

Does HIV Look Like Me? International Society

RECOMMENDATIONS:

THE MEANINGFUL ENGAGEMENT OF YPLWH/A IN NORWAY

&

THE IMPLEMENTATION OF AN EFFECTIVE HIV STRATEGY



PREPARED BY

Brandy Svendson, Executive Director of Does HIV Look Like Me? International Society

Todd Murray, President of Hope's Voice

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1. Introduction

Todd Murray, President and Founder of Hope's Voice and Brandy Svendson, Executive Director of Does HIV Look Like Me? International bring sixteen years of combined experience working with young people living with HIV or AIDS (YPLHIV/A) and a variety of marginalized populations, managing projects, trainings and producing award winning campaigns. They have been innovative and effective in creating approaches, programs and materials that address the needs of young people infected or affected with HIV or AIDS, and have a proven track record for producing real, relevant and emotional materials that inspire and educate young people.

Todd Murray has been living with HIV for eight years. After being diagnosed with HIV at the age of 20, Todd could not identify with mainstream media's portrayal of people living with HIV or AIDS. He did not see himself, and was unable to find a sense of peace, hope or community. He began to understand why, before his diagnosis, he felt disconnected from HIV and AIDS—he was unable to relate so he didn't listen. Todd, refusing to live in fear or be stigmatized, decided to speak out about his status in the hope that other young people would listen and identify. It was at this point he took an active role in the world of HIV and AIDS, and through his own experiences, in 2004 the vision for Hope's Voice was born.

Since founding the organization, Todd has become an advocate, leader and innovator in the field of HIV and AIDS Internationally. Todd, along with Hope's Voice's ambassadors and speakers, have provided education to hundreds of schools and communities. He has been a leading advocate around the world, by representing his organization to governments, communities and by speaking at international conferences. Todd provides his professional recommendations for implementing and improving programs by consulting for non-profit organizations, international media outlets and community organizations.

Brandy Svendson has studied in Brazil, Mexico and Vancouver completing her degree in Anthropology at Simon Fraser University, in Vancouver, Canada. She began her career, in the field of HIV, eight years ago at Youth Community Outreach AIDS Society (YouthCO), Canada's largest and only youth driven HIV and AIDS Organization. She was the project officer for several projects that focused on support for YPLHIV/A, harm reduction, sexual health and HIV education.

Brandy has been invited to present and attend several local, national and international conferences including the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society. She represented Canadian youth as the media co-chair for the International AIDS Conference 2006.

In 2007 she was the Youth United to CAP (Canadian African Partnership) AIDS Project Coordinator. The project promoted women's education, empowerment and sexual self esteem through training, employment and the instigation of micro loans in remote communities in Malawi.

Brandy has been invited on several occasions to sit on committees and to consult around issues of youth engagement and effective HIV education, outreach and support.

In 2009 Does HIV Look Like Me? International was invited by Aksept, in Norway, to development and implement our model of the *YPLHIV/A Leadership Training*. The YPLWH/A Training was generously supported by Norwegian Directorate of Health and a private donor in the Aksept Community. All partners and contributors were able to identify the need for this type of gathering that focused on leadership and action planning for YPLHIV/A in Norway.

The training was a success for many reasons. The YPLWH/A Training allowed us to identify many gaps in services for YPLWH/A in Norway. The young people were very clear on the changes they would like to see. We are honored that our partners and supporters in Norway have asked for us to create this document that highlights our recommendations to ensure the voices of the young people from this training are not lost, and we continue our mission to “educate, inspire, empower, and challenge stigma”.

* When we refer to “young people”, “youth” or “young adults” throughout this document - we are referring to individuals between the ages of 15-29.

2. Background

Although the number of young people living with HIV in Norway is relatively low, the individual experiences and issues of stigma are not reflected in the current quantitative data. We have heard stories from YPLHIV/A in Norway, they feel stigma is a real and damaging issue, and to date, awareness campaigns in Norway have been ineffective in informing the general public about HIV and AIDS.

