From the Margins to the Center: Tackling Stigma and Poor Mental Wellbeing as the Key Global Barriers to Living Well with HIV, a Multinational and Multi-community Position

D.D Diallo, SisterLove, Atlanta, Georgia, US
On behalf of the HIV Community Council, an initiative sponsored by Gilead Sciences
Disclosure of speaker’s interests

Advisor and grantee for Gilead Sciences, ViiV Healthcare and MSD.
The HIV Community Council Members

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Acknowledgement

The HIV Community Council is an initiative sponsored by Gilead Sciences.
People and their communities are central to the UNAIDS Global 2025 targets. 

The HIV Community Council comprises ten community leaders of diverse, key populations of people living with HIV.

Legend:
- Aging with HIV
- BIPOC – Black, Indigenous, and people of color
- Gay and HIV+ men engaging in ChemSex
- Homeless
- LGBTQ+
- Migrant Communities
- Non-binary communities
- People in prison
- PWUD – People who use drugs
- Sex workers
- Trans community
- Women and girls
- Women of color
- Youth
- Migrant Communities

Countries: Canada, USA, France, South Africa, UK, Spain, Taiwan, Italy, USA.
Overview and objectives of the HIV Community Council series

**Meeting 1 Objective:**
Understand the community’s definition of successful long-term management of HIV, identify regional differences and unmet needs, and explore potential solutions

**Meeting 2 Objective:**
Understand the community’s definition of successful long-term management of HIV, identify regional differences and unmet needs, and explore potential solutions

**Meeting 3 Objective:**
To agree on recommendations as a call to action to address long-term HIV management challenges

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**Summary presented at IAS 2023**

**Meeting 1 & 2 Objectives:**
Understand the community’s definition of successful long-term management of HIV, identify regional differences and unmet needs, and explore potential solutions

**Meeting 3 Objective:**
To agree on recommendations as a call to action to address long-term HIV management challenges

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**Meeting 1**
July 2022

- 4 elements to living well with HIV
  - Mental & emotional wellbeing
  - Integrated, comprehensive healthcare
  - Access to ART & achieving viral suppression
  - A life free of stigma & discrimination

**Meeting 2**
September 2022

- 7 global barriers to living well with HIV
  - Accessibility to healthcare
  - Policies not prioritizing HIV
  - Stigma
  - Socioeconomic factors
  - Poor mental wellbeing
  - Lack of empowerment
  - Comorbidities

**Meeting 3**
January 2023

- Key challenges & potential solutions to address stigma and poor mental wellbeing identified from literature review & council experience

- Feedback shared & consensus achieved across 6 recommendations as part of a global framework to address stigma and poor mental wellbeing

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Community recommendations to combat HIV-related stigma and poor mental wellbeing and help empower people to live well

Stigma

1. Reframe perceptions of HIV
2. Use the power of one’s story
3. Amplify the U=U message

Poor Mental Wellbeing

4. Put poor mental wellbeing and the need for care in context for people living with HIV
5. Ensure support networks for mental wellbeing are visible and accessible
6. Bridge the gaps for those with more severe mental health issues

U=U, undetectable = untransmittable
Community recommendations to combat HIV-related stigma and poor mental wellbeing and help empower people to live well

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U=U, undetectable = untransmittable
Zooming In: Using the power of one's story to tackle stigma

What do we mean?

We should utilize influencers and influencer platforms to disseminate engaging and relatable content.

How can we develop it?

Incubator programs and talent scouts to identify and support diverse content creators.

How can we deliver and support it?

Different social media platforms to target specific audiences, in partnership with marketing and media organizations.
Impact of ‘using the power of one’s own story’
‘One’s own story’ has the power to change perceptions and actions
Zooming in: Bolstering community-based support networks for mental wellbeing

What do we mean?

Community and peer-based interventions are an effective and established complement to mental health services

How can we develop it?

Formal Mental Health First Aid training for community leaders and ambassadors

How can we deliver and support it?

Partnerships with established regional organizations dedicated to supporting mental wellbeing

Impact of bolstering community-based support networks for mental wellbeing

Develop leadership capabilities of community members to better support others

Provide the tools for effective community support

Increased [my] confidence in how to deal with mental health

I would like all the staff in my workplace to take this, especially those with a non-medical background

Logos from https://pdlid.ca/, https://paninbc.ca/ and https://www mhfa.ca/
Stigma and poor mental wellbeing continue to impede the successful long-term management of HIV and good health

Our experiences of the barriers to living well with HIV were more aligned than we expected.

Our shared experience showed that strategies and interventions exist to help address these barriers.

Our community-endorsed recommendations offer the potential impact and value to help end the HIV epidemic within the most affected communities and regions.

Working in partnership with existing organizations, communities can be empowered, appropriately resourced, and actively involved in enabling equitable access to HIV care.