Director
4	World Vision	Giunel Ismailova	Healthcare project manager
5	GF PR	Rashid Vezirov	Monitoring and evaluation expert
Representatives of government organisations			
6	Ministry of Education	Aysel Gadzhieva	GF Programme manager
7	Ministry of Social protection of population	Babek Guseynov	Deputy director of the Department of social welfare policy
8	AIDS Centre	Eldaniz Muradov	Deputy of organization and methodology department
Representatives of non-governmental organisations			
9	Harm Reduction Network	Ruphat Nasibov	Secretary of Harm Reduction Network
Representatives of educational facilities			
10	School №304	Irada Guseynova	School director
11	School №152	Verdieva Giulara	School director
12	School №16	Ulviya Velieva	School director
Representatives of medical facilities			
13	Republican AIDS Centre	Velieva Samira	Pediatrician

Georgia

№	Organisation	Respondent	Title
Representatives of international organisations			
1	UNAIDS	Lia Tavadze	Social Mobilization Adviser
2	UNICEF	Nana Pruidze	Health Education Officer
3	World Vision	Tamar Kheladze	HIV/AIDS and Migration Sub Regional Project Coordinator
4	World Vision	Katerina Zezulkova	HIV/AIDS Prevention in South Caucasus Project Manager
Representatives of government organisations			
5	Ministry of Health – LEPLMedical Mediation Service	Alexander Asathiani	Analytics and software development consultant
6	Ministry of Education – ShotaRustaveli national science foundation	Guram Sagaradze	Senior Specialist
Representatives of non-governmental organisations			
7	NGO Tanadgoma	Nino Tsereteli	Executive Director
8	HIV Patients Support Foundation	Irma Shanava	Regional Representative
Representatives of educational facilities			
9	Schools # 86	Levan Bibiluri	Director
10	School #176	Teona Nemstsveridze	Teacher
11	School #176	David Akhalaia	Director
Representatives of medical facilities			
12	AIDS Center	Maia Lomtadze	Pediatrician

ANNEX 6

Virtual regional group for rapid assessment

Name	Organization	Position	Contact
Region			
Albert Pancic	World Vision regional office	HIV/AIDS Advisor	Albert_Pancic@wvi.org Skype: albert_pancic
Jasenko Eminovic	World Vision regional office	Program Quality Specialist for MEER	Jasenko_Eminovic@wvi.org
Armen Martirosyan	World Vision Global Center	Health Research and M&E Associate	armen_martirosyan@wvi.org Skype: armen_mol
Gegi Mataradze	ECUO	Executive Director	g.mataradze@ecuo.org
Olya Panfilova	ECUO	Officer of Programs for children and adolescents	olya@ecuo.org
Hovhannes Madoyan	ECUO	Expert Project	hovhannes@realwrp.com
Armenia			
Arax Hovhannesyan	World Vision Armenia	Health specialist	arax_hovhannesyan@wvi.org
Anna Abgaryan	Real World, Real People	Focal Point for ECUO	anna.abgaryan@realwrp.com
Azerbaijan			
Gunel Ismailova	World Vision Azerbaijan	Health Programs Manager	gunel_ismayilova@wvi.org
Ehtiram Pashaev	Public Organization Against AIDS	Focal Point for ECUO	pashayev70@mail.ru
Georgia			
Mamuka Chelidze	World Vision Georgia	Project Coordinator	mamuka_chelidze@wvi.org
Georgi Soselia	Real People Real Vision	Focal Point for ECUO	georgesoselia@yahoo.com

International Charitable Organization
"East Europe & Central Asia Union of PLWH"

www.ecuo.org

World Vision

http://beta.wvi.org/meero