Furthermore, there is and continues to be a problem with statistics - the statistics tend to focus on new infections and “often are used to advocate solely for primary prevention for HIV-negative young people. But what about all the young people who contracted HIV and become part of this statistic?...Gathering better data on young people living with HIV or AIDS will help us to better understand the current trends and situation and what creates barriers to designing, developing and implementing comprehensive, relevant and sustainable programs and interventions for this group.”(GYCA Briefing Paper, 2009, p.7). The YPLWH/A Training that was held in December of 2009, it was an excellent beginning and I argue must be seen ONLY as the beginning. The work, partnering and support must continue, be broadened and be more comprehensive.

When looking at statistics we must also look at the fact that “a vast majority of young people living with HIV or AIDS do not know their HIV status. The lack of young people getting tested is an issue even in resource-rich settings, which highlights that there are obstacles to testing beyond accessible information, education, services and supportive legislation. Stigma is highly complex and even when services and information are in place in a resource-rich settings, such as Western European countries, stigma can still acts as an obstacle. For example, there are mounting concerns that some young people are opting out of getting tested so that they intentionally will not know their status due to the fear of criminal prosecution in countries where HIV transmission and exposure are being criminalized” (GYCA Briefing Paper, 2009, p.5). In Living with HIV in Norway, Fafo furthers confirms that “among the informants, §155 of the Penal Code emerges as a significant problem. It plays a part in worsening the quality of life and causes problems in amorous relationships, and with respect to daring to embark on new relationships. This is a little less clear among the respondents, even if more than half say the Penal Code worries them”(Grønningsæter et al, 2009, p.149)

Norway is recognized international for having an amazing social and healthcare system that has been successful in facilitating treatment for the majority of people living with HIV within their borders. Fafo reports, the most positive part of what it is like to have HIV in Norway in 2008–9 relates to the physiological health issues. The medicines are improving, the side effects are becoming less extensive and many people experience improvement in relation to health” ((Grønningsæter et al, 2009, p. 148) However, “a study now exists that compares the current living conditions of persons living with HIV with situation seven years ago when the previous HIV strategy was launched” in Norway, individuals living with HIV in Norway are claiming “it feels just as difficult to be HIV positive today as it was seven years ago” (Acceptance and Coping, Preface). These echoed the issues that we found when speaking with YPLWH/

A. We hope to have the opportunity to address these issues in partnership with local AIDS Organizations and the Norwegian Directorate of Health.

3.1 Young People Living with HIV in Norway: In Their Words

According to Norway's national HIV strategy Acceptance and Coping, "the psychological costs of keeping one's HIV status secret are often great for both the individual and the society" (preface). These effects were evident in the experiences and the emotions that the seminar participants shared. The participants shared that they feel "the public doesn't see us like human beings", and that they wish to "change how the public views them" if you change how they view you, it "will change how you view yourself". These are powerful statements, by a group of young people who are willing to step up and be the face of change, if Norway is willing to step and support them, fully.

The young people were asked to identify the main issues they were facing, and to begin an action plan to address these issues. The two main and most pressing issues they wanted to address were stigma and the lack of services driven and directed at young people living with HIV, or at risk of HIV. In turn, they began action planning on two initiatives; 1. Starting an organization specifically for young people living with HIV or AIDS, and 2. Developing an awareness campaign - Does HIV Look Like Me? Norway. From their words, hopes and initial action plan I was able to ensure that these recommendations were driven by the voices of YPLWH/ A in Norway.



3. Recommendations

The following recommendations are based on the requests, voices and the action planning of YPLHIV / A in Norway at our first YPLWH/A Leadership Training, as well as over 14 years combined experience of Todd Murray and Brandy Svendsen working with YPLHIV / A in several countries and settings.

3.1 Meaningful Involvement and Participation of YPLHIV/A

This principle needs to be a key component when implementing the following steps and in everything else that is done in the field of HIV and young people in Norway.

The *Acceptance and Coping* strategy claims “emphasis has been give to involving HIV positive persons”, we challenge that this should also include young people, a not just in in the end stages of programming and funding, but in the preparation, development, implementation and evaluation of any HIV, AIDS activities that target, included or involve young people.

As Træen argues “it is a bold task,...when the authorities exploit the youth culture to help fight AIDS. The key question is whether it is at all possible to mobilize the youth culture from “above”. The youth culture is, and always has been, characterized by revolt and opposition to established society”(Træen, p.51, 1992).

