


First AIDS Action Europe Member Meeting 2016

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1. Background

1.1. Motivation and Aims of the Meeting

AIDS Action Europe organized for the first time the AAE Member Meeting on Saturday 5 November, 2016 in Berlin. The AAE Steering Committee initiates this meeting to identify needs and demands of AAE's member organisations. AAE wanted to involve its member organisations in the discussion on how to support civil society movement at national and European level and to build capacities for advocacy in the WHO European region. Moreover, AAE wanted to have input and discussion on the strategic directions AAE should take after 2017.

1.2. Selection of the representatives


In the preparation phase AAE sent a call for abstracts. AAE tended 10 scholarships to its member organisations to participate in the AAE member meeting. The abstract had to be addressed the following questions and develop concepts for improved civil society involvement:

- How can civil society maintain its role to advocate in the field of HIV policies?
- How can civil society in your region be strengthened in times when the influence of civil society organisations is pushed back?
- What should AAE's role be to support advocacy and how passive, active or proactive should AAE be when it comes to advocacy at national level?

Eligibility criteria for the participation in the selection process were: the organisation had to be a member of AIDS Action Europe. The representative had to be a member of the board or staff.

Five applicants were invited to present their ideas in a presentation. The remaining five presented their ideas on posters.

Candidates have been selected by a committee, composed of an AAE Steering Committee Member, an AAE office staff member and an independent expert. Selection criteria were: quality of the abstract (100 %). The selection was based on the above criteria and the capacity of ten scholarships. Scholarships will be given to 5 participants from European Union countries and 5 participants from non-EU countries.



The scholarships allowed the selected representatives to participate in AAE's Member Meeting 2016, November 5, in Berlin and discuss about AAE's further advocacy development and AAE's way to the International AIDS Conference in Amsterdam 2018 (travel costs were reimbursed). The representatives had an opportunity to meet the AAE Steering Committee, the AAE office staff and other AAE members to discuss and exchange ideas.

There were 33 participants, including 8 AAE SC Members, 4 AAE Office staff. Furthermore there are 10 scholarship recipients and 11 other participants representing AAE Member and Partner Organisations.

Translation was insured by LinguaTransFair, Berlin, technics: green congress, Berlin; Facilitation took over Matthias Wentzlaff-Eggebert.

2. Opening and Welcome

2.1. Introduction into the Meeting by the AAE Steering Committee Chair, Anke Van Dam

In the last years AAE went through some changes, from the former hosts, Netherlands to Germany, Deutsche AIDS-Hilfe. This meeting is a good momentum for the members to participate in the development of AAE, to improve relationship with members, and communication with members.

AAE has different tools for successful communication: website, newsletter, Clearinghouse, however the input from the side of the members could be bigger. The idea of the Member Meeting was born two years ago and could be realised now. The AAE secretariat made this meeting possible; AAE is very grateful to applicants, who applied for 10 scholarships and to those who put energy into writing such good applications.

Anke Van Dam also informed about the Steering Committee Meeting which took place before the Member Meeting and the aims of the SC Meeting. In 2017 AAE need to prepare a new proposal for the New Strategic Framework of European Commission and AAE expects from the member organisations the valuable input for the future direction.



2.2. Interaction

Matthias Wentzlaff-Eggebert, facilitator of the meeting, introduced the interactive activity to introduce participants to one another in the small groups of 3 or 4 people; especially Russian and non-Russian should meet during this interaction. The aim of the activity is to identify the commons.

The results of the interaction in the small groups:

Common aspects:

- HIV field, advocacy, work with drug users, MSM and people living with HIV - sex workers; migrants - to a lesser degree but this have to be mentioned too.
- Latvia, Germany, Greece, Portugal: work with women at risk, MSM and drug addicts
- All from West Europe: Germany, Belgium, Ireland, Germany and France - all are working in the capitals
- Finland, Ukraine, Netherlands: shared a common wish to work together throughout Europe for as long as possible with all groups involved
- Georgia, England, Netherlands and Ireland: all of them like to talk

- Ukraine, Germany, Netherlands, England and France: participants from these countries have been lived in Berlin, already have been here and want to come back again

