Agenda item 6

UNAIDS/PCB (44)/19.10

# FOLLOW-UP TO THE THEMATIC SEGMENT FROM THE 43RD PROGRAMME COORDINATING BOARD MEETING

25-27 June 2019 | Geneva, Switzerland
UNAIDS Programme Coordinating Board
Issue date: 21 June 2019

**Additional documents for this item:**

UNAIDS/PCB (43)/18.31; UNAIDS/PCB (43)/18.32; UNAIDS/PCB (43)/CRP2

**Action required at this meeting: The Programme Coordinating Board is invited to:**

See draft decision points in the paragraphs below:

62. *Take note* of the background note (UNAIDS/PCB (43)/18.32) and the summary report (UNAIDS/PCB (44)19.10) of the Programme Coordinating Board thematic segment on mental health and HIV/AIDS—promoting human rights, an integrated and person-centered approach to improving ART adherence, well-being and quality of life.

63. *Call* on Members States to:
    - Implement evidence-based, people-centred, human rights and community-based policies and programmes to promote mental health and quality of life, including by addressing stigma and discrimination related to both HIV and mental health conditions, in the context of HIV prevention, treatment and care services.
    - Address social determinants of mental health and HIV, including through adopting and implementing social protection policies and programmes to reduce stigma and discrimination.

64. *Call* on the UNAIDS Joint Programme to:
    - Review and revise existing practices and guidelines to ensure the integration of mental health and substance use treatment and prevention services into the HIV service delivery platforms, and HIV services into mental health and substance use prevention and treatment programmes, and provide respective implementation guidance.
    - Take into account the intersection between mental health and HIV, and the importance of improving psycho-social wellbeing and quality of life of people affected and living with HIV, as part of a person-centred and human rights approach, when developing the next UNAIDS strategy for 2021-2030.
    - Report back to a future Programme Coordinating Board meeting on the progress made on the integrated approach to mental health and HIV.

## Introduction

1. The thematic segment focused on mental health and HIV, with panelists sharing personal experiences and presenting and discussing new evidence and good practices. Accompanying the discussion was a background paper and a conference room paper. The latter collated 33 good practices for integrating HIV and mental health. Gathered from countries around the world, the examples showed different approaches for promoting the mental health and wellbeing of people living with and affected by HIV.

2. Laurel Sprague, Special Adviser, Community Mobilization at UNAIDS, moderated the session. She informed the meeting that the thematic segment unfortunately had to be shortened in order to complete discussions and finalize decision points from earlier agenda items.

3. Statements, which the members and other participants had been unable to present to the meeting, but have been submitted in writing to the UNAIDS Secretariat, have been incorporated into this report of the proceedings.

4. The thematic segment began with several PCB members reading the personal testimonies from people affected by mental health conditions.

5. The opening session focused on highlighting the importance of addressing the intersections of mental health and HIV.

6. Doris Peltier of the Canadian Aboriginal AIDS Network, told the meeting that she was a researcher and grandmother who had been diagnosed with HIV in 2000. Indigenous people, she said, had "been researched to death". It was vitally important for indigenous people to understand and tell the stories of their lives. Referring to the Canadian writer Thomas King, she said that "we live our stories and if we can change the stories we live by, we possibly can change our lives".

7. However, Western research traditions perpetuated dangerous and harmful stories about aboriginal people, and those stories had huge implications for people's mental health. She reminded participants of some of the tropes about indigenous people that persisted in dominant research traditions.

8. Ms Peltier said that, after being diagnosed with HIV, she was immediately stigmatized for having a "dirty disease". People used a word which was derived from terms were used to describe the smallpox-infected blankets that had wiped out entire communities two centuries earlier.

9. The language matched the traditional research narrative about indigenous people, which portrayed them as sickly, incompetent and in need of help. That narrative was used to justify the forced assimilation of indigenous people, including by removing children from their families and despatching them to residential schools. Entire generations lost their parenting skills and this did long-lasting damage to indigenous communities. Migration became a central feature of indigenous people's lives. About half of Canada's indigenous population lived in urban centres, with many of individuals disconnected from their identity, culture and language—which affected their mental wellbeing.

10. Ms Peltier told the meeting that indigenous researchers like her were decolonizing research across Canada. She described one project, titled Visioning Health, a five-year study with HIV-positive indigenous women that aim to develop a programme for holistically addressing mental health issues. It differed from the downstream, “rescue

mode" approach of seeking and treating, and instead recognized and focused also on the underlying determinants of mental health, such as colonization, in-country migration, dispossession and discrimination. In closing, Ms Peltier proposed that a future meeting of the PCB devote a thematic segment to indigenous people.

