

# Mental Health and Young People Living with HIV



**YOUTH  
STOP  
AIDS.**

Photography: Victoria Ellen Smith

In collaboration with:



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EXPLORATORY SURVEY  
SUMMARY REPORT  
August 2020

# Foreword

Young people in today's world face a plethora of challenges. For those living with HIV, there are many intersecting factors that impact on their health and wellbeing. Youth Stop AIDS is a UK based organisation campaigning to end AIDS by 2030 in line with Sustainable Development Goal 3. With a specific focus on youth leadership and impact, we seek to champion young people and provide a platform for them to use their power to make change in the world around them.

As a consequence of being a youth-led organisation, we know the challenges that young people face regarding mental health. We are excited to partner with the researchers and sponsors of this report in an attempt to better understand the key factors impacting the mental health of young people living with HIV (YPLHIV) and to work towards evidence-based recommendations for how to improve this. As this report demonstrates, YPLHIV across the globe report significant challenges to maintaining their mental health. This includes lack of trust, lack of training or knowledge, ongoing stigma - both regarding one's HIV status and one's mental health - and lack of available and accessible mental health services.

We partnered with the researchers on this research project because we are passionate about championing young people. We believe that young people are often referred to as a token gesture and that a disaggregated focus on young people has been lacking in other research. In undertaking this research, we were interested to learn what changes young people themselves believed would make a difference. To understand this, it was important that we listened to what young people had to say. This report has been a crucial opportunity to hear the voices and experiences of YPLHIV in order to understand how best we can address the issues that they face. The report also recognises that young people are not a homogenous category and seeks to encourage reflection of how differences such as region, occupation, gender identity, or socioeconomic background may impact individuals differently.

YPLHIV face many interconnected barriers to health and wellbeing; de-prioritisation of HIV services, a lack of focus on mental health, and a severe gap in specialist services for youth and young adults. This report signals key actions and policy changes that we can adopt to ensure better services, health, and wellbeing of YPLHIV. However, to adequately represent the lives of young people we must take seriously their experiences and knowledge.

Going forward, we hope that what we have to say in this report not only addresses key knowledge gaps but also inspires action. We *can* improve the mental health of YPLHIV if we work together and engage with what young people have to say. Youth Stop AIDS are committed to this, and to ending AIDS by 2030. We will draw on this report to understand what needs to change and to inspire our campaigns, and hope to encourage others to do so too.

Finally, many thanks to Dr Nadege, the lead researcher, and the sponsors of this research, Newcastle University's Social Justice Fund, for their hard work and support.

**(Molly Pugh-Jones, London and Southern England Co-ordinator)**

- Youth Stop AIDS

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Thanks go to Individuals who supported the development of the survey, including those who helped to translate the survey into Spanish and Russian, and those who helped to pilot the survey and provided feedback at different stages of the research process.

This report would not have been possible without the young people and stakeholders who responded to the survey. We are ever grateful to participants for taking the time to complete the survey. We will endeavour to disseminate findings widely and to use findings to advocate for improved resource allocation to support mental health prevention and promotion among young people living with HIV.

We would also like to extend many thanks to the organisations and individuals that supported the survey dissemination effort by sharing information about the survey on their social media platforms.

## List of contributors

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## Disclaimer

All quotes used in this report are direct quotes. Author's notes within quotes are demarcated by square brackets. For a global survey such as this, it is inevitable that some statements or phrases or words will be problematic in some contexts than others. We encourage readers to maintain a tolerant attitude towards quotes within this publication.

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# Introduction

Mental health challenges faced by people living with HIV have evolved together with the dynamics of the epidemic. During the initial years of the HIV and AIDS epidemic, mental health challenges associated with being HIV-positive included psychological responses to illness, including end-of-life contemplations and coping with the stigmatising public attitudes. In the era of antiretroviral therapy (ART), mental health challenges revolve around issues pertaining to living with HIV as a chronic condition.

