

What business do youth have making HIV and AIDS laws in Nigeria?

6

by FADEKEMI AKINFADERIN-AGARAU and TEMITOPE FASHOLA

I was denied admission after passing all the admission requirements into a Nigerian university because I tested positive to HIV. They said I was a threat to other students and so my admission was withdrawn. The only thought I had at that point was to commit suicide.

Gloria, aged 24, young person living with HIV/AIDS and a YAG member.

Introduction

In Nigeria youth aged 10–24 account for 60% of new HIV infections (United Nations, 2004). As Gloria's experience highlights, they face significant stigma and discrimination. HIV prevalence among young people age 15–24 is 4.1% which is as high as the national prevalence.¹ So it is essential that any policy on HIV and AIDS fully recognises and addresses the needs of young people. This requires engaging young people in the policy-making process to hear their views. However in Nigeria,

nearly thirty years of military rule has created a culture in which both old and young believe that they do not have a say in public policy and laws.

Education as a Vaccine (EVA) is a national, non-profit organisation in Nigeria. It aims to strengthen the capacities of children, young people and other stakeholders to facilitate and sustain social change on health and education through direct service delivery and advocacy/policy influencing. Our advocacy work on sexual and reproductive health is coordinated by a group of ten young Nigerians aged 18–24 years who attend school or reside in Abuja, Nigeria's capital.

This article highlights how EVA's Youth Advocacy Group (YAG) managed to participate in and influence the development of Nigeria's national HIV and AIDS anti-stigma and discrimination legislation so that it better meets the needs of young people in the country. Using different participatory tools and approaches, the

¹ 2010 Nigerian National Sero-prevalence Sentinel Survey.

YAG educated other young people about the impact of HIV and AIDS stigma and encouraged them to take action on the draft HIV/AIDS Anti-Discrimination Bill 2009. Key lessons learnt about supporting young people's participation in policy-making processes are also shared.

Setting the stage

With over three million people living with HIV and AIDS, Nigeria has the second largest population of people infected with the virus in the world after South Africa. The growth of the epidemic has led to widespread stigma and discrimination. HIV and AIDS stigma can have devastating effects, preventing individuals infected from seeking care and increasing vulnerability to violence amongst both individuals and their caregivers. The fact that Nigeria does not have a national law to protect those affected by the epidemic therefore places many people at risk.

The 2009 draft HIV/AIDS anti-discrimination bill and the 2009 Discrimination of Persons Living With HIV/AIDS prohibition bill addressed some key aspects of discrimination faced by people living with HIV and AIDS.² The bill was first introduced in 2006. However, due to a lack of political will the bill didn't proceed beyond the second reading and had to be reintroduced in 2009.³ The bill's reintroduction was made possible because the newly elected legislators had a better understanding of HIV and AIDS issues and demonstrated increased support by establishing a separate committee for HIV and AIDS in the Nigerian Parliament's House of Representatives.

But while civil society groups were involved in drafting the bill, young people were not part of the process. It was generally assumed that only individuals with

legal expertise could make a meaningful contribution. It also demonstrated a lack of information about the bill amongst young people. The absence of young people was clearly reflected by the fact that the draft bill did not recognise the impact of HIV and AIDS stigma and discrimination within the education system. This was despite documented cases of young people being required to take a mandatory HIV test for school admission and being refused because of their HIV status.

International youth speak out

Initially, EVA's programmes primarily focused on delivering services. However, in 2008 we were selected as the coordinating body in Nigeria for a multi-country project called 'International youth speak out' (IYSO).⁴ IYSO operates in Ethiopia, Nigeria and Jamaica and aims to influence international and national policies and programmes on youth sexual and reproductive health and rights.

One of the core pillars of the project is youth participation. Recognising this, a Youth Advocacy Group was formed to implement in-country advocacy activities and to provide real experiences to feed into international level advocacy.

EVA provides daily technical support to the YAG. The first set of YAG members were selected by EVA staff using an agreed set of guiding principles (see Box 1). The current YAG consists of six girls and four boys. Members represent each of the six geopolitical zones of the country, although all reside in the capital, Abuja. It is also representative of the diverse ethnicity in Nigeria.

The group has a formal meeting twice a month. Temitope Fashola, EVA's advocacy and campaigns programme coordinator, provides YAG members with technical

² The bill was introduced by the Federal Ministry of Labour, the National Agency for the Control of AIDS, the Network of People Living with HIV and AIDS and the Civil Society Network on HIV and AIDS in Nigeria.

