Spotlight: Tanzania

KNOCKING ON EVERY DOOR

The Family-Centred Approach to reaching every child living with HIV

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Neema, aged 12 years, stands outside her home in Rungwe, Tanzania. Through the Family-Centred Approach (FCA) project, a collaboration between Tanzania's Ministry of Health, the National Network of People Living with HIV in Tanzania, and UNICEF, she was provided with HIV testing, treatment, care and support. Neema is thriving and aspires to become a doctor to help others. (2024).

The cover photo has been shared with Neema and her grandmother to confirm their consent, a step taken in addition to our standard process, to ensure we have their full approval to proceed with printing this photo.

Contents

End AIDS in Children by 2030
THE GLOBAL ALLIANCE

Aligned with the Global Alliance's vision to end AIDS in children by 2030, this report is designed to inspire change, enhance knowledge, and galvanize collective efforts toward the ambitious goal of ending AIDS among all children and adolescents.

Treatment Advocate Mwanaharusi (left) is visiting Beatrice, a 23-year-old mother, and her 2-year-old daughter, Zuri, at their home in Rungwe, Tanzania. Now on ART, Beatrice feels empowered to prioritize her and her daughter's health and future. (2024). © UNICEF/UNI685738/Hassam

1

Introduction

Over the last 40 years, remarkable advances in biomedical science have transformed the HIV response, profoundly enhancing the lives of millions. Innovations such as HIV rapid and self-testing; simplified, well tolerated, single-tablet regimens; and most recently, biannual preventive injections have dramatically reshaped HIV prevention, treatment and care. Yet, these breakthroughs remain largely out of reach for nearly half of children and adolescents, who continue to face considerable disparities in HIV testing, treatment and sustained care.[1]

Behind each child missing from HIV testing and treatment is a story shaped by complex social, cultural and economic factors. Structural barriers, such as entrenched stigma, legal constraints and restrictive policies, prevent children and adolescents from receiving HIV testing services, leaving many underserved or entirely without access to essential care. This Spotlight report gives voice to children, adolescents and their families to share their own stories of finding their way to care and support.

In sub-Saharan Africa, restrictive gender norms and consent requirements, such as a woman needing ‘permission’ to travel, or parental consent laws for testing, frequently prevent children and adolescents from accessing healthcare, rendering them invisible to the very services designed to safeguard their health and wellbeing.[2]

In 2023, an estimated 1.4 million children under 15 years old were living with HIV worldwide, with more than two thirds residing in the 12 focus countries of the Global Alliance, including Tanzania.[3] These countries accounted for 66 per cent of new paediatric HIV infections and 64 per cent of AIDS-related deaths among children. The Global Alliance to End AIDS in Children is a strategic initiative launched in partnership with UNAIDS, the World Health Organization, UNICEF, Networks of People Living with HIV, and a coalition of governments and organizations. Its mission is to end AIDS and improve health outcomes for children and adolescents affected by HIV by 2030.

While biomedical advances offer solutions, health systems and policies are not fully translating these breakthroughs into accessible, equitable care for children and adolescents. In 2023, only 57 per cent of children living with HIV received life-saving treatment, compared with 77 per cent of adults worldwide.[4] Meanwhile, only 66 per cent of children living with HIV in 2023 knew their status, compared with 86 per cent of all people living with HIV.[5]

The global AIDS community faces an unresolved challenge. With a persistent testing and treatment gap in many countries, it is time to confront the pressing question: **What will it take to identify every child living with HIV who remains undiagnosed?**

This report examines the structural barriers impeding equitable access to HIV testing, treatment initiation and long-term adherence – essential elements for sustaining health and well-being for children, adolescents and young women. Rooted in socio-cultural norms, gender disparities and systemic inequalities, these barriers obstruct progress by perpetuating stigma, limiting healthcare access and destabilizing treatment continuity, stalling efforts toward the 10-10-10[6] and 95-95-95[7] targets.

A central theme emerging from the collected narratives is stigma, a pervasive barrier with entrenched biases impacting individuals, communities and health systems. Personal stories of children, adolescents and their caregivers within the report reveal how stigma manifests through fear of disclosure, social judgment and isolation, often deterring young mothers from seeking HIV testing for themselves and their children. In contrast, stories of resilience from community Treatment Advocates, or *Wakili Tiba,* offer a hopeful counterpoint. These advocates work to overcome the limited awareness and stigmatizing attitudes toward people living with HIV, promoting HIV testing for children and ensuring continuous treatment access.

