Nothing For Us, Without Us

Geneva, July 2014

Strengthening youth leadership to address the challenge of HIV and advance health and human rights of LGBTQI people in Europe
Background

In the early years of the AIDS epidemic, activists from the gay movement in Europe, North America and Australia responded to its severe and disproportionate impact on gay communities and the accompanying homophobic attacks through an extraordinary community mobilization. The extraordinary mobilization of gay communities in response to the AIDS epidemic also laid the foundation for the new generation of lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) activists, which, in spite of some severe setbacks, in recent years are celebrating remarkable breakthroughs in the political and public recognition of human rights for LGBTQI people globally and especially in Europe.

HIV has, however, in the past decade disappeared as a priority of the contemporary LGBTQI rights movement and is no longer seen as a unifying cause for most leaders of the movement. Still, across Europe the dual and intertwined crisis of HIV and human rights affecting gay and bisexual men as well as transgender people persists. The European Men Who Have Sex With Men Internet Survey (EMIS) reports that an average of 8% of gay and bisexual men in Europe today are living with HIV, with up to 1 in 4 living with HIV in the age group 45-49 years in the western parts of Europe. Studies among transgender women in Europe indicate a very high prevalence of HIV – 24.5% in Italy, 18.8% in the Netherlands and 18.4% in Spain.

Young gay men are particularly affected by a new wave of HIV infections, which have occurred in many European countries the last decade. The new wave is also affecting other gay men previously at lower risk, who are living in rural areas and smaller cities.

So what’s going on, and what can be done?

“8% of gay and bisexual men in Europe today are living with HIV”
The Consultation

A joint meeting of UNAIDS, ILGA Europe and IGLYO, drew together twenty young LGBTQI activists, aged 18-30 from across Europe - with participants from: Armenia, Belgium, Bosnia Herzegovina, Czech Republic, Germany, Greece, Iceland, Ireland, Italy, Malta, Russia, Serbia, Switzerland, Turkey and the United Kingdom.

Aims & Objectives

The consultation Steering Group came up with four clear aims and objectives for the consultation:

• To empower young LGBTQI activists to become champions of HIV and human rights in their communities and organisations.

• To establish a shared understanding of the impact of HIV/AIDS among LGBTQI people.

• To examine the relationships between the LGBTQI activism and HIV/AIDS activism.

• To establish proposed actions and next steps.

The consultation was welcomed by Tim Martineau, Director of the UNAIDS Executive Office who told the participants about the amazing leaps that have been made in LGBTQI rights in recent years, but also noted how HIV had fallen off the radar for many activists:

"The new generation of activists is experiencing a remarkable political and public support of human rights of LGBTQI people in Europe, but the legacy of the movement must be revived to confront the expanding HIV epidemics and support the growing number of gay men and transgender people living with HIV” -

Tim Martineau, Director of the UNAIDS Executive Office
HIV and Key Populations

As a knowledge of HIV wasn’t a prerequisite for participants the morning session was a back-to-basics on HIV knowledge - covering prevention, treatment, terminology and the realities of life with HIV.

The group explored the basics of how HIV is transmitted, how it can be prevented, how HIV is treated today with combination therapy and what life is like for a person living with HIV.

"Whilst HIV is now no longer a death sentence, and can be managed with one pill a day, it’s no walk in the park. The complications, side effects, and social stigma can be unbearable."

Tom Hayes, beyondpositive magazine

Another area this session covered was Key Populations, or Most at Risk Populations. These include, but are not limited to:

- Men who have sex with men (MSM)
- People who inject drugs (PWID)
- Youth, and in particular homeless youth.
- Trans people
- Sex workers.

“Inadequate or inaccessible healthcare is the prime reason trans people contract HIV at the rate we do, as well as being a major barrier to diagnosis. Desperate attempts to access the funds necessary for transitional healthcare often land us in sex work or prison. The mental health consequences of being refused transition and of transphobia go untreated, and mean many of us have little if any desire to protect our well being, and certainly not sufficient to tolerate the misgendering we would face in a GUM clinic: Even something as small as using pink and blue folders can really distress a trans person and prevent them from returning to get tested in future”

Reubs Walsh, LGBQTI Activist
Gay and bisexual men continue to be disproportionately affected by HIV with the numbers of new diagnoses amongst this group rising. There are a number of factors that contribute towards gay and bisexual men being so heavily affected by HIV:

- Lack of appropriate sex and relationship education
- Discrimination and stigma surrounding their sexuality may prevent access of sexual health services - or an open dialogue when using these services.
- Gay and bisexual men are often likelier to have a higher number of sexual partners than their heterosexual counterparts.
- Higher risk sexual activities. Anal sex is inherently higher risk than vaginal or oral sex due to a thinner membrane in the anus and the gut being the site of the majority of the bodies CD4 cells - the cells which HIV attacks.