This report provides a summary of key findings from an exploratory survey conducted by researchers at Newcastle University in collaboration with Youth Stop AIDS, and with support from the Global Network of Young People Living with HIV, Fundación Chile Positivo, and Teenergizer. The survey aimed to provide an overarching picture of mental health among YPLHIV and to explore to what extent mental health challenges are prevented and mitigated by public, private and civil society actors. The survey was disseminated between 17th April and 11th June 2020 among YPLHIV and stakeholders working directly with YPLHIV. The objectives of the survey were to:

- Assess mental health challenges faced by YPLHIV
- Explore existing responses to mental health challenges experienced by YPLHIV
- Identify barriers which hinder efforts to improve mental health among YPLHIV
- Identify gaps and highlight neglected areas in need of prioritisation
- Develop a bespoke definition of mental health relevant to the needs of YPLHIV.

The survey was taken by 214 respondents from Africa, the Americas (Latin America), Europe, South-East Asia and Western Pacific. One hundred and sixty-six respondents were young people living with HIV and 48 were stakeholders in the HIV response, including health providers and activists. The results presented here are a summary of findings from the survey. For detailed results, including Tables and Figures, you can consult the full report, available [here [INSERT HYPERLINK](#)]

# Results and recommendations

## A bespoke definition of mental health for Young People Living with HIV

The following were the characteristics of mental health as perceived by young people living With HIV who took the survey:

- Mental clarity
- Self-love and confidence
- Living in the present
- Inner peace
- Meaning and purpose
- Goals and aspirations
- Self-knowledge/awareness
- Community

We developed a bespoke definition of mental health, applicable to YPLHIV globally, by synthesising bespoke definitions shared by respondents and their feedback on individual components of four existing mental health definitions, including the definition by the World Health Organisation.

“Mental health entails a state of harmony between one’s inner and external self which is based on the capacity of each and all of us to feel, think, and act in ways that enhance our well-being. Mental health is influenced by our biopsychosocial health - it is a sense of physical, social, emotional and spiritual adaptation that respects the importance of culture, equity, social justice, interpersonal connections and personal dignity. Mental health is variable; it exists on a continuum between extreme well-being and severe mental ill health, and an individual’s mental health can vary and fluctuate along the continuum.” Maintaining mental health across the lifespan relies on our ability to deal or cope with challenges and normal stresses of life as well as the ability to adapt to new situations and self-manage. Mental health enables us to thrive, and to be productive members of the community/society.

**Recommendation:** Understanding how young people living with HIV characterise mental health can support the development of bespoke measurement tools and inform mental health promotion initiatives. Further research should refine and validate the list of mental health characteristics as perceived by young people living with HIV. The bespoke definitions can be used as a tool for discussing what mental means in the context of young people living with HIV, and it is open to refinement.

## COVID-19 and the mental health of young people living with HIV

65% of 166 young people living with HIV reported that they felt anxious about COVID-19 because of their HIV-positive status.

*“It makes me anxious to think that the stock of medications can run out, and they cannot guarantee treatment.”* YPLHIV, Americas

*“I hadn’t been taking my meds properly (not taking at the same time each day) for a few months in the past year, so I have been worried that my HIV has become resistant to my medication and that I am detectable again which could make me more vulnerable to COVID-19. I have had to wait until the clinic is a bit safer to go to as well to get my blood checked.”* YPLHIV, Europe

The study shows that COVID-19 and the associated lockdown intensified already existing problems of access to treatment and worries related to health management for YPLHIV. Young people were fearful of having a compromised immune system and a high vulnerability to contracting COVID-19, experiencing severe symptoms, and potentially dying from it. If they did contract COVID-19, their fears circled around the treatment they would get, with some fear, especially in Latin America, of being regarded as not worthy of medical intervention due to a serious pre-existing condition.