## Mental health and HIV: Understanding and addressing the intersections

11. The second session focused on substance use, quality of life, wellbeing and HIV. It included discussion of effective approaches for addressing the interlinked challenges of HIV and mental health.

12. Tedros Adhanom Ghebreyesus, Director-General of WHO, addressed the meeting through a screened video recording. He said that many people living with HIV struggled to come to terms with their diagnosis, and that HIV-related stigma and discrimination frequently led to alcohol and substance abuse and even to suicide. Research showed strong associations between HIV-positive diagnoses and mental health conditions, he said. This showed the need for integrated health services, including services for mental health, and for integrating those services into community-based primary health care, to achieve the goal of ensuring universal health coverage (UHC) for all.

13. Mark van Ommeren, Director a.i., Mental Health and Substance Abuse at WHO, said that Mental health appeared to be emerging from the shadows. Ministries of Health from several countries had created an international alliance on mental health and the first-ever global summit on the issue had been held in the United Kingdom.

14. He told the meeting that one in six people globally experienced mental health or substance use problems. He highlighted the linkages between HIV, mental health and substance abuse care and said that addressing these issues was a "win-win" approach. Studies showed that people with mental health conditions were less likely to access and adhere to HIV treatment. They also showed that affordable depression treatment enhanced ART adherence.

15. Care for depression brought a very good return on investment (US$ 5 return for every US$ 1 spent) as did treating drug dependence (US$ 7 back for US$ 1 spent). Those estimates did not take account of the potential benefits from integrating HIV and mental health services. Yet development assistance for mental health was very low—equivalent to about 1% of the resources allocated to HIV programmes. Governments were also not investing enough in mental health.

16. Dr van Ommeren underlined the importance of including, within UHC, affordable and effective services that address both HIV and mental health. Those services should be available across the spectrum, including in prisons, he noted. Integration could be achieved by providing the relevant services in single facilities or through referrals. He cautioned, however, that referrals work best when designated case managers are used. WHO had developed guidelines for key interventions (including eMental health approaches, which were becoming more popular) and for integrating them effectively.

## Why addressing mental health is crucial for HIV prevention, treatment and care

17. Panelists discussed the challenges related to maintaining mental health and wellbeing in the context of living with HIV, along with examples of good practices.

18. Etheldra Nakimuli-Mpungu, a psychiatrist at Makerere University in Uganda, reminded that HIV treatment alone would not end the AIDS epidemic: prevention was also key.

Effective prevention required tackling the determinants of HIV risk, including mental health issues, she said. Yet the AIDS response had ignored a great deal of research evidence showing the impact of mental health on people living with HIV.

19. Treatment providers seldom took account of people's mental health, Dr Nakimuli-Mpungu told the meeting. When severe mental health symptoms were evident, providers may refer individuals to mental health services. Generally, though, mental health care tended to be neglected, she said. UNAIDS could help change this by championing educational campaigns on mental health and by advocating for the scale-up of culturally sensitive interventions (such as those developed in some African countries).

20. She described a group therapy approach she had developed for people living with HIV who were experiencing mental health conditions. Because of the large numbers of people requiring such assistance, group therapy was more suitable, she explained. Usually, women were more likely to attend such therapy but her approach also attracted large numbers of men. This was partly because the therapy was being linked with poverty reduction support and skills.

21. Evaluations showed that the interventions were associated with emotional improvement, reduced post-traumatic stress symptoms, strengthened self esteem and increased social support Dr Nakimuli-Mpungu reported. When depression symptoms were reduced, adherence to treatment improved and viral suppression rates rose, she said, adding that the benefits were equally evident among women and men.

22. Sílvia Ouakinin, a psychiatrist at the National Health Service in Portugal, told participants that her hospital had begun integrating mental health and HIV services in 1989. She drew attention to the two-way relationship between HIV and mental health conditions. Psychiatric problems remained highly prevalent among people living with HIV and included depression and neurocognitive disorders, she told the PCB. Depression rates in this population were more than twice higher than in the general population, negatively affecting people's quality of life, wellbeing and treatment adherence. Since neurocognitive disorders affected almost 50% of people living with HIV, there was a clear need to screen for such complications.