The report is driven by a guiding vision that “virtually all paediatric HIV infections are preventable, and no child should develop AIDS due to lack of access to testing and treatment.”[8] It presents the Family-Centred Approach (FCA) to reaching children living with HIV who are unaware of their status in Tanzania as a promising model. The FCA is a community-based peer service delivery model that leverages the knowledge, communication expertise and deep understanding of the community and networks of people living with HIV to identify households with children and adolescents who may need HIV testing.

The community voices and insights in this report underscore the need for an inclusive, community-based healthcare system that is child-centred, stigma-informed and equipped to reach the most marginalized and vulnerable children, thereby advancing a more equitable HIV response.

2

Zeroing in: vulnerabilities of children, adolescents, and young women in Tanzania's HIV epidemic

Tanzania has made notable strides in slowing the spread of HIV and reducing AIDS-related deaths. Since the political launch of the Global Alliance to End AIDS in Children[9] in Dar-es-Salaam in February 2023, momentum to improve the country's performance across the Alliance's four pillars has grown.

For several years, early infant HIV diagnosis coverage remained below 50 per cent.[10] However, in 2023, the rate showed a significant improvement to 71 per cent [65–84 per cent].[11] This progress followed a policy change in 2022, which mandated health workers to enrol all HIV-exposed infants into PMTCT programmes within several days of birth, facilitating proactive follow-ups for HIV testing and tracking other essential services, including immunization.

Despite progress, in Tanzania only 66 per cent of children aged 0-14 living with HIV are on treatment, 61 per cent of whom are virally suppressed.[12] In contrast, 82 per cent of people aged 15 and older living with HIV are on treatment, with a viral suppression rate of 80 per cent.[13]

In 2023, 98 per cent of pregnant women living with HIV in Tanzania who knew their status were receiving antiretroviral therapy (Figure 1). However, the rate of vertical transmission of HIV, including through breastfeeding, remained high at 8 per cent (Figure 2). Additionally, more than half of all HIV transmissions to children occurred when mothers acquired HIV during pregnancy or breastfeeding (Figure 3). This highlights the need for enhanced HIV literacy, strengthened counselling services, greater community engagement, regular HIV testing for male partners, and the promotion of pre-exposure prophylaxis (PrEP) for HIV-negative individuals who may be unaware of their partner's HIV status.

Figure
1

New HIV infections among children (aged 0–14 years) and antiretroviral therapy coverage among pregnant and breastfeeding women in Tanzania, 2015–2023