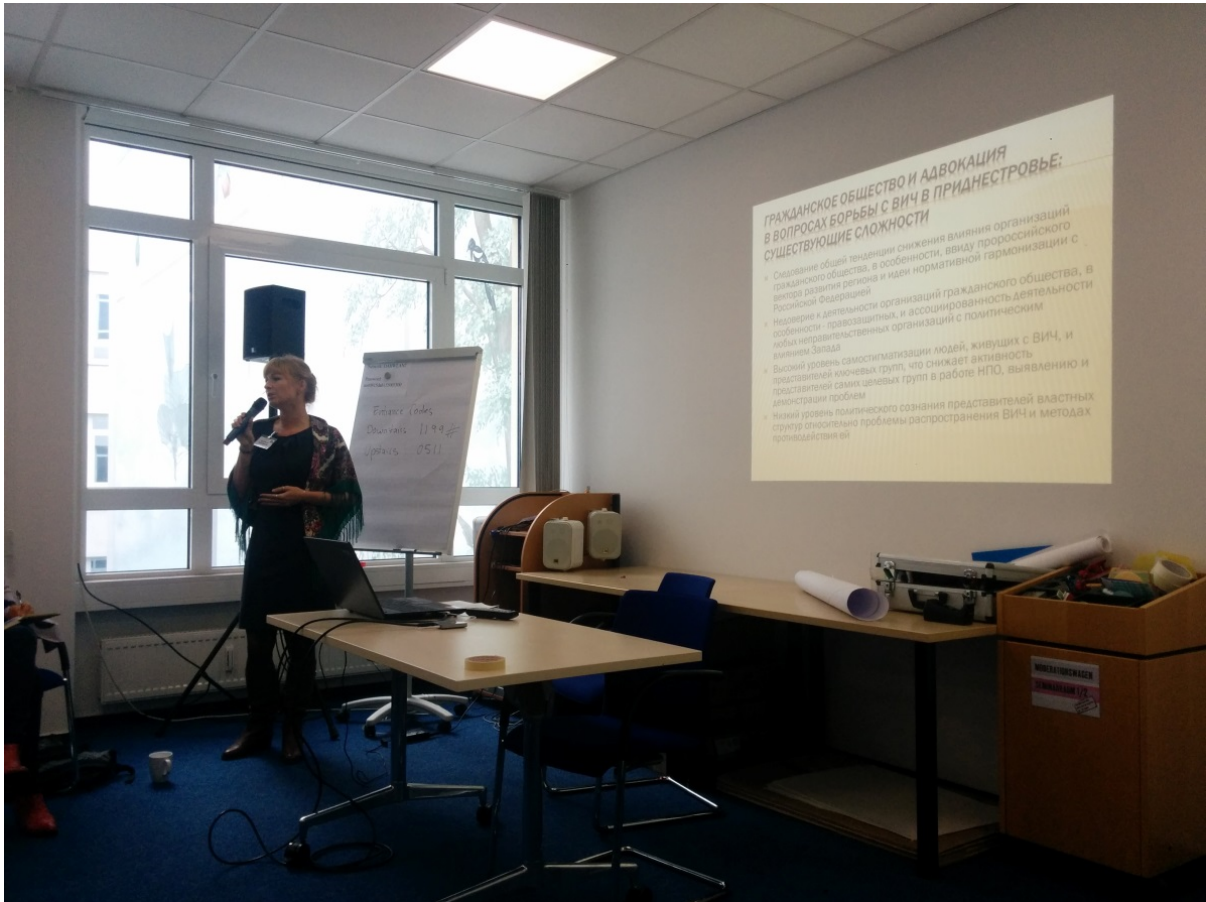
3. Advocacy at national and European level – demands and needs: Presentations' session

3.1. Janna Vilhovaja, Healthy Future, Moldova (*Annex 1*).

Janna is the representative of the organisation from Moldova (Presentation, Annex 1). The region is just small fraction of Moldova but has 1/3 of all HIV infections of Moldova. In her opinion, the reasons are political: there is an underestimation of the issues and of a state assistance to prevent and fight infections.

Advocacy is key element of every organisation in the field, so this is one of the key tasks of her organisation. The role of civil society is to provide services and is directly related to advocacy and other services of the civil society. In her opinion service organisations have to interact with human rights organisations to encourage them to work in field to reach our goals. Another important element is work with the government. In the region there isn't a good approach to human rights. However, her organisation can collect data and evidence based support for its work. They provide evidence to show and to prove why the organisation is necessary and important. This makes them more credible, justified for the government and gives them an opportunity to develop norms together.

Another important factor is ensuring sustainable services for advocacy. It is important to have good long term cooperation with public sector and try to work on normative acts that could simplify their work, defend their organisation and help to reach its goals. Among the problems in region, harmonisation with legal situation in Russia which poses threat due to distrust especially of human rights NGOs and everything associated with the western influences. Other problem is high stigma among HIV infected and vulnerable groups and fear of the stigma which prevents from collaborating with the service organisations. There is a program called "Positive Deviation" on other side of Moldova which is successful but small. There is a low level of consciousness from the side of governmental organisation.



Moldavian organisations try to assist development of advocacy in NGOs to prevent stigma and to present evidence based data and information and so to prove to government that we are necessary to fight against HIV. They are fighting stigma and try to encourage people to come forward and fight for their rights and to use international standards.

They are working with public sector and social services trying to collaborate in promoting goals and tasks on high level. Also the work with church organisations is very important, because the government says, we could save youth by not talking or informing them about STIs. That's why it is so important to go to churches to reach out to young people.


What AAE can do is informational assistance, for NGOs it is crucial to have access to information. Until now international standards have little impact in the region, but when international experts make statements it is convincing to government and the situation can be changed. Moldavian organisation needs assistance with the help of international experts.

3.2. Andrii Chernyshev represents “Gay Alliance”, Ukraine (Annex 2).

The aim of his organisation is strengthened of influence of the key communities and NGOs on HIV/AIDS policy in Ukraine. Here he presents on the first place advocacy efforts and work with governmental institutions.



Ukraine has one of the highest rates of HIV infections in Eastern Europe and Central Asia. So, there is a big need to maintain services of HIV organisations. Key goal is to prevent the spread of HIV in the countries of the region until we have new donors in coming years. In his opinion, there is still time to work out collaboration with the government. There are programmes for medical treatment and substitution therapy. There is a lack of treatment programmes funded by government and public sector. The programmes are funded by Global Fund in Ukraine. The sum of 506,250,133 has been donated: for sex workers, substitution programmes, harm reduction for vulnerable groups, people living with HIV who need support. Another peculiarity with Ukraine is in the process of decentralization: centres which are not in the capital get more funding for activities, which mean



they will get finance for programmes for prevention and substitution therapies funded on the governmental level.

Prevention of HIV and Tuberculosis has been developed at beginning of this year but it is not implemented due to legal structure and system. UNAIDS projects have been implemented, funded for vulnerable groups and PLWHIV. His organisation tries to unite different groups - sex workers, former prisoners, MSM and other groups in order to lead consolidating advocacy, to decrease stigma by government and tackle problems that impact all. These informal groups are more effective than dealing with these problems alone. A national community platform has been established, next meeting of the Platform will take place in the end of November. The aim of the Platform is to insure the stability in HIV policy, to try to increase representation of vulnerable groups.