³ Informal discussion with a representative of the National Network of People Living with HIV and AIDS (pers comms., 16th March 2011).

⁴ The project is funded by Advocates for Youth, Washington, DC.

Box 1: Guiding principles for selecting YAG members

- Member must demonstrate their commitment to speak publicly on youth sexual and reproductive health issues.
- Membership reflects different ethnic and religious groups from Nigeria’s six geopolitical zones.
- At least one member must be a young person living with HIV and AIDS.
- Members must be aged 15–24 years.
- Membership includes young people both in and out of school.
- There is a good gender balance among members.

support in terms of planning and implementing activities at these meetings. But beyond this support, the YAG members are treated as staff members.

Over the past three years, some members of the group have changed. Existing members are responsible for selecting new members, based on criteria in Box 1, which the group itself has chosen. They advertise new posts and also invite friends who fit their criteria to apply. The group conducts interviews for all applicants and jointly decides on new members.

The YAG has three main objectives:

- Increase national budgetary allocation to the Ministries of Health, Education and Youth as well as the National Agency for Control of AIDS to support the implemen-

tation of sexual and reproductive health (SRH) policies and programmes for adolescents and young people.

- Increase the participation of young people in the development and implementation of sexual and reproductive health policies and programmes.
- Facilitate the creation and strengthening of dedicated structures to coordinate the implementation of adolescent and young people’s sexual and reproductive health policies and programmes at State and local government levels.

To achieve these objectives, the YAG use communication and advocacy strategies to educate their peers, adult gatekeepers and policy makers to take actions to improve the sexual and reproductive health of young people.

Out of sight, out of mind?

In October 2009, the draft HIV/AIDS anti-discrimination bill had progressed to the second reading stage. A formal public hearing was called and various stakeholders were invited to participate. At this point, no youth group had been invited. The YAG happened to receive a formal invitation directly from the chairperson of the House Committee rather than the committee office which usually issues invitations. This was because of our personal relationship

Table 1: Timeline for EVA’s YAG advocacy process

| November 2009 | December 2009 | January–February 2010 | March 2010 | March–October 2010 | October 2010 |
|---|---|---|--|--|------------------------------------|
| Gathering information about HIV and AIDS and SRH policies | Discussion with legislators about the video | Campus tours organised to screen the video and to collect signatures for a petition | Submitting signed petitions to House Committee | Follow-up (formal and informal) with House Committee and legislators | House version of the bill approved |
| Reviewing and analysing the House of Representative’s draft bill | | | | | |
| Presenting recommendations at the House of Representative’s draft bill public hearing | | | | | |
| Developing a video based on Gloria’s experiences | | | | | |



Photo: EVA

Co-author Temitope (far left) with Gloria and other YAG members during the making of their advocacy video 'My experience'.

with the chair, developed over time through consistent lobbying on the issue of funding for youth HIV prevention programmes.

Exhibit A: gathering evidence

In preparation for the meeting the YAG, with support from EVA, reviewed the draft bill to determine how the issues of young people were presented and identified gaps. The review revealed that the bill focused extensively on HIV stigma and discrimina-

tion within the workplace and inadequately addressed stigma in school, where young people spend most of their time. The only reference to young people in the bill was: 'refusal to admit into school or not allowing them to continue in an educational institution'. We felt that this statement represented a narrow view of the issues of stigma and discrimination faced by young people as learners.

This gap and key recommendations were documented in a **formal position paper** and presented by a YAG representative at the public hearing (see Box 2). The YAG was the only youth group present at the public hearing and was invited to make an oral presentation of its position in addition to the written paper.

Box: 2 Youth-specific recommendations for the anti-stigma bill

Compulsory HIV testing

No educational institutions should require HIV testing as a prerequisite for school admission and graduation.

Disclosure of HIV status

No educational institution should require applicants or current students to disclose their HIV status whether orally or in writing, as it has no bearing on their academic performance.

Differential treatment based on disclosed HIV status

No learner should be treated differently based on their HIV status within all school settings such as classroom, eating or dormitory facilities.

Even a pebble can make ripples in an ocean

The submission of a position paper alone would be inadequate to ensure that the bill was passed with our recommendations. Realising this, the YAG felt it was necessary to get support from other young people. To make sure that they could constructively participate in the policy process, youth were not only educated

Photo: EVA



A YAG member with a student union representative elaborates on her perspectives during one of the university campus tours.

about the policy but also about how stigma and discrimination can negatively affect access to education. The YAG developed a video called ‘My Experience’. The film showcased the story of a member of their group. The group decided to create this video because it brought a human face to the issue rather than just presenting statistics.

