UNAIDS PROGRAMME COORDINATING BOARD

UNAIDS/PCB (34)/14.5
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THIRTY-FOURTH MEETING

Date: 1-3 July 2014

Venue: Executive Board Room, WHO, Geneva

Agenda item 4

Follow-up to the thematic segment from the 33rd Programme Coordinating Board meeting: HIV, adolescents and youth

Additional documents for this item: *none*

Action required at this meeting - the Programme Coordinating Board is invited to:

See decisions in paragraphs below:

42. Take note of the summary report of the Thematic Session on HIV, adolescents and youth;

43. Encourage Member States to urgently scale up evidence informed, youth-friendly HIV prevention, treatment, care and support programmes;

44. Request the Joint Programme to support countries in reviewing their HIV testing, counselling and treatment policies and address age-related barriers to HIV testing and treatment faced by adolescents;

45. Recognizing the contribution of young people through the full programme cycle and within decision-making processes, *request* UNAIDS to develop indicators to monitor youth participation in the AIDS response.

Cost implications for decisions: *It is expected that these activities can be covered by existing resources from the UBRAF.*

BACKGROUND

1. Recognizing the urgent need to scale-up effective HIV responses tailored to the needs of adolescents and youth, as well as the need and value of working effectively with and for young people, the UNAIDS Programme Coordinating Board (PCB) agreed that the subject for the 33rd PCB thematic segment would be HIV, adolescents and youth. The thematic segment was held on the 19 December 2013, on the final day of the 33rd Programme Coordinating Board meeting.

2. “Adolescents” are defined as persons between the ages of 10-19 years and “youth” are defined as persons between the ages of 15-24. For the purposes of this “thematic segment,” the term “young people” referred to both groupings unless otherwise specified in the text.

3. The day was framed by the Political Declaration on HIV and AIDS (2011) and the UNAIDS Strategy 2011-2015, Getting to Zero. Two imperatives were carried through the thematic discussion on HIV, adolescents and youth:

    a. The need to prevent new HIV infections among young people; and
    b. the need to secure access to high quality HIV treatment, care and support for adolescents and youth living with HIV.

FORMAT OF THE DAY

4. The Thematic day, was developed in full collaboration with the Programme Coordinating Board Thematic Segment Working Group including Member States, Cosponsors and the NGO Delegation, and all sessions were shaped by youth speakers. The UNAIDS Youth Advisory Forum also provided input to the background note. On the day itself, youth delegates were interspersed between representatives from Member States around the table of the UNAIDS Programme Coordinating Board making for a dynamic and engaging dialogue. Chairing of the thematic day was symbolically handed over to the UNAIDS Coordinator of Youth Programmes.

5. The Thematic Segment opened with a powerful performance from a spoken word poet from Nigeria, whose poem focused on the need to end impunity of the violation of women’s rights in the context of domestic and gender-based violence. Using artistic expression to set the stage for the discussion aimed at creating an open and less formal space for dialogue to ensure a frank conversations on the social norms that put young people at higher risk of HIV: the stigmatization of young people who are sexually active, the punitive legal and social environment faced by young men who have sex with men, people who use drugs, sex workers and young people living with HIV.

6. The day was divided into four key sections: first a session titled ’Walk in my shoes,’ offering a frank conversation with four young people living with HIV from different backgrounds and regions. The second segment looked at successful prevention approaches for young people; the third, what is needed to scale up HIV testing among youth; and, the fourth and final segment focused on key strategies needed to improve access and adherence to treatment for young people living with HIV.

7. Reporting back to the formal Programme Coordinating Board, M. Pablo Aguilera, Director of HIV Young Leaders Fund, summarized the key recommendations to the Board in the closing session of the 33rd UNAIDS PCB.

SCENE SETTER: DIALOGUE WITH YOUNG PEOPLE LIVING WITH HIV FROM ALL REGIONS OF THE WORLD – "WALK IN MY SHOES"

8. Four young people living with HIV, from different walks for life, representing different communities including key populations, adolescents living with HIV and young women, participants shared their stories of what it means to be living with HIV 30 years into the epidemic and discussed the challenges that young people living with HIV face today.

9. In 2012, an estimated 5.4 million young people aged 10-24 were living with HIV. Of these, 2.1 million were adolescents aged 10 – 19 including long-term survivors of vertical transmission as well as adolescents infected during adolescence primarily through unprotected sex and sharing of injecting equipment.