**Recommendation:** There is a need for more sustainable and robust antiretroviral treatment procurement and supply chains as well as affordable and flexible care for YPLHIV during crises. It is also crucial that bespoke information is disseminated at the earliest possible time and through trusted and varied channels, to prevent and/or alleviate fear due to uncertainties.

## Mental health challenges and manifestations of poor mental health

83% of all 214 survey respondents believed that the mental health of young people living with HIV was worse than that of their peers not living with HIV.

*"When we think about HIV status, it is a nightmare. I feel lost. Sometimes, I am even afraid to think about the clinic."* YPLHIV, Southeast Asia

*"YPLHIV are more susceptible to stresses and depression as they are forced to face various fears of their own (such as rejecting themselves, fear of not finding a partner) and public prejudice."* YPLHIV, Europe.

This study found the mental health of YPLHIV is highly influenced by traumatic experiences related to HIV stigma and discrimination and managing their HIV. Normal life stressors can exacerbate HIV-related stressors and traumas and vice-versa, leading to mental health disorders such as depression and anxiety.

*"Disclosure is a mental health problem. The way a young person living with HIV can manage his/her social life is different from how a person without HIV can socialise."* Y+ Africa

61% of 162 YPLHIV believed they had enough knowledge and skills to challenge HIV stigma and 33% felt confident about disclosing their HIV status in public.

**Recommendation:** HIV services should take into consideration the intersection of HIV and trauma, including the bidirectional link between the traumatic consequences of living with HIV and other everyday stressors and traumas. Consequently, HIV services should strive to deliver trauma-informed care.

## Substance abuse and mental health

14% of young people living with HIV reported that their alcohol use increased after their HIV diagnosis but 66% of stakeholders disagreed with the statement: *'screening of alcohol and drug use is widely practiced by HIV treatment providers.'*

This study supports other studies that suggest that substance abuse is an indicator of poor mental health. Unfortunately, this study also suggests that screening for substance abuse is not widely practised in clinical contexts, which means lost opportunities for identifying and providing mental health support services.

**Recommendation:** Routine screening for substance abuse should be an integrated component of HIV treatment services, alongside screening for mental health disorders, primarily depression and anxiety. Services should have an ongoing open dialogue with YPLHIV on these matters and ensure HIV high literacy levels regarding alcohol, tobacco and other illicit substance use.

## Availability and accessibility of mental health services

Awareness of HIV services

72% of young people and 42% of stakeholders were not aware of any organisation researching or delivering services addressing mental health among young people living with HIV.

Consideration of mental health in different aspects of HIV services

64% of 33 stakeholder respondents (HIV treatment providers, civil society employees and activist) disagreed with the following statements:

- Comprehensive mental health support is provided in paediatric services
- Comprehensive/full mental health support is provided to adolescents during their transition from paediatric to adult services
- Comprehensive/full mental health support is provided to adolescents after their transition to adult services
- HIV and mental health services are integrated; they are provided in the same facility or within the same consultation
- There are mental health professionals (psychologists, mental health nurses, psychiatrists or social workers) in most hospitals

*"I feel that there is a big emotional breakdown at the time of receiving the diagnosis, it's like grieving, there is a before and after and I feel that everything is focused on treatment and the doctors are somewhat cold to treat us when it is a new world, and one has many doubts and fears, and nobody clarifies anything. I feel a great lack of psychological support and mental health concern." YPLHIV, Americas*

The extent to which mental health is discussed during HIV treatment consultations

20% of 214 respondents reported that mental health is never discussed in HIV treatment consultations and 32% reported that it is rarely discussed.