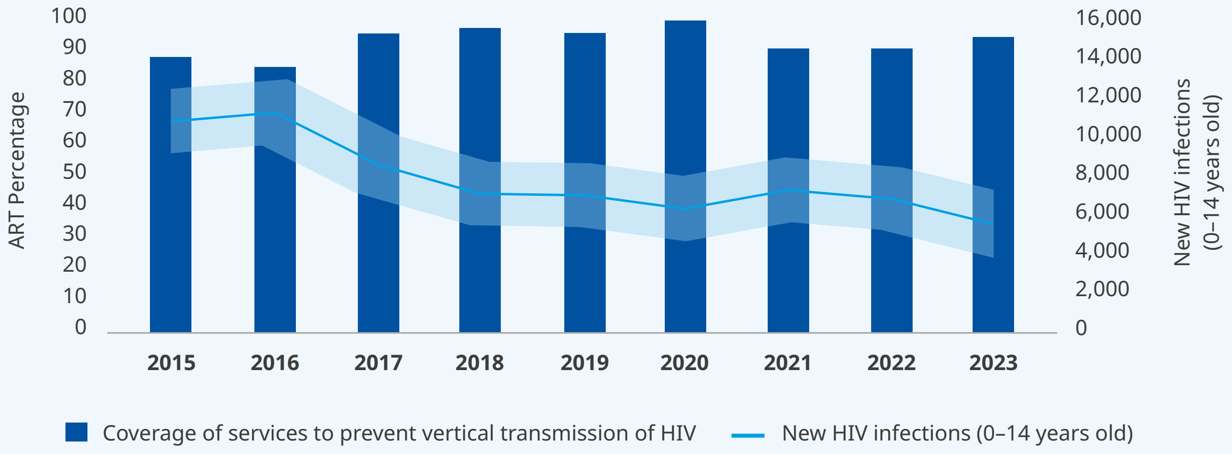


Figure 2

Six-week and final breastfeeding rates in Tanzania, 2015 and 2023

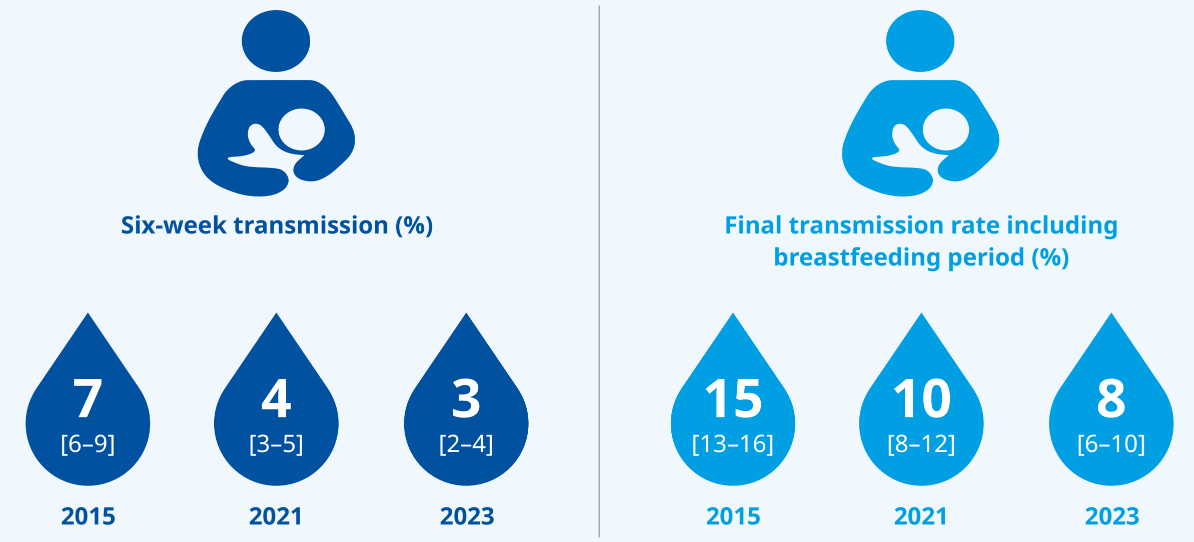
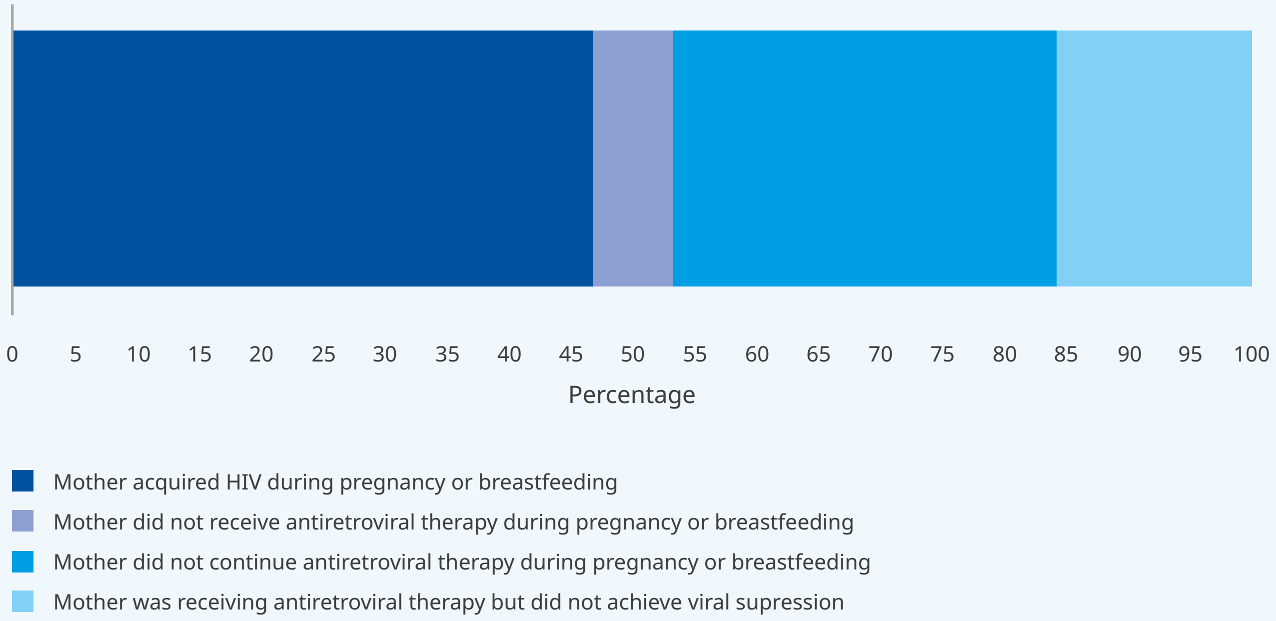


