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UN Staff Living With HIV; Challenges and Opportunities

Survey Report by the UN Plus Team at UNAIDS



Cover Photo: Yvonne Kasine
UN Plus Member

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Executive Summary:

Founded in 2005, UN Plus advocates for UN staff living with HIV, addressing issues like health insurance, stigma, and travel restrictions. Amidst global changes and funding shortages, the organization is strategically reassessing its mission. At the end of 2023, UN Plus initiated a global survey to comprehend challenges faced by UN staff living with HIV, aiming to revitalize its mission.

John Bryant Collier, Chair of UN Plus Advisory Group says: *Based on the information we have, some UN staff members living with HIV are facing stigma, dealing with mental health issues, and experiencing poor health conditions, which negatively affects their professional lives and, in some cases, performance. The fear of stigma is preventing them from seeking help. I strongly believe that the UN Plus team needs to be operational to provide a dedicated platform for HIV-positive staff to seek support when needed on work-place conditions, access to medication and medical facilities, and ensuring access to insurance. Beyond providing direct support to HIV-positive staff the UN Plus team should work across UN agencies to raise awareness about and enhance non-discrimination and inclusion policies. This is essential for the well-being and inclusivity of all in the UN family living with HIV.*"

The survey, conducted by the UN Plus team at UNAIDS, involved 74 globally dispersed UN staff members living with HIV, highlighting diversity in gender, age, and geographic representation. It revealed that 54.1% of participants had disclosed their HIV-positive status at the workplace and that 27% acknowledged experiencing stigma multiple times, impacting their professional opportunities and personal well-being.

While the majority reported access to sufficient healthcare services, a minority expressed dissatisfaction. Over 50% were aware of workplace policies supporting employees living with HIV, with grants, UN Plus support, and the One Stop Clinic cited as positive experiences. Mental health challenges were prevalent, affecting over 33% of participants, highlighting gaps in comprehensive mental health care, especially related to financial barriers and bureaucratic obstacles.

Despite budget constraints leading to a temporary halt in most activities, over 70% of UN staff living with HIV who were surveyed were aware of UN Plus and emphasized the continued importance of the organization. Their recommendations and expectations signal a desire for future initiatives that address the identified gaps and prioritize the mental well-being of all individuals, irrespective of their health status.

In conclusion, the UN Plus global survey provides valuable insights into the experiences of UN staff living with HIV, emphasizing the need for ongoing advocacy, support, and a renewed focus on mental health care. The organization's commitment to adapting to the evolving global landscape is crucial for ensuring the well-being and inclusion of individuals living with HIV within the UN community.

Winnie Byanyima, UNAIDS Executive Director says: *"This report gives us valuable information on the need to continue working with UN staff living with HIV and make the UN system a model workplace for them. I commit to meaningful involvement of staff living with HIV in the decisions that affect them, to continue building spaces free of stigma discrimination and prejudice, and to end the inequalities that staff are facing. Viva UN Plus!"*

Survey Methodology

The UN Plus Team at UNAIDS is initiating the efforts to revitalize its operations and formulate an effective strategic plan responsive to current realities. As part of this efforts, the team sought to understand the current situation of UN Staff living with HIV within all UN agencies worldwide.

The primary objective of the survey was to gather data on various aspects of UN Staff living with HIV, including demography, general wellbeing, mental health status, workplace stigma, insurance concerns, and available supports in the workplace. To achieve this objective, the UN Plus Team hired a consultant with expertise in survey design and analysis. Collaborating with the consultant, an online multilingual survey was developed in English, French, Spanish, Russian, and Portuguese to ensure accessibility for UN Staff globally.

The online survey was disseminated through various channels, reaching UN Staff living with HIV across all UN agencies worldwide. The dissemination strategy included reaching out to individuals already known to the UN Plus Team, as well as utilizing other organizational communication channels to reach staff living with HIV who were not already connected to UN Plus.

Respondents were encouraged to complete the online survey voluntarily and anonymously. The survey was open for a specified period during November 2023, allowing sufficient time for participants to provide thoughtful responses.