“Often YPLHIV / A are overlooked, tokenized, not taken seriously or are simply the targets of policies, programs and services. But, YPLHIV / A have the right to self-determination and to be meaningfully engaged to participate in all levels of program decision- making, and policy processes that affect their lives. This right is called the principle of ‘Greater Involvement of People Living with HIV’ (GIPA) and is often referred to as “nothing about us, without us!” GIPA aims to enhance the quality and effectiveness of the HIV response through the personal experiences and knowledge of people living with HIV. Meaningfully engaging of YPLHIV / A has multiple benefits, including improving self-esteem, decreasing isolation and depression, and improving health through greater access to better information about care and prevention”(GYCA Briefing Paper, 2009, p.6).

Engaging YPLHIV / A in HIV responses can challenge fear, prejudices and stigmatizing and discriminatory attitudes as well as provide valuable experiences and invaluable knowledge that can support and ensure that responses to HIV are relevant, realistic, sustainable and cost-effective (ensuring that resources are not wasted with less relevant interventions). The need for relevant and realistic programs and policies is urgent as countries scale-up their national HIV responses toward the goals of universal access to prevention, treatment, care and support. (GYCA Briefing Paper, 2009, p.6).

3.2 Second YPLWH/A Leadership Training

The training held in December of 2009 was a great success. Following the training other young people and organizations spoke of the training and voiced their interest in being involved in a future one. This momentum is exciting and capitalizing on this is needed to ensure some continuity and sustainability of a YPLHIV / A movement in Norway. As one participant expressed, “I got empowered and felt like I got new inspiration, but I don’t know how to continue with my work. It feels like I’m stuck...”

The second training would follow a similar format to the first, with slight adjustments in response to evaluations. It would include 3-4 young people from the previous training who we think have the makings of strong leaders and would be valuable co-facilitators and could further benefit from additional training. We hope then to find an additional ten participants from throughout Norway.

Once this training is complete we feel we will have another report and another group of young people making a strong base for some of the following steps below.

3.3 Development of a Network

YPLHIV/A networks can be a critical component of a national program for YPLHIV/A, and particularly for YPLWH/A. YPLWH/A are not a homogenous group and providing a mechanism where diverse perspectives and needs can be addressed is critical. Furthermore, YPLWH/A remain stigmatized and may be ostracized from other young people their age. Though they may vary greatly in their individuality, the shared experience of networking with other HIV positive young people can be tremendously important, providing a sense of community, understanding and shared purpose. There are several key functions of a YPLHIV/A network:

- developing a mechanism for communication amongst YPLWH/A throughout the country,
- developing shared/collective advocacy goals for YPLWH/A throughout the country, and a mechanism for moving advocacy agendas forward,
- a credible, collective focal point for engagement with national and regional health authorities and policy makers,
- a community of support for the YPLWH/A involved, including peer support and education components, shared resources, etc
- a "entry point" for newly diagnosed young people to find peer support and community,
- the possibility of linking and representation amongst regional and international networks,
- facilitating young participation in decision-making and ensuring that the voices and experiences of those most affected by health/drug/HIV policies are included,
- facilitating inter-generational communication and partnerships,
- providing tools, training, and resources for YLHIV/A action

This YPLHIV/A network would be critical in developing and supporting the success of the following steps below. Does HIV Look Like Me? International would be honored to be considered as the consultants that facilitate the beginnings of this network as well as supporting it's first years activities.

3.4 A Does HIV Look Like Me Norway Campaign

When Does HIV Look Like me? International was invited to Norway to attend the 2031 Leadership Summit there was initial interest in having a Does HIV Look Like Me? campaign. We were honored by the excitement and of course more than happy to explore the possibility. Our campaign process always begins with a training with the YPLHIV/A to ensure that this is what the YPLHIV/A in the country want and how they envision the success of a campaign.

From this training in Norway we were able to find a small group of young people who were both willing and able to be ambassadors for the Does HIV Look Like Me? Norway campaign. We did however feel the amount of stigma and lack of support for YPLHIV/A in Norway would prove to create many difficulties for it's success and ultimately could cause serious issues for the amazing young people who would be stepping forward. The other obvious concern is that we are unable to identify a group of young people who are able to head this initiative, ensuring it is driven by young people. This is why we have placed the campaign as the third step in the recommendations. The YPLHIV/A network would prove as a valuable support network for the young people, and the projected time frame valuable for all partners involved to prepare for the impact it will have on these young people.