Figure 3

New paediatric HIV infections from vertical transmission of HIV and underlying factors in Tanzania, 2023



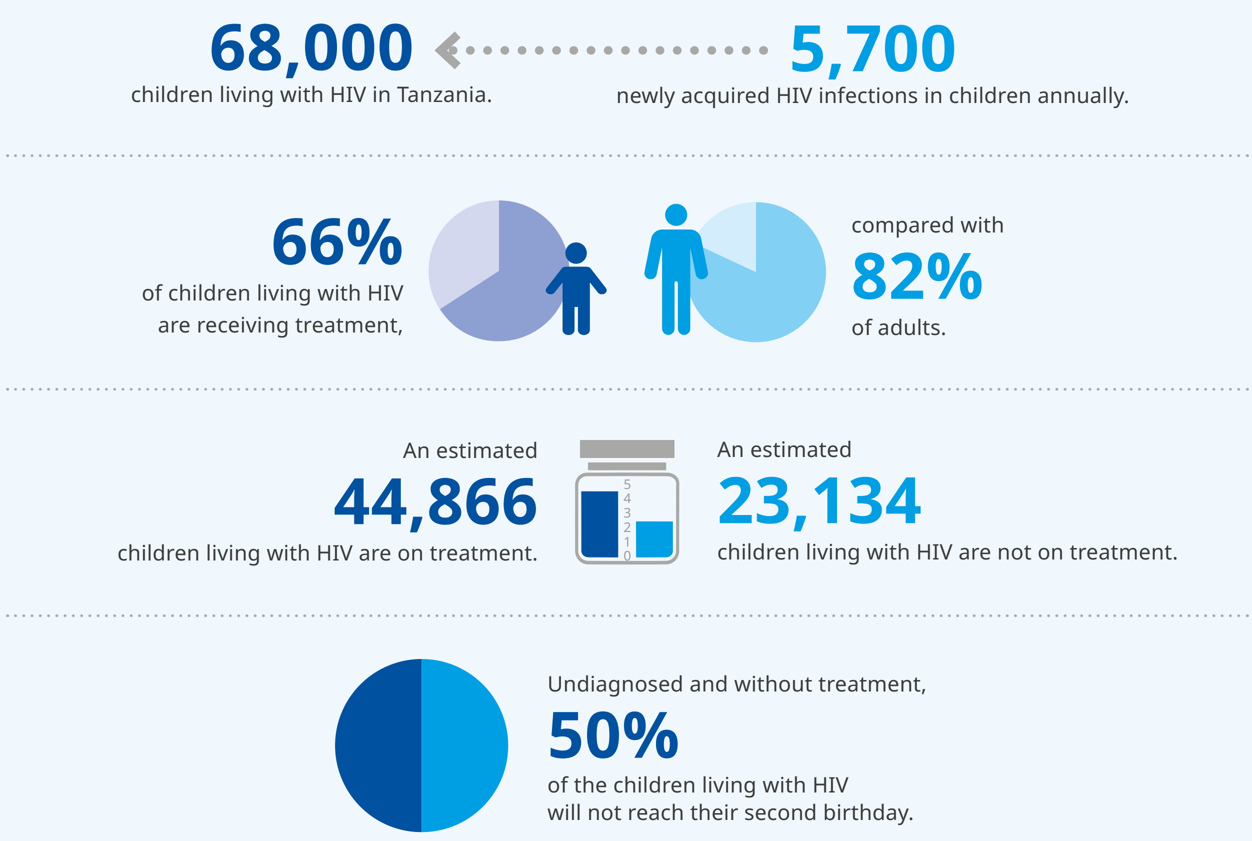
Adolescent girls and young women in Tanzania continue to face a disproportionately high risk of HIV, with epidemic responses failing to adequately address their unique vulnerabilities compared to those of their male peers. The country remains behind in achieving the 2025 Global AIDS target, which aims for fewer than 10 per cent of women, key populations, and people living with HIV to experience gender-based inequalities and violence.[14]