Transitioning from pediatric to adult care

10. One youth participant, infected during infancy, noted that the lack of youth-friendly transition services, psychological support and care resulted in her resistance in taking medicine and negative emotions (e.g. angry towards others and feeling as if it was unfair that she had to live with HIV). Insufficient access to HIV information when she was younger made the transition much more difficult. She also encouraged parents and policy makers to support adolescents and youth to learn their status earlier and provide support during the disclosure process.

Understanding sexuality and key populations

11. One youth participant shared how he as a young man who has sex with other men was sexually assaulted. Because of stigma in society, he was afraid to get tested for HIV and as such attended the health center very late, when his immune system was almost depleted. Another youth speaker stressed the need for sexual and reproductive health services and comprehensive sexual education in schools. The speaker also highlighted age of consent laws and criminalization of same-sex relations as major obstacles preventing young persons from seeking out HIV testing, counselling and care services.

12. Speakers called for comprehensive sexuality education which provides relevant information including introduction of different sexual orientations at younger ages to help them develop healthy and positive future sexual relationships and experiences. Speakers also called for sexuality education for young people living with HIV.

Social change needed

13. A young woman from North Africa shared her story of being married at an early age and having to leave school. After testing HIV positive, her husband and his family accused her of cheating. She was marginalized by her society and judged by healthcare workers. She was forced to relocate to another city where she was able to receive treatment and psychological support. While she has been able to

overcome adversity, the speakers' story showed that stigma and discrimination is not a problem of the past, and new strategies are needed to transform social perceptions around HIV.

WHAT DOES SUCCESSFUL PREVENTION LOOK LIKE FOR YOUNG PEOPLE

14. The second segment focused on successful prevention for young people. The segment was introduced by UNFPA. In 2012, an estimated 780,000 youth aged 15-24 were newly infected with HIV, nearly 40% of them among adolescents aged 15 – 19. About 97% of the new infections occurring in low and middle income countries. Globally, there has been a 32% reduction in the estimated number of new HIV infections among young people (15-24) from 2001 to 2012.

15. Three young people who implement youth-led programmes presented on reaching young women who inject drugs in Kyrgyzstan, young men who have sex with men and transgender persons in the Philippines, and improving sexual health among young people living with HIV in Burundi, and highlighted shared key challenges and lessons learned from their respective programmes.

16. Some overarching challenges that were noted include the lack of data reflecting on the estimated size of young key populations as well as lack of epidemiological and programme data to accurately depict the epidemic and assess the response in most countries. The lack of data on prevention needs and progress in adolescents was also highlighted as a result of the ethical challenges associated with research in children under the age of 18.

Harm reduction services for young people who inject drugs

17. Participants cited legal barriers that prevent young people who use drugs from engaging in harm reduction services (e.g. clean syringes, access to HIV testing in community settings or other forms of support), lack of access to opioid substitution treatment, and compulsory drug testing in schools as major obstacles to successful prevention programming. The speakers also called for increased support for young mothers and women who use drugs, including confidential psychosocial support and comprehensive sexual reproductive health services including family planning and abortion services.

Responding to the sexual and reproductive health needs of young people living with HIV

18. The youth delegate shared insights from the Link-up project that involves young people living with HIV in the design, planning, and implementation as well as the monitoring of programmes. Recognizing the fact that young people living with HIV, as other young people, become sexually active in their adolescence, the speaker highlighted the urgent need to provide clear information on sexual and reproductive health and HIV prevention for both HIV negative and positive youth.

Country Case Studies

19. Sexual and reproductive health services for young people in Mexico—The delegate from Mexico spoke about the declaration, "Educating to Prevent" that was adopted by the Ministers in Latin America and the Caribbean in 2008 on comprehensive sexual education with the aim to link reproductive health in terms of HIV with cross-cutting issues like gender equality and women's empowerment, violence, youth in reproductive health and human rights of adolescents. Its main

objective is to reduce the gap within access to reproductive health education and inadequate services to young people, particularly young key populations.

20. Education: Zimbabwe in October 2013 launched the "Life Skills, Sexuality and HIV and AIDS Education Strategic Plan" in schools. The strategy aims to ensure that the education sector supports all learners with access to correct information and life skills related to sexual and reproductive health, HIV prevention, care, treatment and support by end of 2015. In addition, the strategy aims to ensure that learners with HIV are supported to realize their personal, social and educational potential by end of 2015. Finally to promote HIV workplace policies and activities that will support teachers and other education personnel in HIV prevention, treatment, care and support by end of 2015.