23. Dr Ouakinin stresssed the importance of early, tailored interventions. Health-care providers should screen people living with HIV for potential mental health care needs and processes should be in place to ensure that individuals receive the mental health services they need. Achieving that, however, required successfully tackling the stigma associated with mental health problems and with HIV infection.

24. Marco Castro-Bojorquez, a filmmaker from Mexico and the United States of America, presented emotional testimony of his recent experiences with HIV, stress and depression and the difficult dilemmas they created. Although he wanted to believe that things were improving, he was still losing friends to those combined difficulties. He said people were not drawing enough on the support and strength families could offer them; instead they were often stricken by a sense of being alone and abandoned. Family acceptance was difficult, he acknowledged, but it was a source of great strength.

## Promoting rights and engaging communities to eliminate stigma and discrimination and improve quality of life

25. This session was devoted to approaches for addressing mental health and HIV from a human rights perspective, including through community engagement and people-centred approaches.

26. Dr. Michelle Funk, Coordinator of Mental Health Policy and Service Development at WHO, said that people with mental health conditions were often exposed to physical and/or sexual violence and various coercive practices, including in the health-care context. Often their civil rights were also violated—for example, by being refused the right to marry, vote or decide on health-care options. These violations were disempowering and isolating, and they fed self-stigma. People living with HIV endured many similar experiences, she added, and the harm was compounded for those with mental health conditions.

27. Dr Funk said common approaches were needed in the fields of HIV and mental health, particularly using rights-based approaches to challenge and change discriminatory practices. Affected individuals had to know their rights and had to be able to assert them.

28. The intersection of HIV and mental health had to be addressed at a large scale, she told the meeting. Working on a limited, face-to-face level was not enough. WHO had developed a range of tools, including eTraining tools, and they were showing dramatic results. The tools had the potential to make a major impact in countries, she said.

29. It was also important to build community-based support in line with international human rights. This entailed a shift from a narrow, biomedical focus to a broader, person-centred recovery model that was meaningful to people's lives. Civil society groups had to be supported to advocate and be active in such activities. Dr Funk concluded with a call for strong, implementable policies that address discrimination and increase access to health, social protection, employment and other relevant services.

30. Nyasha Sithole, Programmes Director at the My Age Zimbabwe Trust in Zimbabwe, told the PCB that young people living with HIV faced high levels of stigma and discrimination and had a great fear of rejection. However, very limited social and professional medical support was available to young people with mental health conditions and medical staff frequently treated them with great disrespect. Countries in Africa had severe shortages of psychiatrists, she said. There were about 70 psychiatrists in the entire Zimbabwe, for example.

31. Ms Sithole called for integrating mental health into the care continuum for HIV, with mental health screening available along the chain of HIV services. She added that young people had to be at the centre of any solutions. Zimbabwe's "Friendship Benches" were a good example of an initiative which easily could be adapted for young people.

32. Taweesap Siraprapasiri, Senior Adviser in the Department of Disease Control in Thailand's Ministry of Public Health, described some of the steps taken in his country. He told the meeting that, although HIV testing and treatment was being integrated into UHC, stigma and discrimination remained major problems. Thailand was monitoring HIV-related stigma and discrimination nationally, including in health-care settings. An online complaints mechanism for rights violations was available and the data was being used to develop corrective steps and new interventions.

33. One recently developed package of tools for reducing HIV-related stigma and discrimination included participatory training for health-care staff and steps for improving services. Civil society organizations were participating in the rollout of the tools. Implemented at first in six hospitals, the package was being expanded to more than 100 hospitals across the country and it was being used also in China, Laos and Viet Nam, Dr Siraprapasiri said.

34. Results showed big reductions in stigma and discrimination in health-care settings where the package had been used. However, there was little effect on the internalized stigma among people living with HIV. Tools for reducing self-stigma were therefore being piloted in several hospitals and they would be evaluated during 2019. The project showed that stigma and discrimination, although complex, can be measured and effectively tackled if effective tools are used and if they are implemented them in collaboration with affected communities.

35. Jules Kim, Chief Executive Officer of the Scarlet Alliance and Australian Sex Workers Association, described some of the conditions faced by sex workers and said it was very difficult for people to maintain mental health and wellbeing in such circumstances. Importantly, interventions were being developed to support the mental health and wellbeing of key populations, many of them focusing on people's rights and responsibilities and advising them on how to seek redress for rights violations. She emphasized that supporting the mental health of people living with HIV created "win-win" situations by improving people's health in multiple, mutually reinforcing ways. UNAIDS was asked to provide greater support to communities to meet these interlinked challenges.