There is a Council and expert group on HIV/ AIDS. Andrii is a member of the expert group for key groups for HIV and they are working on advocacy to improve representation of drug users, MSM and sex workers. There is hope that at the level of cabinet of ministers a decision to include one representative of each group will be taken at the end of the year. Current composition of national council on HIV and TB is 34 people. They work on capacity building in five regions for their communities and try to work with decision makers. For his organisation the very important point of work of AAE is the field of experience exchange of experts from different countries. Especially they are interested in cooperation with state, regional and local bodies and funding from state budget on regional and local levels for providing more quality advocacy. AAE supports advocacy that is why meetings like this should happen, in his opinion, once a year for better communication and information for advocacy reasons. He believes that the technical organisational support for NGO is another crucial issue: it is possible to find funding and grants for the project work but there is no money available for organisation for the structural work. What is going abroad? What are best examples for work in social programmes and with vulnerable groups? What are the work schemes in this area of MSM?

Ukraine is going through a development phase. Many young people working in this area are now in parliament. Preliminary budget is less than a half compared with money received by advocacy. Only 32% have an access to therapy. For the first time in history there will be programmes for substitution therapy by government. First time in the history it is not funded by Global Fund. All people in this programme will receive treatment from state budget thanks to advocacy efforts of the lower prices of medication comparing to other countries, e.g. UK. The coverage of treatment from funds of state budget expanded.

Questions for both presenters

For Moldavian organisation: - If you could change one thing concerning what described that is going wrong, what would be your priority?

Janna Vilhovaja: - Hard to pick one point if you want to change so much. We would like to be heard. That people hear us regardless of political factors. Although we have to start with ourselves. We should strengthen our role in the setting of communities and civil society, in responding to them.

For Ukrainian organisation: - What is biggest challenge when you formed for the first meetings with the key populations?

Andrii Chernyshev: - We were afraid we wouldn't accept each other, maybe we would face xenophobia issues or alienation. But we work with representatives of these communities, they are volunteers. They are aware and well informed. We have some situations when people from detention weren't friendly to MSM. We created awareness raising training seminars so they could learn their needs and become more tolerant. However, there are not too many of such difficult cases – the process went smoothly. There is a need to work together, participate in advocacy together. If there is a problem for one community such as substitution therapy which doesn't work for drug users, than the representatives of MSM and sex workers start supporting them. At the moment it's quite OK.

For Ukrainian organisation: If understood rightly you had an influence to the lower cost of treatment. When the Global Fund enters country they suggest scheme for lowering prices. How did your organisation influence lowering prices? In Baltic countries, in Latvia, we didn't try to influence state because what state invents and decides will be done anyway, so there is no point to do that.



Andrii Chernyshev and Iaroslav Zelinskyi: - It was our personal thing that we did. It wasn't Global Fund. Our network buys drugs using funds of Global Funds. Based on accessibility of medication in terms of patents in Ukraine - we had certain problems with pharmacological companies but we had a direct agreement with GSK and other pharmacological companies as a Network to lower prices. We have been member in world trade organisations, so we went along with these requirements too. We need to say that international patient's pool is included. Next year will be one of most accessible medication year in Ukraine. For pharmaceutical companies it has become important to have an agreement rather than to lose the market. It is easy to get patent in Ukraine for medical reasons; there is highest number of those in Ukraine. And they are all generics, so those companies don't develop anything new. International companies register patents and usually can dictate prices. We have interesting situation with Hepatitis treatment: generic drug can easily be sold on the Ukrainian market. An official letter sent by company to government suggested prices of 850 euro for course which is very high for our country. That is why we need to work with patent agency and communicate directly with patent holders. We shouldn't use only one direction of work, but use all competing forces on market which allow affordable prices. The coverage for free or affordable meds will happen by extending competition. HIV treatment is delivered by famous pharmaceutical companies, 130.000 people are registered with HIV, and so there is a need to provide treatment. The

use of generics is a way to do so! Our network used to buy meds for one price - Ministry of Health used funds of the Global Fund which price was twice or three times as high as our price.


For Ukrainian organisation: - I'm from the, let's say, Orient. Our idea of advocacy is something political. Your influence, did it happen before or after political changes?

Andrii Chernyshev: Changes already happened before 2014 because the Civil Society could mobilise different groups by 2013. 2014 we had a revolution which gave a shift to our society. Whatever happened, it gave an impulse; it gave changes in sectors of our country including health which is quite impressive.

3.3. Deirdre Seery, Change Network, Ireland (Annex 3):



Deidre has worked in the HIV field already for 25 years. Change Network was a predecessor of AAE. Many thinks have been born from experience of Euro Networks. How can civil society be strengthened? It should try to be all kinds of things to all people. They are always working hard to do many things, over time involved in civil society organisations and seen changes in the society landscape. Their biggest challenge is funding and funders. To her opinion, there is a normalisation of



HIV, it seems that the urgent problem is solved across Europe and been put in with other infectious diseases.

They observe professionalisation of the HIV fields. Over years state agencies are working in the field and get no sense of HIV and how it affects day to day lives. At one national meeting a public health doctor said, if you talk about stigma and HIV you are keeping stigma alive (!).

The hot topic in Ireland is PrEP, in other countries it is still medication. The goals of NGOs are sustaining and building momentum, promoting human rights of key populations. Sometimes, one uses to say: I don't want to be in the same group with drug users or with women as a gay man. However, if we are talking about human rights, so we must respond with honesty and bring back to human rights this person. Doing the right things right - is the benchmark how to judge what I do. As NGOs we are scattered over Europe - there are fantastic people working in this field.

As Irish singer said what has become of silent song birds? - AAE potential is to break out in a song by giving us scale and knowledge to do so. To advocate one needs to feel personally strong: I have to do something myself! But what makes me feel strong is knowledge that I'm doing the right thing. The scale is larger than the sum, and part of AAE is part of a movement that makes a difference. We have advocacy, research, points to different things in Europe. There is a documental resource which contributes to making us feel stronger. AAE provides the Clearinghouse. It could be better: this is important to show more work in progress to connect to those who have done or are currently doing, this could inspire. Quality action (an EU Joint Action project) countries don't include people from all over Europe.