In researching previous HIV campaigns in Norway it becomes apparent that young Norwegians and Norway in general could benefit from a Does HIV Look Like Me? Norway Campaign. Previous campaigns have not proven to be

successful and used approaches that are now known to be ineffective. As Træen argues; “the general awareness of the campaign... (‘youth culture campaign against AIDS - beat it’), was low, and use of condoms was apparently no higher among adolescents who were generally aware of the campaign than among adolescents who had no knowledge of it. This indicates that a more profound understanding of adolescents’ sexual behavior is needed prior to initiating new campaigns of this nature”(Træen, p. 439, 1994). This profound knowledge, we argue, is best found with the young people that have been directly affected by HIV, as well as their peers.

The previous ‘Interail’ Campaign in 1988, followed that model we refer to as ‘Fear Based Campaigns’ , using the slogan, “Using a condom is so embarrassing that I think I’ll die...” (Træen, 1990, p.34), we argue that young people do not respond well to these. Drug education for young people has thoroughly proved this point. The “second phase in the history of drug education involved the use of fear approaches. If people could not be exhorted to avoid recreational drugs, perhaps they could be made afraid to do so. Again, we know that such approaches did not work. In fact, the use of fear does not appear to lead to appropriate behavior change unless specific actions are recommended that will overcome or reduce the fear that is aroused” (Flay and Sobel p.5, 1983).

Instead, we understand that “creating balanced messages that are designed to prevent new HIV infections, but also normalize the lived experience of YPLHIV/A is a real challenge in every day practice” ... and argue that “involving YPLHIV/A in all aspects of HIV prevention campaign design that are aimed at young people will help to ensure that messages are supportive, relevant and not stigmatizing” (GYCA Briefing Paper, 2009, p.6). “If people experience a campaign message has high personal relevance for them, their attention to the message, as well as their information-seeking on the topic in question tends to increase” (Træen, 1990, p.40). What can be more relevant than young Norwegian mothers, students, daughters, sons, husbands and wives telling their stories and experiences living in Norway and living with HIV?

The messages around HIV not only have to be relevant, but direct. Træen’s research regarding the previous Norwegian *Beat it!* Campaign “indicates that the campaign was not conducted intensively enough for the adolescents to notice it in the various media and distinguish it from other campaigns. This illustrates the difficulty in achieving positive results from indirect messages. The content, structure and style of the message is important if media campaigns are to succeed. Septrup has suggested that the design of a message should build on the principle of the bipartite message. First, the problem should be communicated emotionally or in a striking way...Second, the message should contain information about how to solve the problem”(Træen, 1992, p.51). The Emmy award winning *Does HIV Look Like Me?* Campaigns prides itself on having emotional and striking messages that deliver a clear message. We use the voices of YPLWH/A to capture the attention of other young people, then in partnership with the YPLWH/A and the country campaign partners we deliver the community / country relevant messages.

As noted with the *Beat it!* Campaign, “the campaign was not run with sufficient intensity or at the right times in the media with widespread impact” (Træen, p.54, 1992). This is an important note as we consider our partners. The Norwegian Broadcast Corporation (NRK) must be an invested partner from the start, to ensure that the voices of the young people does not take a back shelf, and that the NRK will commit to not just airing the campaign but will also commit to further programming specific to HIV in Norway.

3.5 Development of a Young Adult Driven Sexual Health Organization

“Beyond knowledge (and awareness)...people need the skills to negotiate for safer sex, and they need to have the attitudes which make the adoption of certain behaviors seem worthwhile... even in rich and reasonable liberal countries, there are few formal environments in which skills such as these can be acquired, particularly by young people”(Aggleton and Campbell p. 288, 2000).

Many countries have successful sexual health organizations that are youth driven and ran. The founders of these organizations all share similar stories of not being taken seriously in the beginning and a lack of support and funding. One model I would like to present here is Youth Community Outreach Society (YouthCO - www.youthco.org). YouthCO was started in 1994 by a small group of young people , some living with HIV or AIDS, who saw an obvious gap in youth driven services that addressed the HIV epidemic among young people. This organization opened it doors hoping to reach out to young people at high risk or HIV infection as well as create support and a support network and community for young people infected.