According to Tanzania Demographic and Health Survey (DHS 2022), 33.6 per cent of women report physical or sexual violence by their husband or intimate partner, underscoring a significant public health challenge.[15] Comprehensive domestic violence legislation exists, encompassing physical, sexual and psychological abuse; however, inadequate implementation leaves many women without effective legal recourse. In addition, Tanzania's legal allowance for marriage at 15 years of age heightens these risks, as early marriage often restricts young women's autonomy and escalates health vulnerabilities. Low condom usage among women, with only 13.5 per cent of those with multiple partners reporting consistent use, reflects broader issues of disempowerment and limited access to sexual and reproductive health and rights (SRHR) services.[16]

The vulnerabilities faced by adolescent girls and young women have far-reaching implications, translating into increased risks for their children and perpetuating cycles of HIV transmission. Addressing these vulnerabilities through comprehensive policies, gender-sensitive healthcare and community empowerment is essential to achieve Tanzania's 2025 Global AIDS targets and to build a future where all young women and their families can thrive.

Figure 4

Children aged 0-14 years in Tanzania



68,000 children living with HIV in Tanzania.

5,700 newly acquired HIV infections in children annually.

66% of children living with HIV are receiving treatment,

compared with **82%** of adults.

An estimated **44,866** children living with HIV are on treatment.

An estimated **23,134** children living with HIV are not on treatment.

Undiagnosed and without treatment, **50%** of the children living with HIV will not reach their second birthday.

3

Reaching every child living with HIV:

Stories behind *Locate, Link, Test and Treat*

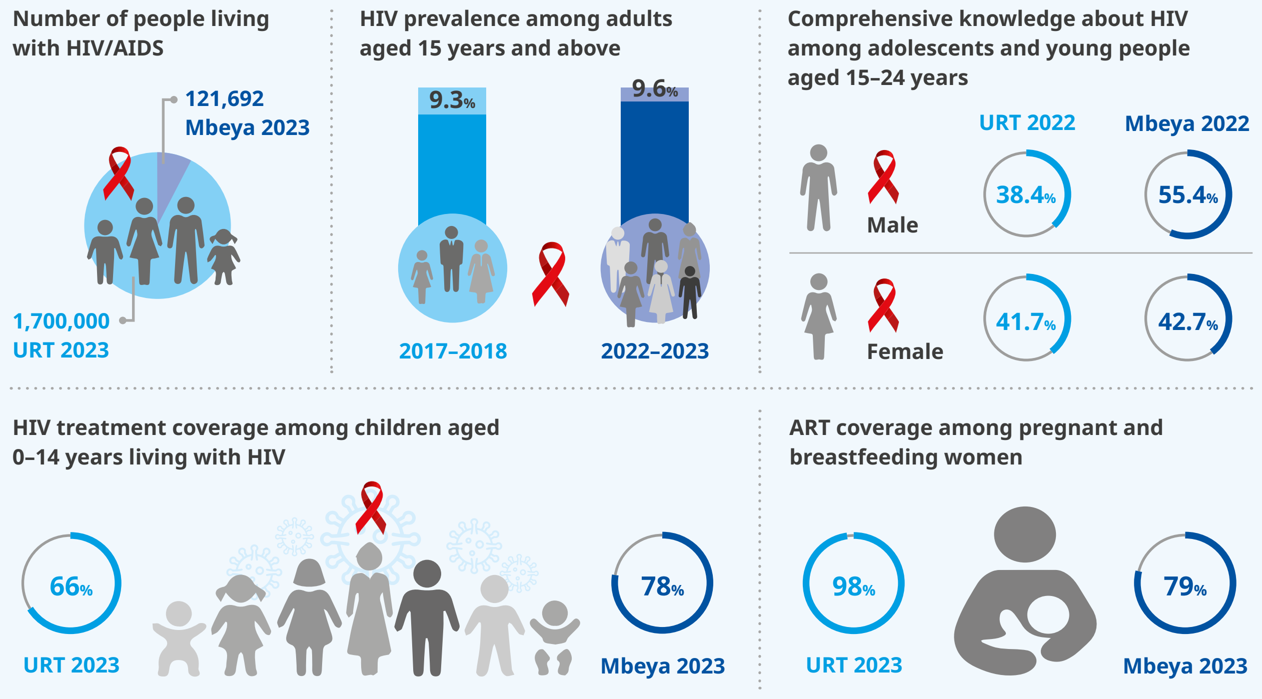
The children and adolescents who shared their stories in this report would very likely still be among the 23,000 undiagnosed and untreated children living with HIV in Tanzania, if Treatment Advocates hadn't knocked on their door.