What makes us stronger? – This question is a corner stone of advocacy. AAE can help to gather evidence that we are doing things right. Advocacy of the role of civil society at European level keeps key populations on the agenda. It can improve feedback loops into civil society; can inform what's happening elsewhere.

The question to the AAE role: is it passive, active, proactive? There is an imbalance across Europe relating to HIV, sex orientation, drug use, sex in general, respect for Civil Society Organisations. HIV is not so high on the agenda now, so we can continue advocacy work, continue to use human rights and community groups – our governments can't bring that. So there is a need of strengthen advocacy on national, regional and local levels. Are the issues the same for all of us? - No. The Irish organisation can have an active advocacy role at the national level. They wouldn't like AAE telling them what to do in Ireland.

Quality Action Charter is an important issue. What is good in AAE is a professionalisation, providing a huge service that is not tapped into enough. We are all Aids Action Europe.

3.4. Martin van Oostrom, AIDS Alliance, Netherlands (*Annex 4*):



In his opinion, civil society needs a stronger and united agenda and advocacy to be well informed and mobilised on each other's strategy. There is a window of opportunity and we have to use it - now or never.

Being asked three questions by AAE, we suggest underlying the analysis of the current situation. Martin suggests civil society has a role in advocacy and assumes civil society has had a role in the past. He believes we need planned action; we need a strong and united agenda to advocate in the field. The main aim is not pushing to develop policies; this could be just one of the means we have to reach our goals. We need a civil society and community declaration to end HIV which could be quoted on diversity of responses. We need to identify key issues in West and Central Europe for EECA which is in a transition process.

"United" - means shared but not same. We need shared key aims and shared implementation plans. Regional differences in Europe should be taken into consideration. An implementation plan could be our framework, to which political leaders have to commit. AAE should take a role of facilitator presenting agenda to EU, European Council etc. An other important tool could be an HIV Atlas, similar to one UNAIDS has for indicators and key populations.


3.5. Niall Mulligan, HIV Ireland, (Annex 5):



Dublin AIDS Alliance changed name two years ago into HIV Ireland. For him that is great to hear that human rights coming up again and again as hugely important issue.

There is a long tradition of civil society activism in Ireland. The church played an important role. The church helped where the state didn't and the church is still influential and powerful. The social work of the church is focussed especially on homelessness and addiction.

Protecting national interests can cause further isolation of the most vulnerable groups. However, the emphasis on human rights is growing in Irish civil society. Unfortunately at the moment there is a still poor national mechanism of questioning of government about implementing human rights obligations. There is a lack of transparency in this field. Current recession impacts on society,



especially on the most vulnerable people who can't advocate for themselves. In Ireland it is worth to mention the fact that people living with HIV are now involved. Positive people are presented on Irish media and seated in all relevant decision groups; it has changed in the past 10 years. There is definitely a need to place human rights, law and legislation in the centre of our work.

Constitution is about how a state treats citizens. Basic rights are there and through judicial system they are implemented. In Ireland they are just starting to use these in advocacy and law on the basis of the interests like public interest, establishing law alliance, in which advocates are acting on behalf of homeless people and other vulnerable groups.

Things are changing in Ireland: they have to stop talking and win over hearts and minds. In the questions of civil society policy and HIV policy they need to be trustworthy and credible voice, because they come from the ground working directly with HIV.

Also HIV research will lead to advocacy. There is a study on impact of northern model of HIV. The report based on this study was sent and read and discussed by high level governmental authorities, because it is evidence based. The question is: are we united into the discussion? As civil society we can say things which government can't and they can open doors we can't.

What is a human right based approach? All people are entitled to protection and promotion of human rights. To implement them in our work, as civil society, we have to consider five principles: human rights legislative frameworks, conventions, treaties, on the UN and EU level, to know them well and to understand.

The other aspect is equality, non-discrimination and attention to vulnerable populations accompanied by the empowerment of these groups. There are many charters, only a few are listed here in the presentation. How does it help when he works on the ground? He can list cases on member states and sees impact of these charters on peoples' lives: e.g. in France article 8 (transsexual recognition) and art 10 (it can insult head of the state).

This is a long way, but this is what can be achieved. On the ground we can build coalitions: Who are decision makers and what is the rationale behind decisions?

Another help is a human rights advocacy tool kit, it is "like a human rights Bible" in Ireland, it will be given to all new employees.

Important what AAE could do is capacity building for the people living with HIV.



Questions:

To Niall and to Deirdre about situation in Ireland: - How well does your government fund medical treatment for HIV prevention? Do you have any information? How is the situation with pre-contact prevention? Will it be implemented?

Deirdre: - HIV treatment is free to everyone. There is no PrEP in Ireland. We are looking at guidelines and it amazes me. Something proven to be effective still needs two years to write a guideline. It is a delay for clinical, medical reasons.

Questions:

To all: - The situation with positive people changed over the last ten years from being silent to very active. How is it done? As we know, in Eastern Europe counter propaganda uses HIV as "Western value" model that shouldn't be adopted in Eastern Europe.

Martin: - It was a hard work, very hard. The alliance was working 2 or 3 years building the self esteem or confidence. One person was the spokesperson, who burnt out and then there was a gap in the work. To be positive meant to have multiple people so they could rotate and establish statements together.



Deirdre: - National AIDS Strategy Committee was elaborating multi-sectoral response set up in 1992. It had 4 representatives from civil society; one of them had to be HIV positive. Over years people died from AIDS and then there were gaps, there were no representatives, because there were no organisations. Civil society organisations tried to get representative structure. We wanted them to represent all people with HIV which led to positive now. How effective the changes are depends on who is involved.

Question: - Research was brought up but do we have evidence?