Group discussion showed that different key populations carry a higher burden of HIV in different countries. For example MSM have the highest rate of new HIV diagnoses in the United Kingdom - whereas in Ukraine the largest group of HIV diagnoses are amongst those using intravenous drugs.

“Various factors contribute to gay men being disproportionately affected by HIV/AIDS. In the context of East Europe and Central Asia, it is mainly socially constructed and enforced negativity towards and discrimination against homosexuality that fuels HIV among MSM. Stigma and negative attitudes towards gay men and MSM affect their own decision to be tested, regardless of their sexual practices. This impedes their understanding of risks and, hence, leads to engaging into practices that increase the chance of acquiring the virus.”

Oleksandr Martynenko, European AIDS Treatment Group

**HIV and LGBTQI activism: One strand or two?**

The afternoon saw a session on activism. The group discussed the history of LGBTQI and HIV activism, how they once worked hand-in-hand but have since gone down separate paths.

Why? Should they be working together, and if so how do we achieve this?

The group heard two very different stories of activism. The first, presented by Henning Mikkelsen, was how Denmark’s gay population worked hard to establish HIV support organisations and raise awareness - but then over time HIV dropped off the agenda and the gay organisations focused more on civil partnerships and equality.
“Nothing for us without us! The dual crisis of HIV and human rights of LGBTQI people in Europe can only be solved with the full involvement of the LGBTQI movement

Sophie Aujean, ILGA Europe

Ashot Gevorgyan gave his experience from Eastern Europe. Whilst Armenia was a part of the Soviet Union homosexuality was not discussed, and initial cases of HIV were blamed on the US Pentagon. Armenia declared independence from the Soviet Union in 1991, and in 1993 homosexuality was decriminalised. LGBTQI and HIV organisations now work very closely together on HIV in Armenia as LGBQTI groups take the cause more seriously than other sectors. Funding is still a big issue however.

The participants then took time to reflect, in groups, on LGBTQI and HIV activism in their own countries and regions. They discussed what they shared, and what was different - as well as what they could learn from one another. This was then presented back to the larger group.

Participants from the United Kingdom told the group that despite an initial close working relationship HIV and LGBTQI charities have now, largely, gone their own way. Some of the larger gay charities also don’t represent trans people - who are at a much higher risk of contracting HIV.

**LGBTQI and HIV Stigma**

Day two saw discussion on LGBTQI and HIV related stigma. Stigma is defined by the Oxford English Dictionary as “A mark of disgrace associated with a particular circumstance, quality, or person”.

“Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world”

Ban Ki Moon - UN Secretary General

The group, discussed the difference between stigma and discrimination, what kinds of stigma there are and how they can affect people in different ways.

Participants then split up into groups to debate the big question - Why is HIV so stigmatised?
Some of the biggest factors identified as contributing to the stigmatisation of HIV were the inextricable links with sexuality, sex and drug use. Other factors included fear of infection - due to a lack of education, and laws criminalising HIV transmission.

A number of suggested ways to tackle HIV stigma arose during the group discussions:

- Remove laws criminalising HIV transmission
- Improve access to, and the quality of, sex and relationships education
- Make people living with HIV more visible.
- Get involvement in HIV awareness and prevention work from all sectors of society

**What do we need? A lesson in action planning**

The final session of the consultation asked the participants to create an individual work plan detailing how they intend to put HIV back on the agenda in their country or region. The planned:

- What is the issue?
- What should be done about it?
- Who should do it?
- Who are the allies and who the opponents, who can be swung?
- What resources do you need?
- Where would you find them?

After the individual work the participants then reconvened in their geographical groups. They were tasked with working together to create a group poster for presentation to the wider group and a delegate from the European Union.
Access to comprehensive sex and relationship education and healthcare services are not sufficiently inclusive!

Sex education needs changing:
• Inclusive of the diversity of the types of sexual acts, relationships, identities
• More robust national minimum requirements, reflect human experiences.

Improve healthcare professionals basic knowledge of human diversity and their needs through compulsory training.

Expansion of specific “closed clinics” for certain groups

Locally work with councils, CCGs, NHS Trusts, schools / colleges / universities, youth groups, LGBTQI groups, HIV groups...

Nationally work with government departments (Education & Health), NGOs, bodies such as NICE and Public Health England etc.

National campaign groups, trade unions, and national charities.

Target all youth via compulsory Sex and Relationship Education.

Specific outreach programmes to work with and empower trans people and sex workers.

Barriers will be put up by some parents, politicians, social conservatives and media.

Systematically review current legislation, national curriculum and NICE guidelines, sex education survey to review holes in services.

If successful STI testing will increases, proportion of undiagnosed HIV cases will decrease and service user diversity will increase.

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The Current Issues

- Increase of HIV and STI infections amongst young people, and especially LGBTQI youth.
- Stigma and discrimination

The Objectives

- Internationally: Implement international standards, including the key principals of REC200.

AT ALL LEVELS THERE NEEDS TO BE BETTER COLLABORATION BETWEEN LGBTQI AND HIV ORGANISATIONS

Targets

- Political organisations, Official authorities, NGOs & International bodies, educational institutions, health institutions, all LGBTQI organisations.