Upon completion of the survey period, the consultant, with support from the UN Plus coordinator, analyzed all responses. Quantitative and qualitative data were examined to draw meaningful insights into the situation of UN Staff living with HIV.

The report's findings and recommendations will form the basis for the development of the UN Plus relaunch plan, strategically revitalizing support mechanisms and addressing the diverse needs of UN Staff living with HIV across all UN agencies worldwide.

Overview:

Established in 2005, UN Plus has consistently supported UN staff living with HIV. Initially focused on advocacy, addressing issues like health insurance, stigma, confidentiality, and travel restrictions, the organization later identified the increasing need for global peer support, especially in regions lacking local structures.

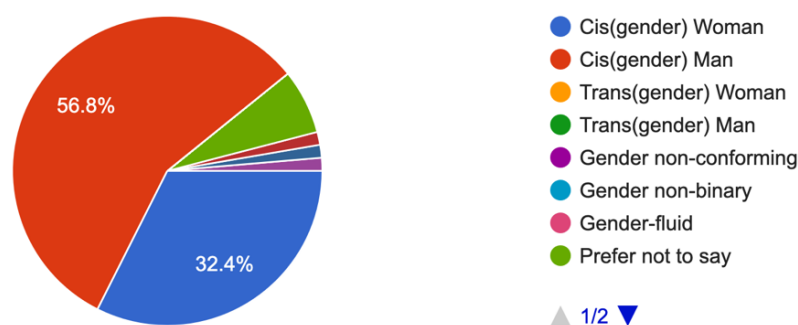
The political, economic, and social landscapes influencing UN Plus's strategies and programs have undergone significant changes since 2005. The organization has witnessed the transformation of the UN's approach to the recruitment of staff living with HIV, starting actively in 1995 and gaining momentum by 1996. As the number of staff members living with HIV increased globally, the need for an environment that supports them became apparent.

Adapting to the changing global political and funding landscape, UN Plus is currently reassessing its strategies and programs to better align with its mission. To revitalize the work, a global survey was conducted specifically for UN staff members living with HIV. This survey aimed to gather insights into their health conditions and address the challenges they face, marking a crucial step in revitalizing UN Plus and ensuring the continuation of its vital mission.

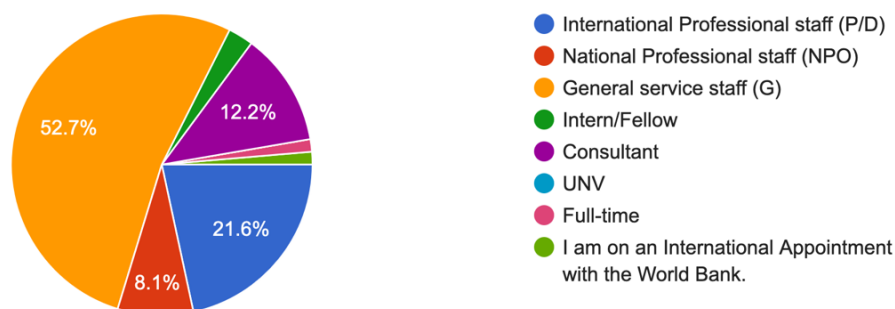
Demographic Information:

The UN Plus team at UNAIDS recently conducted a global survey to understand the challenges faced by UN staff living with HIV in the workplace. A total of 74 UN staff members living with HIV participated, sharing their experiences.

Among the participants, 42 were men, comprising 56.8% of the total. There were also 24 women, accounting for 32.4%, and 8 individuals (10.8%) who identified as transgender or did not specify their gender. The survey aimed to illuminate the various perspectives and experiences of UN staff members living with HIV.