Answer: - A lot of research is going on. If we could get information on what's going on before and it's published, than it could be useful to the NGOs. In the second half of the day we can address the research.

Question: Have austerity measures impacted anti-retroviral treatment? Are they strong enough to question medicament prices?

Deirdre: - I don't think austerity measures have this impact because the treatment is free. But it may have pushed drug users or homeless from services. There is a huge increase in homelessness in Ireland. HIV medicaments come from hospital budget, so nobody knows how much they cost across hospital system. PrEP is new and expensive in Ireland - this is what has been resisted. Some of

medicaments are 80 times more expensive in Ireland than in Britain. Many are made in Ireland but pharmacological industry provides jobs to everyone. If we are coming from European network, than mapping and reporting remains important. "Shadow reporting" comes back regularly, but the right way to do has not been found yet. Plus platform became a sort of failure for example. How is it possible to collect better data from a community point of view? Ending AIDS by 2030, 90-90-90 is an unrealistic target. How can we deal with the dynamics in Europe? How to come to policy plans which are achievable and rewarding for everyone?

Poster presentations

3.6. Igor Medvid, HPLGBT, Ukraine (*Annex 6*):

In Igor's opinion, we need to collaborate with NGOs that can produce shadow reports and data to have an alternative to our governmental reports. They work on sexualised violence against women and protection for trans men and women. Trans community in the region is in the first phase of development, in the consolidation, we are still forming our voice.

In this account they see large opportunity or need for AAE to state their needs and demands and promote them. The question about the role and impact of the Civil Society: it needs to develop new profile to work in the more effective collaboration with the state sector. Global development shows that the trans community participated in forming strategies that could be implemented also for Ukraine. On this account they tried to keep up to date and be proactive and developed a strategy within their organisation where they tried to include trans people into representatives of key populations, key groups. They see MSM, sex workers but not transgender representatives. If they talk about the widening key groups and key populations, they also should talk about transgender people.

Aids Action Europe – Igor likes because of the word "action" – can't be passive! AAE could help by adopting recommendations today: e.g. we heard about the human rights Bible. It would be great to see it in Russian, because Russian is a lingua franca for our region, our connecting language. If we talk about our goals for 2030 – without addressing our region it's impossible to reach that goal statement of the UN document.

Concerning coordination elements we would like to use them in their organisational documents. It would be nice if their members were part of our coordination body and body of others. They have

members in Ukraine coalition for men's health – Igor is a representative there. They have already become more visible, more heard.



It is important to make the use of the international experience. If no numbers are available they can't do anything, they need to get numbers for the trans people, which represent the situation of trans people. Then they can learn from meta analysis.

3.7. Elisavet Antoniadou, Centre for life, Greece (Annex 7)

Elisavet's organisation provides support to PLWH and their families since 1991. It includes special services. Volunteers have an important role in its work. HIV positive and negative is important to provide services together and work together. This experience refers to most recent practices of the past 5 years. Their advocacy works links towards three main directions – building efficient networks among organisations, using mass media and social media to pressure for social justice. ARV therapies are running out this year - it reflects Greek government relation to hospitals. It needs to be changed; they have to give warning to the government. Last year the government didn't take necessary measures; there was a lack of ARV therapies for some weeks.



The organisation tried to find informal ways to help, to protest and intervene. Fight HIV is related to stigma with campaigns. Current implications that they have to overcome and two achievements in Greece (see the poster). The AAE role should be active and proactive; it should be an observatory for Europe and Central Asia.

3.8. Tolibjon Saidaliev, Sudmand Tajikistan (Annex 8):

In terms of how civil society can maintain role, Tolibjon thinks in the current situation Tajikistan is in danger by lack of funds for HIV prevention, the civil society needs to continue a dialogue and to gather information to promote national HIV policies and promote reforms that might be useful for the issues. They need more coalition building among activists, need to exchange information and organisation gatherings for the interested groups. Civil society can be strengthened in this region. Developing of the target funding programmes without involving or including persons from those communities is our biggest problem: there is a need to speak about integration of efforts from different organisations. In 2012 they offered 4 types of services: two of them were offered by public organisations and two offered by the NGO of Tolibjon. Thanks to this programme supported by an organisation in the Netherlands they could provide HIV related services; 65% are offered by health care organisations.



What can be the role of AAE in terms of advocacy? - AAE is an important source of technical support for their region. It can teach civil society how to use innovative democratic tools in order to develop the evidenced based databases on regional and national level, so they can come to them with their government. AAE can develop technical support for representatives of civil society, in talks between civil society and political decision makers to make them cooperate with civil society to develop national strategy for HIV response.

3.9. Hana Malinova, Bliss without Risk, Czech Republic (Annex 9):

“Bliss Without Risk” is an organisation with the target group sex workers. They are already 24 years on social market, next year will be the 25 year anniversary. They provide health care services (comprehensive information about organisation). Majority of women reported sex without condom. One of the methods is to play with sex workers theatre. This is a trans person on the poster, he’s very famous, he is in an organisation named Pragolik. He can show you special places in Prague with dark corners – so if you come to Prague ask him for the guiding.

The organisation of Hana did research in the last two years about the violence against sex workers and conclusion of research was that social stigma had more of a slap. Stigma is the worst thing people face.



3.10. Iatamze Verulashvili, Woman Centre, Georgia (*Annex 10*)



Iatamze thanked for the invitation, for the possibility to be present and to meet all of you who do important work in Eastern and Central Europe. Thanks to the Ukrainian colleagues who have achieved so much in such a short time. In Georgia it's not that bad thanks to Global Fund that worked well. However, in 2 years they will leave Georgia and Iatamze's organisation is looking for ways to continue their work that has started and is going on right now. Georgian state has ascribed to continue work and wants to do it, but from the experience of Iatamze and her organisation it will be not so easy. They are working for 19 years for women's rights, they are working with different vulnerable female groups and they have a human rights approach. They developed a plan and think it will work. People need to protect and promote their rights. They are doing their work on community level: local groups are so active that they need and can unite to protect their rights. As a member of agency for Eastern and Central Europe – protection for abortion rights for Poland – everyone has stood up all over Eastern and Central Europe, all groups need to stand up for their rights in order to make government to hear it and implement according the changes in the laws and on the normative levels. They need to take over the control, need to know the problems and issues to work on.