Some young people living with HIV expressed a fear of bringing up mental health during HIV treatment consultations because of different reasons such as:

*"Because I think the health provider may not take it [mental health] seriously as I do." YPLHIV, Africa*

*"Because I don't want to seem like a person who constantly complains." YPLHIV, Europe*

*"The health care provider does not enough time to discuss mental health because of a big number of clients at the health facility." Stakeholder, Africa*



Accessibility of mental health services

Over 70% of 166 young people living with HIV disagreed with the following statements:

- Young people living with HIV know where to access mental health services (visibility)
- Young people living with HIV have a short distance to travel to access mental health services
- Young people living with HIV have free access to mental health services
- Mental health services are provided in an adolescent/youth-friendly environment and approach (confidential and non-judgemental)

The major barriers to mental health access reported in this study were lack of specialised providers, cost, distance, long waiting time, lack of knowledge of where to access mental health services, unwelcoming service environments, including fear of poor provider attitudes and non-confidentiality, and poor mental health literacy and young people living with HIV, and community.

**Recommendation:** Governments and donors need to provide longer-term funding for programme sustainability and channel funding directly to local or youth-led civil society organisations delivering services at the grassroots level. Government and donors should invest in increased training of mental health professionals and increased provision of specialist mental health services in rural areas through outreach services and mobile clinics. mental health should be an integrated component of HIV treatment services, from paediatric through adolescent to adult services. Mental health should be treated, but also the mental health impact of treatment approaches should be considered.

## Prioritisation of mental health

83% of YPLWH felt that mental health was prioritised in the organisations where they were volunteering however many of them (33%) felt that many health facilities were still not prioritising mental health sufficiently. 74% of all 214 respondents disagreed with the following statement: “There is adequate funding to promote mental health.”

This study demonstrates a suboptimal prioritisation of mental health at both organisational and policy levels and suggests that most of the available services and support systems have little to no national policy basis.

**Recommendation:** There is a need for increased funding for the promotion of mental health among YPLHIV globally but most especially in low and middle-income countries. Health facilities should prioritise mental health in their policy and as a minimum standard, health providers and educators should be trained in mental health promotion.

## Making a change

46% of the young people living with HIV believed that YPLHIV were not involved in the development of interventions and programmes in the organisation they worked or the facility where they received treatment.

43% of the young people living with HIV disagreed with the following statements regarding the involvement of young people in the development of policy and interventions at the organisational level:

- YPLHIV are involved in the development of mental health interventions/programmes
- I am satisfied/happy with the way in which my organisation's programmes and interventions addresses mental health

This study proposes that YPLHIV find meaning and a purpose in being meaningfully involved in the HIV response. This study also found that young people's general outlook on life was also thought to influence mental health; this was connected to the availability of opportunities for self-realisation and achieving their dreams. Some YPLHIV who took the survey found involvement in HIV advocacy activities and peer support meaningful and a few expressed the opinion that YPLHIV can play an important role in improving the mental health of PLHIV by sharing their experience of living with HIV and challenging stigma and discrimination.

*"People living openly with HIV in the community have the power to promote positive mental health among YPLHIV through challenging stigma simply by talking about living with the condition and challenging misconceptions. Reducing such stigma can have a powerful impact on improving the wellbeing of YPLHIV by making sure the stigma of the condition does not have a negative impact on their mental health." YPLHIV, Americas*

**Recommendation:** Donors, governments, and organisations should involve YPLHIV in all processes of the response and their involvement should be on their own terms. In particular, the potential of young people openly living with HIV to contribute to the eradication of stigma should be capitalised on. While YPLHIV should be supported to accept their diagnosis and to reach a point where they feel ready to disclose their status, who, how and when to disclose should be a personal choice.

## Conclusion

Attending to the mental health needs of YPLHIV requires a renewed and galvanised commitment to delivering 'youth-friendly' health services within the HIV sector. Integrating mental health into HIV services is necessary to prevent the onset of severe mental ill health among YPLHIV and to promote their mental health. Involving young people in planning and delivering HIV and mental health services is critical to achieving the desired health outcomes. Lastly, there is a need for continued research on the impact of HIV on the mental health of YPLHIV and how this can be prevented and/or mitigated. All these activities require an increase in financial investment towards addressing the impact of HIV on YPLHIV.