The whole process of making the video made me feel like I was making myself relevant and at the same time helping young people like me and Gloria amplify our voices.

Kikelomo, aged 23 years, EVA YAG member.

Working in partnership with the Student Unions of the target schools, the YAG organised campus education events.⁵ These took place in the three states with the highest HIV prevalence rate in Nigeria (Federal Capital Territory, Benue and Nassarawa states). These tours featured screenings of the video, group discussions on the policy led by a YAG member and

signing a petition calling for the inclusion of the YAG recommendations in the draft bill. The combination of personal experiences shared through the video and opportunities for open discussions had a great impact on the young people.

The ignorance that exists about stigma is more dangerous than the disease itself and that is why through these signed petitions we hope the Parliament will take an accelerated action as proposed already by the YAG in the anti-stigma bill.

Yakubu, aged 24 years, Federal Polytechnic Nassarawa.

The YAG did not relent with the submission of the petitions. They continued to have formal and informal follow-up meetings with the chairperson and members of the House Committee on HIV and AIDS. After a year-long process, the HIV and AIDS anti-discrimination bill was passed by the House of Representatives in October 2010 – with our recommendations included.

⁵ Campus tours took place at the University of Abuja, Federal Polytechnic Nasarawa and Benue State University.



A student reacting to the issue during discussions at a campus tour.

Here comes the Red Card...

Nigeria operates a bi-camera legislative arm of government. For a bill to become law, it must be passed by both the House of Representatives and the Senate. So although the bill was passed by the House, it was not yet actually law. Building on their success, the YAG launched the Red Card campaign to facilitate the passage of the Senate companion bill.⁶ The campaign ran for three weeks (8th November to 1st

December 2010) and targeted individuals and groups representing the States and constituencies of the members of the Senate Committee on Health.

Youth were asked exercise their electoral power by completing a template red post card with messages and stories about the effect of HIV stigma and discrimination. The cards were sent to the Senate, calling on senators to pass the bill. We consciously targeted young people above the age of 18 years – and therefore eligible to vote in the upcoming 2011 elections – as a means of getting the attention of their representatives.

To popularise the Red Card campaign, young people were encouraged to share the campaign message with their friends verbally and through social media channels. This included changing their Facebook profile picture to the red card and updating their profile status with campaign messages. As a result, young



⁶ In football, misconduct may result in the player either receiving a caution from the referee (indicated by a yellow card) or being dismissed from the field (indicated by a red card). The YAG Red Card campaign represents a call to end HIV/AIDS stigma and discrimination within schools by enacting the anti-discrimination bill with the inclusion of youth-specific recommendations.

Photo: EVA



A young woman participating in the discussion during the campus tour at University of Abuja.

people outside our immediate networks were able to contact the YAG to request cards to participate in the campaign. We set a target of getting 2,010 post cards to symbolically tell the senators that in the year 2010 they could make a real difference to the lives of young people in relation to HIV and AIDS.

The YAG members presented the cards to the House Committee and its members on the 1st December 2010, World AIDS Day. This focused the attention of the Senate on the anti-stigma bill and has hopefully laid the foundation for the bill's passage in the Senate.

Small numbers can make a big impact

Despite its small number of members, the YAG managed to mobilise over 1,500 young people to support the passage of the House bill with youth specific recommendations. Following this, a further 2,172 young people have given a 'red card' to HIV and AIDS stigma and discrimination in

Nigeria. Several young people acknowledged that the process was empowering and the first time they had actually participated in the law making process.

I am so happy with the opportunity the Red campaign gave me as an advocate to mobilise my peers and call our policy makers to action. You can imagine the kind of reaction I got from even youth in some northern states the moment they realised that the postcard talked about issues related to HIV. This is important and people must know the implications.

Aliyu, aged 21 years, EVA YAG member.

Watch out for the bumps...

These achievements were not without a few challenges. First, the YAG faced difficulty in getting the attention of some members of the National Assembly.⁷ Generally, Nigerian culture does not encourage young people to speak out

⁷ The National Assembly is Nigeria's bicameral legislature and the highest elective law-making body of the country. It consists of 109 Senate members and 360 House of Representatives members. Source: www.nassnig.org



Photo: EVA

YAG members received a formal invitation from the chairperson of the House Committee to attend the public hearing.

because they are perceived as immature and lacking the knowledge and expertise required to make a meaningful contribution in governance.