This is future on level of civil society and civil society organisations. What kind of groups can it be? They can coordinate actions with organisations in the same field. In Georgia a good law exists; municipal bodies have their own fund: people in communities can apply for projects at the municipalities and this funding will be allocated accordingly. What it could be done? On a Global Fund level – on the level of regions, municipalities – there are a lot of services that have been established. These services have told that they need advocacy. They know how to be autonomous and independent. They need help or assistance for advocacy with laws and lobby work. Laws have not been passed and do not exist so they need them to be developed. This is no news for all international organisations that work in our countries, there is the problem of funding. The financial aid would be a great option if there will be joint action to get on community level to continue work with a proper financing.

4. Strengthening Civil Society - the role of AAE in supporting its members.

Breakout session in working groups were based on the contributions from AAE Members in the morning Planned are four working groups (one in Russian focusing on needs and demands exist in Non-EU countries) and three thematically linked working groups on Monitoring, Capacity Building and Communication. Guiding questions for the working groups are:

- What are the main objectives or strategies that you need support for?
- Which parts of this support can and should AAE provide?
- What other support do you need and where could it come from?
- ✓ Presentation of working group results
- ✓ Summary of the session with recommendations to AIDS Action Europe

4.1. Group work

After the brainstorm and discussion, groups have to summarise the discussion and report back 5 key points to the plenary.

Group presentations

- 1) Monitoring
- 2) Needs and support: What are needs and role of AAE to provide for them? (only in Russian)
- 3) Capacity building
- 4) Communication and information

4.1.1. Working Group: Monitoring

Coordination: Michael Krone

Presentation and discussion: Brian West, EATG



Deliberately the group went for four points instead of five:

A - Monitoring policy and prevention – A tool kit to ensure that what is happening there is really happening as it was done by AAE in Latvia regarding initiation of treatment. AAE can put pressure on local governments. This isn't about intervention –. There is a need to monitor the policy implementation on that level.

B – Monitor the extent to which human rights criteria are respected

C – Sustainable monitoring of long term trends – this is not what's happening now but over time, Especially privatisation about how much better services could be delivered and which resources can be used.

D – Monitoring of the monitors – Data by monitoring organisations are sometimes simplifying to an extent that it can be harmful. Civil Society needs to monitor the quality of data with regards to the real situation CSO do work in.

4.1.2. Working Group: Communication and information

Coordination: Oksana Panochenko

Presentation and Discussion: Marianella Kloka PRAKSIS



A - **Interactive and enabling communication Interaction:** seeing that communication goes from office to members, but also in the other direction. To provide a platform for networking and enabling communication - early engagement.

B – **Mapping Networks and Initiatives.** Some initiatives already exist – don't reinvent wheel. Mapping is needed to look who is doing what. This also includes sharing good practice.

C – **Identifying key topics every year and map the situation in each country.** Monitoring what is happening at national level on a standardised basis.

D – **Curated content** – produce key points per issues and make content available for different kinds of use.

E – **Advocacy Templates** would help people to use what is going on elsewhere but in their own countries. The Civil Society Forum produces interesting things – “this was discussed at the forum and we want you to pursue these issues”. Others could be around how you do advocacy.

4.1.3. Working Group: Needs and Support

Coordination: Olga Aleksandrova

Presentation and discussion: Andrii Chernyshev, Gay-Alliance



A – the most important is the necessity of institutional development of our communities.


Participating organisations usually receive money to implement concrete projects. But they can't receive money to develop structurally because donors don't think this is a worthy topic. In two years when Global Fund is gone from the countries – organisations might cease to exist. Instead they could train or connect with new donors who help with structural and organisational development.

B – Comprehensive and reliable data. There are two types of data: official governmental data with regards to vulnerable communities which doesn't reflect situation in real life. AAE could help to advocate this issue via WHO or CDC in the USA and other structures, which would help to gather reliable data that reflects on situation that is actually happening in communities.

C – Cooperation between civil society and state bodies or authorities. In the countries of the region it is weak. They could use strengthening of role of community in different coordination committees of the countries. In Ukraine at the moment organisations want to include three representatives of vulnerable groups into state national coordination mechanisms. In three months they will have sex workers, MSM and drug users in the committees.

D – Insufficient access to services: to the treatment, to therapy, insufficient access to the preventive mechanisms. Which support could it be? - It's advocacy, they can use the AAE contacts. Advocacy takes place at Civil Society Forum. These are the questions that can be solved on such levels. Different organisations can help here.

E – Destroy legislative obstacles that prevent good access to HIV related services. Unfortunately there are many of those in Ukraine. Sex work is crime; other states have other legal acts on drug use, for example. Russia has legislation against LGBT communities. It is important to exchange best



practices - to see how dialogue between officials and civil society can emerge, so they can bring experts to Berlin where they can see that some things are possible and how they can be done. The members strongly believe, behind this is a lack of information. People don't know how it's done so they can't work on it.