- HIV & AIDS

Visibility and Awareness Raising

WHY?
Objectives: Education, stigma removal, safer sex.

Goals: Reduction of HIV transmission, improving the quality of life for people living with HIV.

WHO?
Target: General Population of a specific city / area - with a focus on key populations.

- Allies: Local organisations (HIV and LGBTQI), Health Sector (public and private), Government (Local, Regional and National), International bodies (EU, UN, WHO, Council of Europe etc)

HOW?
• Reach out to the population (be visible in public spaces)
• Non-formal education
• Variety of activities, events and methods (to fit everyone’s needs)
• Make it fun, interesting, and appealing.

WHEN?
• Ongoing project, not just one day
• Big promotion on and around World AIDS Day (December 1st)

WHERE?
Wherever there are people!

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HIV & AIDS
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Presentations

After lunch each group presented their poster to the larger group, as well as Lourdes Chamorro, First Secretary, Permanent Delegation of the European Union to the United Nations Office and Richard Burzynski, Senior Advisor, Universal Access Partnerships at UNAIDS.

The participants of each group took turns to talk through the aspects of the poster which were important to them, and which key issues they would champion at home.

Each group was then asked to sign their poster with a hand print as a personal pledge to act on the plans they have built over the two days of this consultation.

Lourdes Chamorro, having watched the poster presentations and talked with a number of the participants then gave her thoughts on the current HIV landscape, and how essential the role of individual and organised activism is in changing attitudes.
Key messages from Nothing For Us, Without Us

- Across Europe the dual and intertwined crisis of HIV and human rights affecting gay and bisexual men as well as transgender people persists\n
- Young gay men are particularly affected by a new wave of HIV infections, which has occurred in many European countries the last decade. The new wave is also affecting other gay men previously at lower risk, who are living in rural areas and smaller cities.

- The LGBTQI rights movement has a significant potential to leverage its momentum and re-gain its role as a strong political voice and force for the HIV response

- The HIV response must be anchored in a broader agenda for health, equality and inclusion of LGBTQI people

- Strengthen youth leadership to address the challenge of HIV and advance health and human rights of LGBTQI people in Europe

Joint Declaration by UNAIDS, ILGA Europe and IGLYO

On occasion of the consultation Nothing for us without us - Unleashing youth leadership to address the challenge of HIV and LGBTQI rights in Europe, organized jointly in Geneva, 15-16 July 2014, UNAIDS together with ILGA-Europe and IGLYO call upon the European Union, governments, local authorities and member organizations in Europe to support and strengthen youth leadership and empowerment to address the challenge of HIV and advance health and human rights of lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) people in Europe.

Across Europe 8% of men who have sex with men today are living with HIV, with up to one in four living with HIV in the age group 45-49 years in the western parts of Europe. Studies among transgender women in Europe indicate a potentially very high prevalence of HIV: 24.5% in Italy, 18.8% in the Netherlands and 18.4% in Spain.

Young men who have sex with men are particularly affected by a new wave of HIV infections, which has occurred in many European countries the last decade. The new wave is also affecting men who have sex with men previously at lower risk, who are living in rural areas and smaller cities. At the European level, there is a rapid growth of new infections among men who have sex with men living in the central and eastern part of Europe. Access to internet and increased mobility in Europe may have increased the scope, size and density of networks of men who have sex with men, but little has been done to address the prevention
needs of young men who have sex with men and transgender women that are now at increased risk.

On the opposite, several European countries have sharply reduced funding for prevention among men who have sex with men. The rise of new infections threatens to further intensify and ignite stigma and discrimination towards LGBTQI people, especially in countries with high levels of homophobia, and in countries, where populist movements who are against the human rights of LGBTQI people are gaining foothold. New approaches, tools and technologies have potentials to significantly bring down the number of new infections, but are not well known and yet to be fully harnessed.

Governments, local authorities and civil society organizations should as a matter of priority work towards:

1. Strengthening the capacity of young LGBTQI activists and organizations to develop and implement innovative approaches to address the challenge of HIV and advance their health and human rights, and ensuring their full and meaningful involvement in national responses to HIV

2. Strengthening sexual education in schools in accordance with the international technical guidance, as well as online-communication and other approaches that addresses the urgent needs of young men who have sex with men and transgender women for access to tailored, non-judgmental and anti-stigmatizing HIV information, prevention commodities and HIV testing, counseling and care services.

3. Ensuring the rights and empowerment of young men who have sex with men and transgender women across Europe to make informed choices in relation to treatment initiation and prevention strategies, including on the reduced risk of transmission for people in effective treatment, condom use and new tools such as pre-exposure prophylaxis

4. Reducing stigma and discrimination related to sexual orientation and HIV status, and ending criminalization of homosexuality and an overly broad criminalization of HIV non-disclosure, exposure and transmission.