To say YouthCO is a success is an understatement. YouthCO’s 2009 report states that it directly reached over 10,000 youth through it’s many outreach, educational workshops and trainings. This number does not reflect the young people who accessed the website, volunteer, received resources or heard about this informations through their peers. The organization is used as a model for success by the Public Health Agency of Canada that provides YouthCO with the majority of it’s funding. YouthCO as been invited by several countries to share and implement it’s models, as well as to present at several local, national and international conferences. It is the only HIV, AIDS Organization serving young people in Canada that is driven and directed at all levels of the organization by young people, it is also the most successful.

YouthCO’s support program for YPLHIV/A is supported and partially funded by the Vancouver Coastal Health Authority (VCH). VCH is an internationally recognized leader in affective and innovative HV/AIDS strategies. They believe in a philosophy called “Promoting and Drawing on Strengths”, meaning:

“every individual possesses strengths and weaknesses. Wellness and resilience can best be increased by affirming and building on these assets rather than cataloguing and repairing weaknesses. This approach can strengthen people’s confidence in their own capacities and inspire them to take action on their own health and that of their community. Strength-based approaches emphasize the value of an individual’s agency and population empowerment. Instead of treating the individual as as passive recipient of service., this approach engages and supports people to pursue their own solutions.” (VCH HIV/AIDS Strategic Plan 2007)

I argue that this philosophy has not been implemented with young adults affected or infected by HIV or AIDS in Norway. It never seems to be an issue when gay men, or drugs user demand a different and supported solution to address there needs, often resulting in the development of a separate organization, why should an organization for young people be taken any less seriously?

When Fafo did it’s report in 2009 titled “Living with HIV Noway” they explained “people with HIV make up a multifarious and composite group. Gay men – whether Norwegians or immigrants – heterosexual men and women – whether from countries in the North or from countries in the South – and drug users are quite different groups, with varying social challenges”(Grønningsæter et al, 2009, p. 145). Although I could not agree more with the first statement, I again I highlight young people are left out. This is a huge oversight. The only specific reports or qualitative research on young adults living with HIV that I have been able to come across or source is ours.

The engagement and participation of young people in sexual health education and outreach has been argued time and time again as one of the most successful approaches. In the field of HIV and AIDS Peer-to-Peer education has been recognized as effective and necessary element in the fight against HIV. Prevention and support in HIV needs a comprehensive approach that looks at why young people are having or not having sex, how they view sexual self esteem, how they are receiving and sharing information about sex, and how they are, or are not negotiating safe sex. I argue, this information can only be communicated and shared effectively by young people, for young people.

The Partners for Children Fund have described youth community development and youth health promotion and participation as having these characteristics:

- youth feel safe to speak
- the options of youth are solicited, respected and applied
- youth determine what constitutes youth participation and empowerment
- youth identify their own issues, problems and possible solutions
- youth and adults feeling fully informed about what matters to youth
- youth initiated project ideas, planning and goal setting
- youth are involved in all stages of decision making, project design, implementation, evaluation and follow-up
- youth decide on spending priorities
- youth are involved in and responsible for, budgeting, allocation, of funds and cheques
- youth teach other youth and pass along the skills and
- youth are satisfied with the results of their participation

Youth Led Health Promotion, Youth Engagement and Youth Participation: A Research Review. 1999, p.3

The development of this organization will also create an excellent opportunity and referral for children who are positive and once sixteen or seventeen might have before found a place for themselves. Now they will have a natural transition and be able to meet peers who understand the issues of going to school and adhering to medications, seeking friends and possible partners they feel safe to disclose to. But most importantly a safe space to talk about the unique issues that a young person has dealing with being a teenager and being HIV positive that no doctor, teacher, parent nor care provider will ever understand like a peer will - this is an invaluable space and resource.

I further recommend that it is best that this organization be free standing. Of course, the organization and young people driving it will need support, mentoring and some resources from existing AIDS organizations in Norway to get going and to ultimately be successful. But, it is important for the new organization not to be inadvertently involved in old politics, or be housed and driven by individuals who are not within the mandate.

In closing, this new and exciting organization can begin it's initiatives with the support of the YPLWH/A network and use the Does HIV Look Like Me? Norway materials and campaign to begin it's work and gain recognition among other young people and Norwegians as a strong, organized and supported force, that can then hopefully be used as a model by other Scandinavian countries.

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