The trans community really requires such knowledge because there are no data on how many of such people there are, and about the spread of HIV, and which legislative obstacles can be removed. They want to add something about Baltic States, which are between Eastern and Western European regions. The last issue on legislation with regards to trans people: they are not visible, they are not there, also on the official level in Eastern and Central-Eastern Europe. This is why the member organisation dealt with similar aspects. Concerning institutional support: as already said on the Civil Society Forum – the Think Tank is not paying attention or acknowledging their organisations as equal actors. They have learnt today as well: in the Country Coordinating Mechanism they are forced to implement programmes by Global Fund but when Global Fund leaves it's not clear how work will continue. In their countries they invite one or two NGOs and this person tries to represent 5 different groups. They don't give access to people to information. They keep everyone at level of information they have because they are anxious about giving it away, thinking people are unable to understand or don't know what will do with information. This is why the AAE members asked to give them capability or competency to control and monitor organisations and to speak with governmental organisations as equal. They want to enter the network, similar with trans, to fight for their rights.

The first group already said that monitoring has to be organised. Our group also came to this conclusion. Some of the organisation of the working group is an active participant at Civil Society Forum – you spoke about PrEP and went far and advanced but still there are countries still speaking about lack of services, treatment, of ARVs. They are still at this level. Eastern Europe and Central Asia region has to be paid more attention to. The working group wants this topic to be addressed and tackled. They want, for example, concerning testing, to see results of their work and to tackle issues we have and measure our goals about existing testing. AAE in their eyes is responsible for addressing issues within 3 months and they have to feel that they as an organisation are taking responsibility for their region. Without this region we won't reach our goals.

4.1.4. Working Group: Capacity Building

Coordination: Anke Van Dam,

Presentation and Discussion: Silke Klumb, Deutsche AIDS-Hilfe



A - **Platform + / to connect** – more for exchange rather than just database. Additionally, they are looking for collaboration and consecutiveness itself.

B – The **social capital of the members** is most precious we have – members as orgs and as people. To find how to profit more from each other’s social capital – perhaps through elaborated platform or other ways.

C – **Need to link conventions on human rights to practical work.** Human rights are most important part of basis of our work. How to use conventions in a daily work? There is a need to invest in linking in this field.

D – **Work with religious leaders** should provide training for CBOs to get in contact and work with religious leaders.

E – **Social media and web marketing.** **Webinars** could be a way for providing trainings.

5. Strategic directions for AAE for 2018-2021

- What are key issues that processes need to promote over next period of time?
- What kind of work AAE has been doing?

Michael Krone (*Annex 12*):



Michael thanked participants for their contributions. He wants to make them concrete with regards to future in terms of strategic framework development – 2018-2021. AAE has a grant from European Commission until 2017. To prepare for the next phase the members' contributions are extremely helpful. In order to put it in perspective Michael introduces the current work plan.

There are three main objectives:

1. Ensure civil society's contribution to regional and national HIV/AIDS policies

The members have already heard about the Civil Society Forum, an advisory body to European Commission where civil society organisations from EU and Neighbouring Countries come together – organised by EATG and AAE. Also Commission and Agencies are there. It's a body where AAE can address issues, bodies, things, etc. The Civil Society Forum looks very technical but it can decide

what to have on the agenda and can address issues to Commission and to the agencies. .AAE also participates in the Think Tank, consisting of representatives of governments (ministries of health, public health agencies). Apart from this AAE participates in conferences, advisory boards, joint actions, projects in order to ensure that civil society's voices are being heard. Since last year AAE has a seat on the UNAIDS programme coordinating body (PCB). AAE brings in the European perspective of civil society organisations.

Under this objective AEE also implements the following projects:

- 1. European HIV Legal Forum** – access of undocumented migrants to treatment, with a forum consisting of 10 AAE members.
- 2. Affordability** – three advocacy trainings on accessibility to treatment which will continue next year (3 regional trainings)
- 3. Community based voluntary counselling and testing (CBVCT)** – done by various projects and networks with provision of a lot of data. AAE tried to wrap up what has been doing on European level with this project.
- 4. Upscale access to HIV prevention for gay men and other MSM** - also tomorrow AAE will have a meeting on gay dating applications for prevention and information dissemination. Moreover, AAE is participating in the PrEP in Europe initiative.
- 5. Joint action on harm reduction (HA-REACT)**, AAE has a role in the dissemination work package.
- 6. ESTICOM** – AAE is responsible for the promotion of the first survey and trainings on community health workers working in the gay community.

2. Linking and Learning

- Knowledge exchange and collaboration between AAE's members, partners and other stakeholders. For this aim we re-launched the Clearinghouse, an ongoing process.
- Re-launched AAE website, works well as database for all member organisations in order to look for an organisation that members may want to contact, which happens when one wants to know about an issue in a particular country.
- Work with social media has improved. AAE is a bilingual network in both English and Russian.
- The Member Meeting – this is the first one, contributes to activities listed under objective two.

3. Ensure governments of AAE through its Steering Committee

Steering committee is important body of AAE – many of them are here. Our budget is: app. 330,000 Euros this year. It isn't a lot but it's enough to keep this work going.

Core thematic areas 2015-2017 are:

- Improved access to HIV services and treatment for migrants with irregular status
- Affordability of medicine specifically regarding HIV and Hep C treatment
- Community based voluntary counselling and testing outside medical settings
- Up-scaling access to prevention for gay men and other MCM (PrEP, gay apps)
- Advocacy for a new policy framework at EU-Level
- Advocacy at international level (UNAIDS PCB)
- Reducing stigma and discrimination in order to ensure access to prevention, treatment and care for key populations as cross-sectional theme

Based on outcomes of discussion – AAE will apply for a new framework partnership agreement for four years to the European commission in 2017. AAE will create its strategic framework 2019-2021.