Treatment Advocates, themselves living with HIV, serve as specialized community health workers in Tanzania's Mbeya region, engaging parents, grandparents and caregivers to encourage HIV testing for children. Although they are unable to carry out HIV testing themselves, instead referring children to a health facility or practitioner, Treatment Advocates are instrumental in breaking down the social and structural barriers to HIV testing and treatment for children and adolescents in this region.

These stories present the passion, resilience, and unwavering dedication of Treatment Advocates, who work tirelessly to reach undiagnosed children and adolescents living with HIV in their communities. Their dedication extends beyond service delivery, as they navigate complex social and structural challenges to connect these children with life-saving care. With courage and determination, they confront and dismantle the stigma, fear and systemic barriers that stand in the way of HIV testing and treatment for children, adolescents and young women. Each story is a testament to the relentless pursuit of equity in healthcare, underscoring the urgency to support these efforts at every level.

The names of the children and adolescents in this report have been changed to protect their identities.

Figure 5 HIV status of children, adolescents and young people, Mbeya region



3.1

Daina

Breaking generations of silence, overcoming HIV stigma and disclosure

47-year-old Daina began her role as a Treatment Advocate with the Family-Centred Approach in Rungwe in the Mbeya region of Tanzania in June 2024. Having lived with HIV herself for more than twenty years, Daina understands the complex issues that surround HIV testing, treatment and disclosure, particularly in more remote communities like Rungwe.

“The fear of HIV is still there. Stigma is still a big problem,” Daina says. “There are a lot of people in my community who haven’t tested themselves for HIV, so how will they know to test their children? For those who know they are living with HIV, they feel ashamed. They would rather not test them than explain to their children that they are HIV positive.”

In July 2024, Daina made her way to 12-year-old Neema’s home, nestled within the banana and cocoa plantations of Tanzania’s Mbeya region. This rural farming community sprawls across rolling hills, where homes are scattered, often accessible only by foot along narrow unsurfaced roads. Reaching children and their caregivers in this landscape poses significant challenges, as the distances and terrain can hinder regular health outreach and services. Neema and her sister Flora, who is 14, have lived with their 60-year-old grandmother, Nasta, since they were young. Their parents died from suspected HIV-related illnesses.

“As soon as I saw the girls, I knew they were sick. Neema could barely stand,” Daina says. She sat down with the girls’ grandmother to talk about the importance of HIV testing for the girls. “To convince her to test, I told her that I was living with HIV and that I was working with the government to ensure that all children in the area are tested for HIV,” Daina says.

Treatment Advocate, Daina (right), speaking to grandmother, Nasta, outside Nasta’s house in Rungwe, Tanzania. Nasta is the sole caregiver of 12-year-old Neema and her 14-year-old sister. (2024).
© UNICEF/UNI681542/Hassam

(2024). © UNICEF/UNI690344/Hassam

Nasta, the girls' grandmother, recalls that Neema and Flora were born at home without any assistance from healthcare providers. "My daughter was often unwell but refused to take an HIV test," Nasta says. "Her body was wasting away, and her husband had died before her. I don't know if he ever got tested either." One day, Flora found her mother lying on the floor of her home; she had died alone. "For as long as I can remember, my granddaughters have also struggled with recurring fevers, stomach problems and painful blisters on their skin," Nasta continues. "I tried everything I could think of – taking them to a local dispensary for antibiotics and even visiting traditional healers. But their health only worsened, and they missed weeks of school at a time."

Nasta was quick to agree to HIV testing for Neema and Flora, and Daina offered to accompany the girls to the clinic because Nasta cannot walk long distances. "I explained that their grandmother didn't know about HIV testing", Daina says. "That if she had known, she would have taken them to be tested earlier so that they would be able to get better."

The results confirmed what Daina had suspected – both girls were living with HIV. The news was difficult, but it brought some relief. “I was happy to know what was wrong,” Neema says. “That I could take medicine and get better.” But Daina’s involvement didn’t end there. She continued to visit Neema and Flora to make sure their health was steadily improving. On a return visit, Nasta told Daina that the girls had two younger siblings, aged six and nine, who were living in a different village with their paternal grandmother. Using her own resources, Daina travelled to find the children. The following week, both children were tested, and the nine-year-old was also found to be HIV positive and is now receiving treatment.