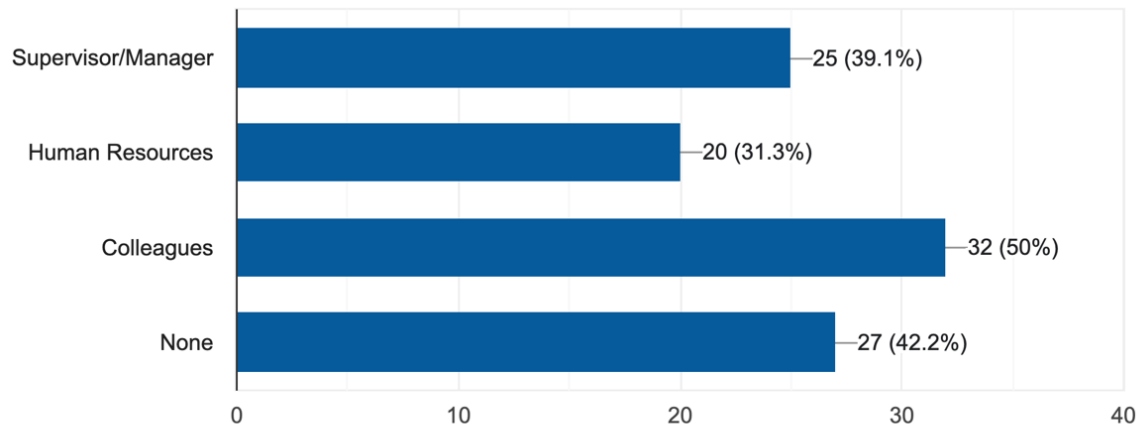
The survey included participants from diverse age groups, covering individuals below 20 to those over 55, with a noteworthy concentration in the latter category. The statistical findings from the survey indicate a significant representation of UN Staff living with HIV within the General Service category. Notably, some of these individuals have devoted several decades—up to 35 years—to their service within the United Nations.



This survey brought together UN Staff living with HIV from various locations worldwide, including, Zambia; the United States; the UAE; Thailand; Switzerland; Rwanda; Italy; Portugal; the Netherlands; Malawi; Kenya; Jamaica; Hungary; Germany; Finland; Cuba; and Botswana. The statistical breakdown reveals that Kenya hosts the highest number of participating staff, followed by Malawi in second place, and Switzerland securing the third position.

In line with the responses gathered from the survey, despite HIV being considered taboo in many places, where individuals living with HIV may face stigma, some UN Staff members have chosen to break this silence. A majority of survey participants, 40 individuals (54.1%), have disclosed their HIV-

positive status within their workplace. They have shared this personal aspect of their lives with supervisors, Human Resources Officers, and other colleagues. In contrast, another group of participants (42.2%) chose not to disclose their HIV status within their offices. Some felt it unnecessary to reveal, while others expressed fear and anticipation of potential stigma in the workplace. However a small number of survey participants have chosen not to answer this aspect.



HIV Status and Disclosure

Among the notable challenges faced by UN Staff living with HIV, 'Stigma' stands out as a significant hurdle. The UN Plus Team conducted this survey to find out how much stigma HIV-positive UN staff face at work. They wanted to collect various experiences and stories to better understand the issue. A total of 20 individuals (27%) among the survey participants acknowledged experiencing stigma multiple times in their work environments.

These individuals have shared some of their encounters, and this report briefly touches upon a few of these stories, providing insights into the real-world impact of stigma on the professional lives of UN staff living with HIV.

1. **Stigmatization by Colleagues:**
 - Colleagues initially avoided sitting with the person due to their HIV status.
 - Some colleagues made inappropriate comments about the individual's health, indirectly stigmatizing them.
2. **Professional Impact:**
 - Supervisor linked the individual's medication expenses to job reclassification, potentially affecting professional opportunities.
 - Due to their HIV-positive status, colleagues in the workplace characterized them only by their HIV status and directed matters related to HIV to them rather than to the appropriate Health Section.
3. **Privacy Violation:**
 - Supervisor shared the individual's HIV status with other international staff, violating their privacy.
 - Exclusion from activities and denial of field activities and promotions despite qualifications.

- Experiences of exclusion and avoidance by colleagues as a result of "privacy violations" regarding HIV status in the office, and incidents like sharing their health statuses issues with other staff.
- 4. **Negative Office Dynamics:**
 - UNJMS Nurses were reported to be discriminatory and gossiping about staff HIV statuses, contributing to a negative office environment.
- 5. **Lack of organizational support:**
 - Management is unwilling to provide a secure space for UN+ members to meet, prioritizing cost considerations over the well-being of the staff.