21. Youth leadership and empowerment: Iran—A Systematic Health Education Promotion model (SHEP) was developed to position young people as the communicator, decision maker and manager in HIV prevention and intervention via online counselling and various communications tools.

22. Youth involvement in the global AIDS response: China—Through the sale of “do it yourself” products, a group of 10 young people used funds generated to help young people living with HIV in China. This initiative aims to raise awareness of HIV and how it’s transmitted in order to reduce stigma and discrimination against people living with HIV.

23. Peer intervention: Australia—Peer intervention is particularly important to build youth leadership. By providing enough learning opportunities and mentorship, young people can have a significant impact on the HIV response which will inevitably maintain its effectiveness.

24. Youth Network Development: Norway—A youth network was developed in Norway to advocate to prioritize HIV into foreign policies in Norway and initiate cooperation with other youth networks in other parts of the world to advocate for HIV policies worldwide.

Prevention—youth recommendations

The following key recommendations emerged from the youth delegate's discussion in this component:

- Create an enabling environment for harm reduction programmes and rehabilitation centres with linkages to health services for young people who use drugs;
- Develop international guidance in relation to harm reduction programmes for young people who inject drugs to inform governments, NGOs, and international organizations who provide services for these populations;
- Ensure commodity security for HIV prevention in countries, such as male and female condoms;
- Ensure an environment that allows for discussion about sexual and reproductive health and rights, sex and sexuality, for example through comprehensive sexuality education, to generate demand among adolescents and youth for prevention commodities;
- Address stigma and discrimination and other structural barriers such as gender inequality and remove punitive laws that criminalize key populations to create an enabling environment for HIV prevention programmes;
- Ensure meaningful participation of young people, particularly young key populations and young people living with HIV, in the design, implementation, monitoring and evaluation of policies and programs at local, national, regional and global levels.
- Integrate sexual and reproductive health services into treatment programmes for adolescents living with HIV.

DO ALL TESTS HAVE TO BE HARD: CREATING ENABLING SOCIAL AND LEGAL ENVIRONMENTS FOR HIV TESTS

25. While testing is the only way to determine HIV infection and link people to HIV prevention and treatment and care services, young people in general and adolescents in particular are not reached with current HIV testing approaches. The segment was introduced by UNICEF. In sub-Saharan Africa, based on data between 2005 and 2010, an estimated 10% of young men and 15% of young women aged 15-24 had tested and were aware of their HIV status.

Global guidelines on HIV testing, counselling and care

26. In 2013, WHO and partners released the first-ever HIV global guidelines on HIV testing, counseling and care specifically for adolescents living with HIV. The guidelines focus on the importance of scaling up adolescent-friendly services in order to ensure access to testing and counseling for adolescents including adolescent key populations. UNICEF provided a short overview presentation of the guidelines highlighting the need to address legislative barriers including age of consent laws and identify HIV treatment and care related needs among adolescents. UNICEF noted the importance of expanding adolescent-sensitive service provision and age disaggregated monitoring of access and outcomes for adolescents as well as innovative initiatives for demand creation and engagement of adolescents to improve HIV testing and counselling and access

to treatment. UNICEF urged all countries to support the rapid adoption and implementation of the new guidelines.

Parental consent

27. Reflecting on UNICEF's presentation, one youth participant described how young people under 18 are not able to access HIV testing and receive the results without being accompanied by their parents thereby hindering the progress of providing HIV testing services. The speaker pointed out that when sexuality is taboo in a country with parental consent laws, a young person would prefer not to get tested for HIV than share details about their sexual lives with their parents.

28. Another participant highlighted that there is a perceived lack of maturity amongst young people and a notion among healthcare workers and adults in general that adolescents are incapable of making their own decisions. The speaker pointed out that statistics and previous discussions have revealed that young people are making their own decisions in relation to their sexual relations and therefore it is imperative that this reality is acknowledged and HIV programmes are developed with this in mind.

Gender-related barriers to HIV testing

29. Another youth participant focused on the gender-related barriers to HIV testing, stating that the stigma attached to gender-based violence often prevents women and girls from talking about their experiences and prevents them from seeking life-saving services such as ante-natal care, HIV and STI testing and/or post-exposure prophylaxis. The speaker noted that police and health service providers should be trained to be sensitive to victims' perspectives. She also noted that it is important to provide dedicated healthcare and psychosocial support for women who experience gender-based violence.