In her role as a Treatment Advocate, Daina confronts the pervasive stigma surrounding HIV in her community, witnessing firsthand the profound challenges it creates for children and adolescents living with the virus. For many, like Neema, disclosing their HIV status is an insurmountable barrier, fraught with fear of judgment and social ostracization.

“I don’t even talk to my sister, Flora, about it,” Neema confides. “I haven’t told my friends. I’m afraid.” Her words highlight a critical issue in the HIV response: the silence that surrounds HIV status. Fear of disclosure within an individual’s immediate support network remains complex and unaddressed, particularly for children and adolescents. Lack of HIV disclosure perpetuates feelings of isolation, contributing to self-stigma, and hindering access to healthcare and mental health services, and the broader support necessary to navigate life with HIV.

It is within this context that the role of Treatment Advocates, such as Daina, becomes invaluable. By openly sharing her own story of living with HIV, Daina breaks down barriers and creates a safer environment for those around her. Her willingness to speak openly and advocate for others offers a lifeline to children who may otherwise remain silent in the face of stigma.

Daina envisions a future where adolescents like Neema and Flora can speak openly about living with HIV, free from the fear of stigma that their mother felt. “I feel very peaceful and happy that I’m able to help these children,” Daina says. “Just like when people came to my village and tested me, I now have the chance to help others.”

3.2 Queen

Bridging the treatment gap, ensuring every child's right to HIV testin

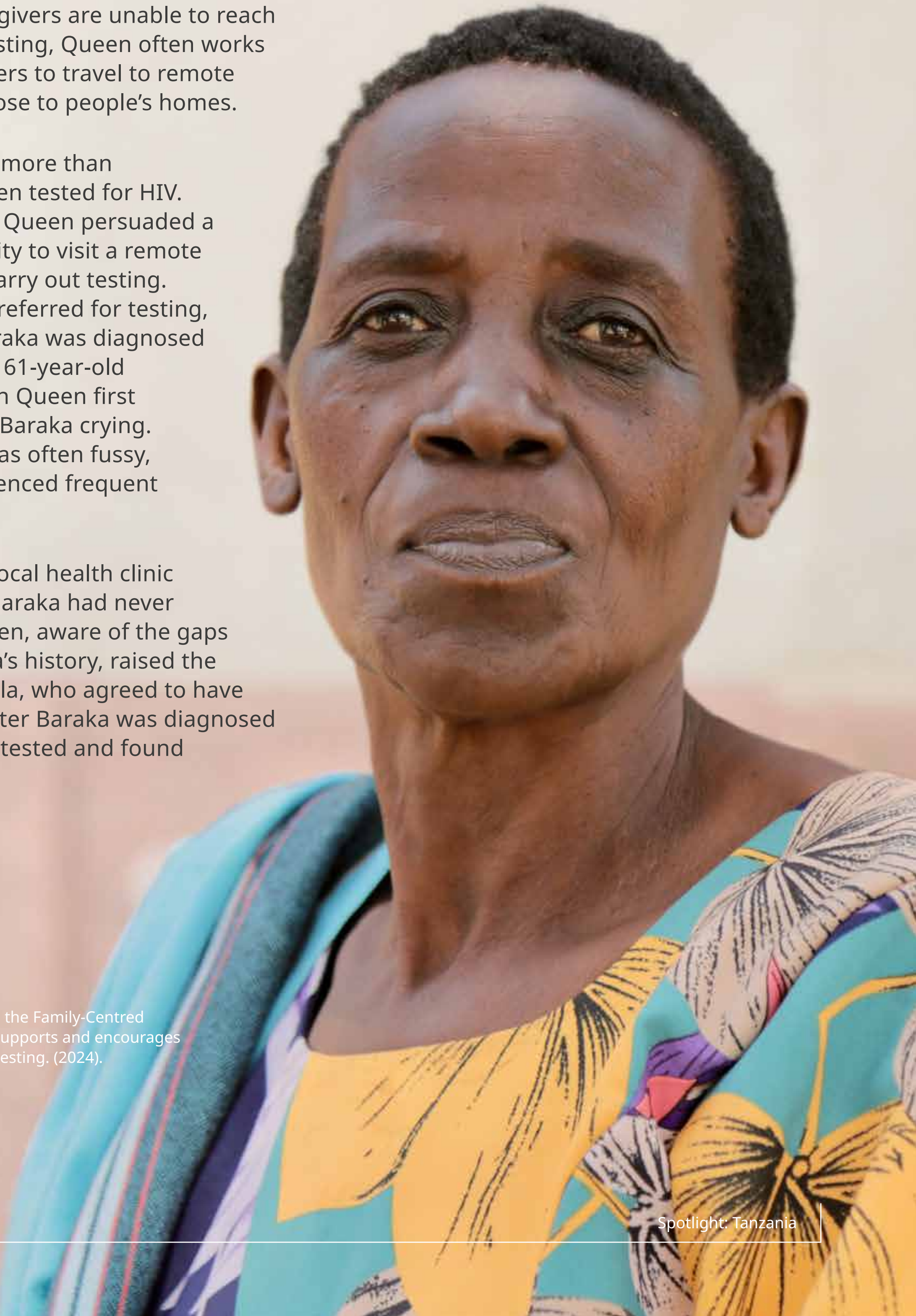
Queen, who's 60 years old, has been a Treatment Advocate with the FCA for just three months, yet she is already making a profound impact. She has long been open about her own experience living with HIV, which has become a powerful tool in her advocacy in her community in Rungwe District.