These quotes collectively illustrate the challenges and discrimination faced by the individual in their workplace due to their HIV status, impacting their professional opportunities and personal well-being.

Below are number of the quotes related to the stigma as part of the survey findings.

"My supervisor told me I use a lot of money for the organization on my medication when I asked him for my job reclassification. Not directly but hearing stigma related conversation happening within groups. One time someone came to our office looking for partnerships with my Organization and that person was representing an association of youth living with HIV. One colleague said that they should check with me because that is my business instead of directing him to Health Section. One time my colleagues who was on Temporary position went to our supervisor requesting her contract extension because I am HIV positive and not able to do the work alone."

"At first, some of my colleagues didn't want to sit with me because of my HIV status. At that time even my family felt ashamed of me."

"Denying me field activities and possible promotions despite being qualified for the post."

"I disclosed my HIV status to my supervisor during a challenging period, seeking support. Unfortunately, my second supervisor not only ignored my disclosure but also shared my HIV status with other international staff, disregarding my privacy. Additionally, I faced exclusion from various activities."

"Management refusing to let UN+ members meet in a safe space; they are more concerned with the cost for the meeting and not welfare of the staff."

"Denying me field activities and possible promotions despite being qualified for the post."

"Tried to print documents of the tests results from a common printer, another staff came and collected the copies and shared with her friends. Now days they avoid me"

"The UNJMS Nurses are very discriminative and discuss every staff's HIV status with other people. It's quite disappointing"

Access to Healthcare and Insurance

The survey statistics indicate that the majority of UN Staff members living with HIV have access to sufficient healthcare services to manage their condition. However, four individuals out of 74 participants have emphasized that they lack access to adequate healthcare services. The data from the report reveals that a significant portion of these individuals express satisfaction with the available services, while a minority rates the service quality lower than their expectations. The feedback provided by the participants is categorized as follows:

Satisfaction Comments:

- The UN Plus buddy program in Malawi is praised for providing information and eliminating stigma.
- Colleagues respecting confidentiality regarding HIV status has given individuals a sense of freedom of mind.
- ARVs, care, and support are offered at 100% coverage, allowing access to treatment and support. (in X country)
- Healthcare services provide access to the best available treatment and care in the country.
- Positive remarks about the encouragement to take medication on time and live a fulfilling life, regardless of HIV status.
- In Rwanda, ARVs are provided free of charge in public health services.
- High quality care is acknowledged, but concerns are raised about the associated costs and reimbursement processes.

Dissatisfaction Comments:

- Lack of information and recommendations on health-related services when traveling or relocating.
- Challenges in dealing with on-site missions and official traveling in countries with strict rules on admitting HIV+ individuals.
- Limited focal points for information about HIV+ benefits/restrictions in the workplace.
- Dissatisfaction with the management of co-morbidities for illnesses without adequate specialization in the country.
- Concerns about the expense of healthcare services, including consultation and medication costs.
- Challenges in accessing quality care and treatment due to lack of recognition of health insurance in the duty station.
- Lack of specific mental health services for people with HIV, despite excellent medical care.
- Issues with the availability of prescribed medications in hospitals and concerns about fueling stigma in clinics.

Overall, the comments highlight a range of experiences, with satisfaction stemming from support programs and quality care, while dissatisfaction is linked to issues such as inadequate information, financial challenges, and bureaucratic hurdles.

A total of 37.8% of participants highlighted challenges related to insurance coverage, as outlined below:

- About the 80% coverage provided by UN insurance, resulting in substantial out-of-pocket expenses for medical bills.