Innovative use of social media in HIV testing and counseling

Shuga Love Sex Money

30. UNICEF described a multiple-platform intervention in six countries, Cameroon, Democratic Republic of Congo, Kenya, Lesotho, South Africa and Tanzania, with the aim to improve demand among adolescents and youth for HIV testing and counselling. The public-private partnership based initiative achieved wide coverage in these countries and allowed young people to follow and discuss HIV related issues each week via social media, phone-in radio, television programmes and mobile SMS. Data collected through the initiative showed significant increases in utilization of HIV testing and counseling among adolescents and youth and was used to strengthen capacity and advocate with National AIDS Commissions and Ministries of Health for routine age-disaggregated reporting of HIV Testing and Counselling and linkage to care in adolescents.

U-Report in Zambia

31. UNICEF and the representative from Zambia highlighted a collaboration providing a youth-friendly SMS platform that allows a continuous and tailored demand creation for high impact HIV prevention, treatment and care services by capturing real-time feedback from adolescents about availability of services, barriers in specific geographical locations, and quality of HIV and sexual

reproductive health services. The real-time data gathered through this mobile platform provided decision-makers with a unique understanding of perceptions among adolescents and youth around HIV Testing and Counseling services as well as barriers and facilitators influencing their use of voluntary medical male circumcision services.

Enabling legal environment for comprehensive services for HIV for youth

32. The participant described the current framework in South Africa which allows access to HIV testing and counselling for young people starting from the age of 12, which provides free youth-friendly services within the community and health services sector.

HIV testing—youth recommendations

The following key recommendations emerged from the youth delegate's discussion in this component:

- Work with young people through conducting formative research and message development workshops to define the 'what', 'when', 'where', 'how', and 'by whom' of HIV testing programmes to ensure they are youth-friendly;
- Invest in peer-based and develop capacity of lay-counselors to ensure quality of services and effective linkage to care for young people who test positive.
- Review and consider changing age-related restrictions on HIV testing as well as other sexual and reproductive health services, treatment and harm-reduction services, taking into consideration evolving capacities and mature minors;
- Scale up effective and innovative approaches including rapid testing, to ensure access to HIV testing, counselling and treatment for young people and young key populations;
- Enhance efforts and capacities at the country and global level to ensure age disaggregated data on coverage of HIV testing, counseling and treatment among adolescents and adolescent key populations and outcomes in these populations in order to better identify their needs and inform programming.

WHO IS RESPONSIBLE FOR EFFECTIVE HIV TREATMENT FOR ADOLESCENTS AND YOUTH

33. The last segment of the thematic day focused on ensuring effective treatment for adolescents and young people living with HIV. The segment was introduced by WHO. Global AIDS-related death among adolescents aged 10-19 has increased by 50% between 2005 and 2012 while deaths across all age groups fell by 30%.

Quality of care

34. Key findings from the report, Lost in Transition: the needs of adolescents living with HIV in Asia Pacific, developed by the Asia Pacific Network of People Living with HIV with support from UN partners were presented. The report found that the HIV response for adolescents is failing in terms of treatment and overall healthcare services as it failed to recognize a number of stages of development among adolescents and their changing needs. One participant pointed out that although the goal is to keep adolescents living with HIV on first line treatment for

as long as possible, there are only a handful of national programmes that support adolescents living with HIV to adhere to treatment.

Peer support

35. Providing young people living with HIV with the support of their peers who are have also been diagnosed HIV positive does not only support disclosure and adherence, but can also inspire a sense of community and hope for the future. According to participants, there is a need to develop youth leadership programmes and establish linkages between peer support and HIV treatment and care services. In addition, local counseling services should be developed that address the needs of specific groups, e.g. MSM, people who inject drugs, sex workers and migrants, understanding that it is easier for people with similar backgrounds to share experiences among each other.

Treatment programmes for young key populations

36. Young men who have sex with men face higher HIV prevalence as compared to the general population; yet, young men who have sex with men are often left out in research, policy and programme designs. There are gaps in funding, access to services, and youth-specific services to men who have sex with men. One participant spoke of a youth group of 18 young men who have sex with men advocates who are working to address the health and human rights issues faced by young men who have sex with men in Latin America.

37. Another participant introduced the Y+ mentorship initiative that produced a guidance document for organizations and networks to help institutionalize the leadership development of young people living with HIV. Organizations are able to sign on to the document, agreeing to a set of key principles and actions to foster an enabling environment for leadership development of young people living with HIV.