### Substance use and HIV: what has been overlooked?

36. In this session, attention focused on issues surrounding HIV and the harmful use of drugs and alcohol and HIV.

37. Marcelo Ribeiro**,** psychiatrist and director of the Centro de Referência de Álcool, Tabaco e Outras Drogas (CRATOD) in Sao Paulo, Brazil, began by describing the extent of cocaine use, especially crack cocaine, in the city. The centre of the city had an open-air drug scene known as "Cracolândia", where up to 2,000 crack users congregated daily. CRATOD screened and treated these men and women for HIV and other infectious diseases. Rates of syphilis and HIV were high (up to 12%), especially among lesbian, gay, bisexual and transsexual individuals (up to 25%).

38. Dr Ribeiro said a challenge for the Centre was to move beyond merely containing the harm that was being done. Some patients were seriously ill, both physically and mentally, and there was a clear need for more treatment services. This led to the creation, in collaboration with the AIDS Reference Centre, of a fast-track system that now screens as many as 80 people a day and provides them with care, as needed.

39. David Subeliani of the Eurasian Network of People Using Drugs and the NGO, White Noise, briefed the meeting on drug use trends in Georgia, where the use of stimulants and other noninjected drugs is on the rise. He said hundreds of psychoactive stimulants were on the market, many of them new and poorly understood. Harm reduction projects had to adapt to this reality, since people seldom stuck to using only one specific type of drug. Evidence showed that noninjecting drug use was also associated with high risk of HIV infection, he reminded the meeting.

### Taking care of the mental health and wellbeing of activists and service providers

40. This interactive session examined the challenges activists and service providers face in protecting their own mental health.

41. Daniil Stolbunov from the Teenergizer project in Ukraine shared some of his experiences as an adolescent HIV-positive activist living and working in a conservative

environment where it was difficult to maintain his mental health. He told the meeting that mental health services were ill-equipped to serve young people. Doctors typically lacked the communication skills and experience they needed to treat young people living with HIV with dignity and respect.

42. Iregi Mwenja of the Global Mental Health Peer Network in Kenya described his own, similar experiences. Living with a mental health condition in low- and middle-income countries was difficult due to poor access to services, pervasive stigma and cultural beliefs about mental health.

43. Yet effective low-cost solutions existed at grassroots level and they could make a significant difference if they received enough support, she told the meeting. For example, PDO (Psychiatric Disability Organization) Kenya, operating on a small budget, had provided therapy to over 5,400 people in the previous 2.5 years and trained 186 peer counselors in secondary schools in the previous year. In South Africa and Zambia, the SMH Foundation was running mobile phone support groups for HIV-positive adolescents, while the #FriendshipBench initiative in Zimbabwe showed that some of the gaps in mental health services could be bridged by using trained lay health workers. The Global Mental Health Peer Network was also sharing best practices, especially those related to peer support.

44. Mr. Mwenja highlighted a development in Kenya which was making it more difficult to provide rights-based, comprehensive services. He said HIV service providers were increasingly "chasing numbers" as they sought to reach quotas and satisfy the metrics of donors and upstream management systems. It was not uncommon for people visiting hospitals to be compelled to take an HIV test, for example. All prisoners were also required to take an HIV test within 24 hours of imprisonment. Testing and treatment programmes could not be effective in the long term under such conditions, he warned.

45. Funding for social and psychosocial support for people living with HIV was declining as donors targeted technical treatment services and commodities. People’s wellbeing was suffering as a result, Mr Mwenja said. He suggested that UNAIDS expand the 90–90-90 targets by also requiring that 90% of people who test HIV-positive be enlisted in a psychosocial support programme.

46. Ms. Cecilia Chung, activist and founder of the annual Trans March in San Francisco, told the meeting that service providers faced enormous pressures and frequently experienced trauma, which they typically had to bear alone. This affected their decision-making and conduct at work and in their personal lives. She emphasized that mental health had to be integrated into the entire platform HIV-related services. Even for transgender people on HIV treatment, she added, the medicines were not always the top priority: often what people lacked most in their lives was support, trust and care.

47. Due to time constraints, discussion from the floor had to be abbreviated. The statements summarized below include several written contributions which, due to limited time, could not be presented at the session itself.