6. Open discussion on core thematic areas of AAE in its upcoming Policy Framework

6.1. The discussion starts with brainstorm and key words

Following topics were named

- 1) Access to medicine and expanded to include hepatitis and TB
- 2) Access to prevention for vulnerable groups
- 3) Fighting against stigma
- 4) Regarding prevention and harm reduction – emphasize coverage because in Western Europe they say it's there without realizing it's only available in one prison for example.
- 5) Add about prisons and treatment – in some countries people are treated by medication bought from ministry of justice and don't report what kind of medication or quality. Access has been low.
- 6) Improving quality applies to all
- 7) Human Rights and criminalisation and legal impediments towards HIV issues
- 8) Migrants have been underserved for a long time – not only talking about non-documented, there are many barriers for documented as well.
- 9) Empower people with HIV to stand up for own voices and not just represent them. AAE: added to fighting stigma.
- 10) Under-representation of countries where infection is quite prevalent.

AAE Steering Committee has no Spain or Portugal now but do have people from Southern Europe – e.g. Athens.

11) Statement of boy in picture – attend school and make elections for pupils – learned that HIV people are part of society. How people are living in society, information, education– so how to fight stigma? – AAE: - Education is an answer.

12) Prevention is very general issue – it can be harm reduction, testing, condoms, information, apps. The key word is access.

13) Necessary to work with governmental representatives – if the government doesn't collaborate r it will be impossible to make any kind of change. AAE should focus on how to work with government as strategic topic? Concerning every aspect and point, AAE could organize a separate meeting. Much to be said about each of these points!

6.2. Prioritizing and justification

Highest priority: access to treatment and access to prevention; EU policy has access and affordability less in focus. Access to treatments – AAE is adding Hep and TB.

Dimensions – price, intellectual property, delivery, system, patients demands, transparency (about who is clear about who is getting treatment, pricing, research and development, etc.); medical protocols, state financing of health care programs, precondition, knowledge about treatment, evidenced based knowledge, treatment as prevention.

Things to add:

Intellectual property from Europe or America should be facilitated – on example of Gilead – profits were used to pay share holders and not to pay for more research. It's ironic to speak about this in 2016: prices can't help maintain profits, price should be open and put up by community Intellectual property rights are clearly cause of high price of medicaments in the USA but nothing on this is in Europe. We can leave the room with one question – what is value of innovation if not accessible? This is an opportunity for EU countries with highest infection rates to gain the compulsory licenses issued by United States. Euro countries don't know that mechanism that can be used under extreme circumstances and this isn't just for political circumstances.

Now to access to prevention:

- PEP, PrEP
- Harm reduction
- CBVCT
- Condom access

- International standards
- Normative guidelines
- Shared best practice
- Normalisation of homosexuality
- Intersectionality
- There are more than one vulnerable group: MSM, trans, sex workers, trans sex workers, etc.

Further contributions on how to focus even more:

- PrEP: what would be a formula for introducing in Eastern European countries where it won't be on table for 5-6 years?
- International AIDS vaccines initiative



EU Policy

- Basis for all other work
- Conservative environment
- Anti-EU environment
- Main gap in Eastern Europe between government and CS

- EU policy from member states, we have only the government's voices and we need to provide another voice
- WHO region Europe includes Central Asia and fast track to end AIDS in 2030
- Integration of Hep and TB

The organisers didn't want to spend long time by summarizing: they have managed to really focus on some of key topics. Some of them still persist, unsurprisingly. Some good ideas are here to start the focusing process.

7. Closing words, Anke van Dam, Chair of the AAE Steering Committee

Anke noted that it is a very difficult task to summarise because it has been a rich day. The meeting has been started with 5 very good presentations and 5 very good posters, responding to questions asked by the Steering Committee. It has become clear that Civil Society has already achieved a lot on raising awareness on HIV, reducing prices, raising budgets. In Ukraine organisations have the budget for OST, ensured their role and health services. Participants have indeed many challenges: Eastern Europe and Central Asia influenced by Russia, where key populations are not included. The focus on human rights is diminishing; however we have to keep this focus up!

AAE should take up the role of ensuring, providing technical assistance, should break in song, should gather evidence to make advocacy based on it's now or never, shared vision and strong and united agenda, should not be silent and keep focus on human rights, should collect better data from Civil Society.

Anke thanked the 10 presenters for their work: they formed the basis for the rest of day. She thanked all members for an active participation and contributions and for coming to Berlin. She thanked Matthias for the very good facilitating and interpreters for a good interpretation. Without their work everybody wouldn't have gained the meaning. She thanked last but not least secretariat – Michael, Oksana, Ferenc and Alexej. Without all AAE office efforts, AAE would not be where it was.

7.1. Final sentences from the participants

- Happy to join and met so many interesting people again.
- Good format, do a lot and share experience and evaluate best needs and have nice lunch.
- Challenge to do meetings in English and Russian and you managed to make easy so congrats.
- Feels like a Christmas party and feels like family finally together.
- After today's meeting I feel like part of something larger than us and this gives us something more confident and strength to fight.
- East meets West and other way around and showed that we are one Europe.
- Learned a lot and will be better because I was here and learning from all of you so thank you.
- I am inspired for today's meeting and opportunity that you gave us.
- Thank organisation committee – meeting was very successful. Get a lot of knowledge of what is being done in country. I hope in future we can collaborate.
- Thanks everybody – taking away a lot of perspectives especially human rights including the way to effective therapy,
- Thank you all for coming to Berlin where East meets West and that is the good thing about this city.
- Thank you all it's been very inspiring meeting.
- In NGO sector there is a lot of talking and meetings – now I think there is reason to talk more and figure out how to do better work on different levels.
- Learned a lot and gained new perspectives – it was a cool day.
- We have language wall in Europe and we made steps forward to break it down thank you.
- It was a unique day for me – thank you all and Aids Action Europe. I have a lot of great things to discuss with my colleagues in Greece.
- Thank you and really look forward to the next meeting.
- As someone from the edge of Europe I'm proud and pleased to meet people from the other edge of Europe
- I've got a new person motivation for my work – thank you very much for this meeting.
- It was helpful and informative – thank you Aids Action Europe.
- I would like to thank you – despite the fact that I had to go a long distance, you invited me. From the transit country which is the source for drugs.