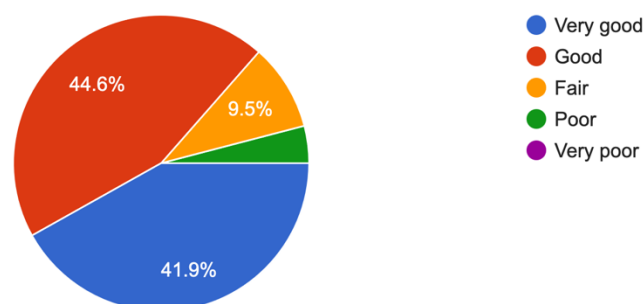
- Reimbursement for treatment expenses is excessively time-consuming.
- Paying for medicines in duty stations poses a significant financial burden.
- Treatment in Lebanon involves purchasing ARVs at the original price due to ministry unavailability, initially causing reimbursement issues with CIGNA.
- The mandatory 20% deduction from salaries, consolidated over time, proves to be financially challenging.
- Frustration with the insurance system deducting 20% from salaries impacts the motivation to seek medical help.
- Insurance sometimes does not cover 100% of treatment costs.
- Viral load test costs are not reimbursed, adding to financial strain.
- Submitting lab test results and HIV+ status disclosure to the insurance company is a tiring and mentally challenging process.
- Relocating from New York to Geneva created challenges in accessing expensive medicine, requiring special permission and full upfront payment before seeking reimbursement.
- Private insurance companies often reject applications due to HIV records, leaving individuals without supplementary coverage and facing discrimination.

Workplace support

Survey findings show that over 50% of the participants are aware of workplace policies supporting employees living with HIV. However, a noteworthy number of participants are unaware of such policies. Among those familiar with UN support policies for HIV-positive staff, some mentioned receiving grants when reaching medical cover limits, assistance from the UN Plus supporting team, and the One Stop Clinic as workplace supports they have experienced.

General Well-being and Mental Health Challenges

According to the survey data, 31 UN staff members living with HIV (41.9%) reported having a very good health situation, and an additional 33 individuals rated their well-being as good. However, a portion of the participants indicated being in poor health.



More than 33% of the participants have also experienced mental health issues. They mentioned that their mental health challenges mostly stem from their HIV status, impacting their professional lives to some extent.

The comments shared depict a range of experiences in dealing with stress and seeking mental health support. Some individuals found helpful resources, such as stress counselors and therapy groups facilitated by management, to cope with challenges.

However, there were difficulties encountered in accessing comprehensive mental health care. The need for therapy related to HIV-related discrimination and stigma was delayed by the lack of full coverage from WHO SHI, indicating financial barriers to essential services. Additionally, bureaucratic obstacles within the workplace, as seen in a failed HR process for a self-funded retreat, highlight the importance of smoother processes that prioritize individual well-being.

A significant observation was the hesitancy to seek help for depression and anxiety due to fear of stigmatization from colleagues. This underscores the ongoing need for workplaces to improve understanding and acceptance, fostering an environment where individuals feel comfortable addressing mental health challenges openly.

In summary, although there are positive examples of seeking support, the comments highlight gaps in mental health care, especially related to financial barriers and bureaucratic challenges. Closing these gaps is vital to establish workplaces that prioritize the mental well-being of all individuals, regardless of their health status.

UN Plus Team

Although the UN Plus Team previously conducted activities, these were halted due to budget constraints. Nonetheless, a significant majority, over 70% of UN staff living with HIV, are aware of this team. They have conveyed their recommendations for the team's future initiatives.

Some of the recommendations are listed as follows:

1. Encourage a workplace environment that respects the privacy of employees with HIV and prohibits discrimination based on health status.
2. Promote mental health resources explicitly tailored to individuals living with HIV.
3. Conduct awareness campaigns among UN staff, supported with sufficient funds for better health outcomes.
4. Be active regionally and globally, addressing workplace stigma, self-stigma, and providing access to care and information on HIV and AIDS.
5. Regularly disseminate information to enhance awareness.
6. Strengthen global and local support groups.
7. Conduct more HIV awareness training sessions.
8. Sensitize UN staff to ensure awareness of available support for people living with HIV.
9. Provide clear information about support available through UN Plus and other UN staff services.
10. Empower staff with training for updated information on HIV to better support colleagues.
11. Emphasize managerial commitment and support for the UN Plus group.
12. Promote information through the UN staff organizations, and the UN departments.
13. Increase visibility through effective communication strategies.
14. Organize retreats for members to meet, interact, and provide mutual support.
15. Improve visibility to ensure members are aware of the existence of UN Plus.
16. Advocate for easier access to medications for staff living with HIV in various duty stations.
17. Advocate for managerial commitment to prevent stigmatization of UN+ members.