Accessing information on the Senate bill has also been difficult, particularly as Nigeria does not currently have a Freedom of Information Act. This makes planning our advocacy work difficult.

Since the bill had a national outlook we wanted to ensure national representation of young people in the process. However, this was difficult because all YAG members are located in Abuja and so we needed to partner with other youth groups. Coordinating these groups presented additional challenges because of the number of partner groups, geographic spread and inconsistency in communication channels. For example, some youth groups did not have regular access to the Internet so we had to rely heavily on phone calls which cost a lot more than anticipated.

Finally, the amount of funds available

for carrying out the advocacy work was limited. As a result, the YAG had to significantly scale-down their youth education and engagement activities. For example, the campus events were limited to only one school per state. On the positive side, we were forced to think of other, low cost activities. This led us to use Facebook to compliment our face-to-face strategies.

What have we learnt?

Reflecting on our experiences, there are a number of lessons we have gained from the process. We hope these lessons, bearing in mind the importance of local context, will help others working with young people or young people themselves who want to influence policies and laws.

- Educating young people about their rights and how to exercise these rights is a critical part of supporting them to engage with policy issues. By strengthening their knowledge, awareness-raising activities can build confidence among young people

Photo: EVA



YAG members at the public hearing about the draft HIV/AIDS antidiscrimination bill.

and encourage them to take action.

- In settings where access to public information is limited, it is important to build relationships with government and policy makers. Through these relationships, campaigners can get information about potential events and activities where advocacy messages can be directed.
- Combining formal strategies such as public hearings and lobbying meetings with informal strategies like the Red Card campaign can make successfully influencing government policy more likely.
- Getting involved in law or policy-making might sound uninteresting to adults, let alone young people. However, these processes can be fun and engaging if the right tools and methods (e.g. campus tours and videos) are used. Simple 'take action' activities such as petitions and letter writing are very effective with young people. As they do not require a lot of time or additional financial commitment, young people realise that it can be easier

than they think to participate in policy processes.

- The benefits of social media, as a complementary strategy, in increasing young people's awareness of the issues featured strongly in the Red Card campaign. Social media works best for mobilising and motivating young people to take action when combined with more conventional, face-to-face approaches.

Where do we go from here?

For a bill to become a law, both arms of the federal legislators must approve the bill and harmonise differences. There still needs to be additional follow-up on the Senate Committee to urge the passage of their counterpart bill and to track the harmonisation process to ensure that the youth-specific language is retained in the final law. At the time of writing, Nigeria is preparing for a general election and the majority of the incumbent legislators are not standing for re-election. This presents

both a challenge and an opportunity. The YAG is educating young people on development issues and encouraging them to select legislative candidates that are committed to addressing HIV and AIDS issues and so more likely to support the bill.

So: what business do youth have making laws?

We acknowledge the fact that our small group of young people are not legislators and do not have formal legal expertise. As a matter of fact, the majority of our members are undergraduates or out-of-school. But the reality is that advocacy by the group has shaped a bill that will – if passed – better protect young people and others from the stigma and discrimination

often faced when living with HIV and AIDS. Drawing on experiences to date, the YAG and EVA are in a strong position to push for the Senate companion bill to be passed and, eventually, a harmonised national HIV and AIDS anti-stigma and discrimination bill.

Being a YAG member has made me better appreciate the challenges that youth face in my country and my ability to make a difference. The opportunity to express myself has enhanced my capacity to be responsible not just for myself but for others. I believe this whole experience will be instrumental in preparing me for the future. It means a great deal to me.

Blessing, aged 22 years, EVA YAG member.

CONTACT DETAILS



Fadekemi Akinfaderin-Agarau
Executive Director
Education as a Vaccine
No 2 Kutsi close, 4th floor Standard Plaza
Beside Redeemers Private School
Off Aminu Kano Crescent, Wuse 2
Abuja
Nigeria
Email: Fadekemi@evanigeria.org



Temitope Fashola
Programme Coordinator, Advocacy and
Campaigns
Education as a Vaccine
Email: Teepee2010@gmail.com

REFERENCES

- UNAIDS (2004) *Report on the global AIDS epidemic*. Joint United Nation Programme on HIV/AIDS.
- Federal Ministry of Health (2010) *Nigerian national sero-prevalence sentinel survey*. Federal Ministry of Health Abuja, Nigeria.