Supporting a new generation of treatment access actors

38. The youth participants also raised the critical challenges in relation to access to medicines in low and middle income countries, and outlined the need for young activists to be aware of how politics can influence availability of and access to HIV services in general. It was noted that networks of young people and adolescents living with HIV, have started exerting political pressure on their governments, in relation to treatment and healthcare services. A request was made for partners to support this transition of knowledge from established to younger treatment activists to ensure renewed leadership in the response.

Treatment—youth recommendations

The following key recommendations emerged from the youth delegate's discussion in this component:

- Provide a continuum of care, integrated and holistic health services including treatment of multiple health issues such as treatment for opportunistic infection, the prevention and treatment for hepatitis B & C, mental health and psycho-social support;
- Highlight the need for tailored, youth-friendly services to support adolescents in

their transition period when they are experiencing social and physical changes and are exploring their sexuality;
- Increase knowledge about treatment among young people living with HIV in order to empower them to take care of their own health and well-being and make informed choices about their treatment options;
- Address the bottleneck of access to services due to stigma and discrimination related to unwanted disclosure, complacency with treatment and side-effects;
- Eliminate political barriers to ensure adolescents and young people have access to affordable medicines including 2nd and 3rd line, and build the capacity of a new generation of treatment access advocates;
- Invest in community health centres to guarantee the availability of CD4 and viral load testing to monitor treatment adherence.

CONCLUSION

39. Two imperatives ran as red threads through discussions during the 33rd Programme Coordinating Board Thematic Segment on HIV, adolescents and youth: (a) the need to prevent new HIV infections among young people and (b) the need to secure access to high quality HIV treatment, care and support for adolescents and youth living with HIV. The ambition was to create an open and less formal space for dialogue to ensure a frank conversation on the social processes that put young people at higher risk of HIV and often prevent young people from accessing the services they need. Young people from different walks of life, young people living with HIV and young people among key populations were supported to participate, side-by-side, with representatives from Member States, around the decision-making table.

40. While discussions were diverse, some key common themes across the components of the day emerged and the following conclusions drawn:

    a. Evidence informed programmes are delivering high quality support for young people's HIV prevention needs, HIV testing, as well as treatment care and support the needs of young people living with HIV. These programmes must urgently be scaled up to have impact.
    b. Progress to ensure access to HIV testing, counseling, treatment and care among adolescents has been significantly slower and more needs to be done to make existing programmes more sensitive to the needs of adolescents.
    c. Parental consent laws and policies are preventing adolescents and youth from accessing services including HIV testing and counselling, harm reduction and treatment. Such laws and policies have been reformed in some countries without adverse effects and with an increase of uptake of service; other countries could follow to ensure adolescents can independently consent to medical services in line with their evolving capacity.
    d. Investing in youth participation through the full programme development cycle can lead to more effective and more appropriate programmes. Young people's insights and experience should inform the 'what', 'how', 'when,' 'why' and by 'whom' of HIV prevention, treatment, care and support programs; as put by one of the participants: "We know the market, because we are the market".
    e. There is very limited data available in relation to adolescents aged 10 – 19, young key populations and young people living with HIV. This is particularly an issue in countries with concentrated epidemics. Routine data should be disaggregated by age; investments in research for adolescents and young

key populations should strengthened and guidelines for research protocols clarified for research involving adolescents under 18s recognizing the evolving capacity of adolescents and young people and the need to address the gap in data needed to inform tailored decision making and programming.

41. UNAIDS will continue to work with the youth sector in the AIDS to increase mobilization, ownership and leadership of young people, particularly young people most affected by HIV and young people living with HIV at national, regional and global level to reach the targets of the Political Declaration on AIDS by 2015 and beyond.

RECOMMENDATIONS

Based on the discussions from the December 2013 thematic segment, the Board is invited to:

42. *Take note* of the summary report of the Thematic Session on HIV, adolescents and youth;

43. *Encourage* Member States to urgently scale up evidence informed, youth-friendly HIV prevention, treatment, care and support programmes;

44. *Request* the Joint Programme to support countries in reviewing their HIV testing, counselling and treatment policies and address age-related barriers to HIV testing and treatment faced by adolescents;

45. Recognizing the contribution of young people through the full programme cycle and within decision-making processes, *request* UNAIDS to develop indicators to monitor youth participation in the AIDS response.

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UNAIDS
20 Avenue Appia
CH-1211 Geneva 27
Switzerland
+41 22 791 3666
unaids.org