18. Maintain a database of treatment access in different countries, including HIV-related laws.
19. Create an "induction pack" with a chapter on HIV for mandatory staff training.
20. Share information on the current development status of HIV treatment.

Additional Comments from the UN staff living with HIV.

1. Link UN Plus to the Mental Health Strategy for enhanced support and managerial commitment.
2. Consider HIV status as a valid reason to manage other illnesses effectively, including provisions for medical evacuation to prevent complications due to a fragile immune system.
3. Activate the UN Plus website.
4. Encourage Cigna to explore ways to assist this group with more favorable health cover terms, as the 20% recovery deters many from seeking necessary medical appointments.
5. Emphasize the importance of reactivating country or duty station chapters as a buddy or peer support system, with a call for managerial commitment to support and finance these activities.
6. Express a desire for UN Plus to restart in all countries, as it was before.
7. Look forward to the re-launch of the program, citing the emotional support and understanding of treatment options it previously provided.
8. Call for clarity on insurance matters to benefit UN staff living with HIV, and request financial support for planning events for people living with HIV.
9. Suggest educating clinic staff to understand that HIV is not a crime, eliminating the stigma associated with the condition.
10. Advocate for continued assistance even after staff members leave the organization, including post-retirement.
11. Express the need for more tools and support for UN employees living with HIV, including campaigns for U=U, open support groups, focus groups, and assistance with medications.

Stories

Miriam Msiska Nyoni: a Woman Fighting Stigma and Empowering the HIV Community

Miriam, born in 1964 in Malawi, is a mother of six children and has dedicated 28 years to working for UNFAO in the Mawawi UN Country Office. Additionally, she serves as a member of the UN Cares Working Group, acts as a Peer Educator at FAO, and actively participates in UNPLUS Malawi Chapter.

Miriam's journey with HIV spans two decades, marked by challenges and victories against the prevailing stigma. She recalls a time when stigma was pervasive, saying, "In those days, stigma was a hundred percent everywhere, people were talking about me, saying that you are dying, you should stay home." Generally, she experienced stigma within the community, healthcare staff, and her workplace.

Facing financial constraints for treatments and with only one hospital ward in Malawi treating HIV-positive patients, Miriam initially struggled to accept her health issues. Her concern was profound, especially for her children, as she contemplated, "My fear was much on my children, who was going to care for them? I thank God I am still alive and very healthy."



Counseling within the United Nations and participation in UNCARE programs played pivotal roles in motivating Miriam to combat stigma. She emphasizes, "I managed my daily life because I accepted the challenge, I feel HIV is within me, I have to move on, I accept and I mix with other peers, I accepted that I am who I am."



Despite facing stress, anxiety, and strong depression due to financial struggles and societal judgments affecting her mental health, Miriam chose to disclose her status openly. Rather than succumbing to the challenges, she emerged empowered, leading a life akin to others.

Miriam has become a well-known activist within her workplace and community. She actively engages in advocacy campaigns, providing awareness through face-to-face and indirect campaigns, stating, "Stigma fuels HIV, and now it fuels more mental health; we need to talk more about stigma." She emphasizes the importance of valuing people living with HIV.

In her workplace, Miriam is thankful for the great support, a stigma-free environment, access to medications, and up-to-date vaccinations. She joyfully shares, "We are encouraged to be active

and to stay and Eat Healthy and to care for our Mental Health by having aerobics and other outdoor games every day."

Miriam highlights numerous supports and facilities in her workplace, including frequent sessions by UN Plus Malawi Chapter, managerial commitment allowing physical meetings for HIV-positive staff, and access to information on topics like positive living, mental health, HIV, and non-communicable diseases.

To empower UN staff living with HIV, Miriam recommends initiatives such as professional development, learning opportunities, leadership development, and prioritizing mental fitness to build psychological safety and trust. Her story stands as a testament to resilience and the transformative power of support, awareness, and acceptance.