48. Speakers thanked UNAIDS for organizing the thematic segment on this important but often-forgotten topic, and thanked the panellists for sharing their experiences and expertise. They applauded the efforts of activists, practitioners and researchers to draw greater attention to this neglected area. The speakers also commended UNAIDS for showing sensitivity to the terminology used around mental health. They welcomed that the background paper included more neutral expressions rather than the language that could contribute to perpetuating stigma around mental health conditions.

49. It was noted that more than 1 billion people around the world were estimated to have experienced a mental health condition, a substance use disorder or an alcohol use disorder—an estimated 16% of the global population – and that people living with HIV were at an increased risk of developing mental health conditions. Yet mental health was often stigmatized and overlooked.

50. Emphasizing the "two-way" relationship between mental health and HIV, speakers pointed to the strong evidence of the links between mental health conditions and limited HIV treatment access or adherence. The meeting was informed of a recent Global Values and Preferences Survey report, *Building a safe house on firm ground*, which highlighted the mental health challenges experienced by women living with HIV.

51. Several contributions urged stepped-up, concrete actions and investments to integrate mental health and HIV interventions as part of a fully-funded AIDS response. That should include increased actions to challenge the social determinants of poor mental health and HIV—including the prevention of violence against women and girls.

52. Speakers agreed that the approach to mental health had to be human rights-based. It had to shift from an exclusively biomedical focus to a more balanced and holistic model that integrates biosocial aspects and is grounded in human rights. Strengthened collaboration was needed for reviewing and reforming laws, policies and strategies to advance human rights-based approaches to both HIV and mental health.

53. The meeting was reminded of the 2017 Human Rights Council Resolution on Mental Health and Human Rights and the 2018 Report of the UN High Commissioner for Human Rights on Mental Health and Human Rights, which urged action against the social determinants of mental health conditions. The Human Rights Council resolution called on States to develop mental health services that do not involve overmedicalization, power imbalances and inappropriate treatments. It also called for human rights education and training for health-care workers, police, law enforcement officers, prison staff and other relevant professions.

54. A human rights-based approach was also crucial for tackling the stigma and discrimination that was still attached to HIV and to mental health conditions, the meeting heard. The elimination of HIV- and mental health-related stigma and discrimination should be a priority. Contributions from the floor provided examples of efforts to end stigma and discrimination, including through PEPFAR-supported programmes as well as activities supported by the Disability Rights Fund and the Robert Carr Civil Society Networks Fund.

55. Speakers told the meeting that tackling stigma and discrimination was everyone's responsibility and included avoiding stigmatizing or denigrating language. It was preferable, for example, to speak of mental health “conditions” rather than “burdens” or “disorders”.

56. The meeting heard that mental health was a major issue also for people with disabilities, including people with intellectual or developmental disabilities. In a recent survey by the AIDS Committee of Toronto, for example, autistic and other persons with developmental disabilities reported widespread neglect and human rights violations, including in health-care settings. All respondents who were HIV-positive had acquired HIV through some form of sexual violence. Countries were urged to ratify the Convention on the Rights of Persons with Disabilities.

57. Contributions from the floor also noted to the links between drug use, mental health and HIV. The meeting was informed of technical guidance which the UN Office on Drugs

and Crime (UNODC) had developed for addressing HIV and viral hepatitis among people who use stimulant drugs. The importance of changing patterns of drug use was noted and it was suggested that the PCB consider hosting a thematic segment on the issue. UNODC was developing a training package that included modules on HIV interventions for people who used stimulant drugs such as amphetamines, meta-amphetamines and crack cocaine.

58. Several speakers noted that although effective and culturally appropriate interventions were available, the mental health needs of people living with HIV often went unnoticed by policy makers, health-care providers and programme funders. Good practices from Kenya, Malawi, Poland and the United Republic of Tanzania, for example, showed that mental health issues experienced by people living with HIV can be prevented and treated in responsive and respectful ways. UNAIDS and donors were urged to support both core and ongoing programme funding for transformative community-led initiatives.

59. UNAIDS was asked to advocate for the integration of mental health and psychosocial support into HIV programmes and to increase the sharing of best practices in these interlinked areas. Contributions from the floor also pointed to a need to develop clear guidance on integrating services for HIV and mental health, and requested UNAIDS and WHO to explore ways forward.

60. Given the reduced time allotted to the thematic segment, it was proposed that the next PCB meeting should dedicate time to continue the discussion and arrive at decisions and conclusions regarding the integration of mental health and HIV services.

61. The Chair thanked the speakers and organizers of the thematic segment and apologized for the abbreviated discussion.

## DECISIONS

**The Programme Coordinating Board is invited to:**

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