Resilience and Advocacy: Yvonne Kasine's Journey Beyond Stigma and HIV

Yvonne Kasine, a 50-year-old woman from Rwanda, a country in East Africa, is a survivor of the 1994 Genocide against the Tutsi in Rwanda. Having dedicated 15 years to working with the UNICEF Office in Rwanda, Yvonne is also a mother of four children and the grandmother of a 5-year-old handsome boy.



Living with HIV for over two decades, Yvonne faced the challenge of discovering her own HIV-positive status after her husband succumbed to AIDS. Reflecting on that difficult time, she shares, "I was shocked when I heard that he had AIDS. I was pregnant with my fourth child and feared that my child and I could have been positive too."

Running for a test immediately, she was found positive but had to delay starting medications due to her pregnancy. Fortunately, her pregnancy was followed up at the only health center providing PMTC services in the country at that moment, and her child was born HIV-negative, bringing immense relief. After a very trying period, Yvonne got all her children tested, and she expressed gratitude, saying, "At least I was happy that all my four children tested HIV-negative."

Recalling the stigma she faced, she says, "It was a nightmare for me when my husband passed away. Everyone was pointing fingers at me and used to say to each other, 'Be careful; she has AIDS.'"

When she later started ARV in 2004 and almost failed to find the best combination, resulting in a life-threatening illness, depression set in as Yvonne contemplated her own mortality and the potential consequences for her children.

Choosing not to remarry due to societal stigma, Yvonne experienced discrimination even within healthcare settings. She recounts a disturbing incident at a clinic where a nurse, upon learning of her HIV-positive status, refused to take a blood sample.

Yvonne would never forget the stigma her child faced at school following the sessions where she shared her HIV status with all UN staff during UN town hall meetings.

Despite pervasive stigma in her community, workplace, and various institutions, Yvonne found support from family, friends, and colleagues. Determined to overcome the challenges, she decided to confront stigma by disclosing her HIV status personally, believing it was crucial for people to hear it directly from her.

Motivated to lead a fulfilling life, Yvonne pursued higher education, earning bachelor's and master's degrees in business administration and a certificate in human resources. Becoming a role model, she demonstrated resilience and capability, proving herself equal to or better than her peers.



To combat misinformation about HIV/AIDS and dispel stereotypes, Yvonne embarked on advocacy efforts. Starting within her family, she educated her children and her family about HIV/AIDS and later extended her outreach to the wider community. Describing her approach, she says, "On the weekends, when I was going to picnics with family and friends, I used to have discussions with people about HIV. Sometimes they had funny questions, but I was giving them awareness."

Yvonne's personal journey led her to champion the cause, providing help to women, men, and youth within her community and UN colleagues through the UN Clinic. Volunteering in regular HIV awareness sessions and campaigns, she later became an advocate as part of the UN Plus and UN Care teams, utilizing the platform to share messages and presentations.

Despite facing numerous challenges, Yvonne is fortunate to have access to up-to-date treatment, support from her office and colleagues, and a professional work environment within the United Nations.

Observing a decline in attention and budgets for HIV-related issues within the UN, Yvonne stresses the continued importance of advocacy and education. She emphasizes the need for UN Care and UN Plus Teams to persist, as they are vital platforms for HIV-positive staff seeking support. She urges the revival of UN Plus, recognizing its potential to be a crucial resource for staff infected or affected by HIV/AIDS.

Acknowledgment

We extend our heartfelt gratitude to the following individuals, teams, and organizations whose unwavering support and dedication were instrumental in the successful dissemination of the survey and encouraging active participation from UN staff living with HIV:

- The UNAIDS Senior Leadership Team, especially Winnie Byanyima, UNAIDS EXD, for their guidance and commitment to the cause.
- Laurel Sprague, Cleiton Euzebio de Lima and Alicia Sanchez from UNAIDS, CYE, for their valuable assistance.
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- UN Plus Members for their ongoing commitment and active involvement in promoting the survey initiative.

We extend our gratitude to Yvonne Kasine and Miriam Msiska, UN Plus members, for consenting to have their voices, stories, and photos included in the report.

A special acknowledgment goes to all the survey participants who generously devoted their time and shared their valuable perspectives. Your active participation has been crucial in shedding light on important issues and shaping the future initiatives of the UN Plus team. Thank you for your dedication and contributions.

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