"It's easier for me to convince people in the villages where they know me," she explains. "In other areas, it can take longer, but once they hear me speak about HIV, they usually say, 'Please take our children to be tested.'"

Where children and their caregivers are unable to reach healthcare facilities for HIV testing, Queen often works to convince healthcare providers to travel to remote villages to carry out testing close to people's homes.

In July 2024, Queen identified more than 30 children who had never been tested for HIV. Of these, 28 were tested after Queen persuaded a nurse from a local health facility to visit a remote village in Rungwe District to carry out testing. Out of the 28 children Queen referred for testing, a two-year-old boy named Baraka was diagnosed with HIV. Baraka lives with his 61-year-old grandmother, Hobokela. When Queen first visited their home, she found Baraka crying. Hobokela explained that he was often fussy, had little appetite, and experienced frequent diarrhoea.

Despite multiple visits to the local health clinic to address his eating issues, Baraka had never been offered an HIV test. Queen, aware of the gaps in testing and knowing Baraka's history, raised the possibility of HIV with Hobokela, who agreed to have Baraka tested immediately. After Baraka was diagnosed with HIV, his mother was also tested and found to be positive.



Queen serves as a Treatment Advocate with the Family-Centred Approach in Rungwe, Tanzania, where she supports and encourages caregivers in her community to access HIV testing. (2024).
© UNICEF/UNI687203/Hassam

“I didn’t think about HIV,” Hobokela says, reflecting on the missed opportunities for diagnosis. “Even though he’s positive, it’s good we know now, and the medication is free. That’s what I told my daughter.” Baraka’s mother works selling biscuits at a bus stand in Mbeya, two hours away, and is only able to visit him once a month. She was just 15 when she gave birth and had to drop out of school, as Tanzania previously banned pregnant girls and mothers from attending school. This policy was reversed in November 2021.

Just one month into antiretroviral treatment, Baraka’s transformation is visible. He laughs and plays outside his grandmother’s house, his once-swollen belly now shrinking, and his bouts of diarrhoea almost gone.

In the rural farming communities of Tanzania’s Rungwe District, paediatric healthcare often takes a back seat to daily survival. **For many parents and grandparents, the demands of farming leave little time to prioritize trips to the clinic, even for something as critical as an HIV test. Queen knows this all too well.** “People in my community are much more likely to get their children tested when a healthcare worker visits the village, like in Baraka’s case,” she says. But, Queen says, healthcare workers are often too busy or unable to make the journey, especially when the cost of transportation is too high for them. “The problem,” Queen explains, “is that as a Treatment Advocate, I can’t carry out the initial testing myself. I must refer them. But many parents or grandparents say they have little time to prioritize trips or don’t have time to take their children to the clinic.”

While free, optimal antiretroviral therapy is a public health triumph, significant barriers to timely diagnosis and treatment persist, particularly for children in underserved, rural communities. The fundamental rights of children to access healthcare, enshrined in international agreements like the Convention on the Rights of the Child, remain out of reach for too many. Without the advocacy of Treatment Advocates like Queen, children like Baraka would continue to fall through the cracks, deprived of the early diagnosis and life-saving treatment they need.

Baraka, aged two years, with his grandmother, Hobokela, outside their home in Rungwe, Mbeya. Thanks to Treatment Advocate Queen, Baraka was identified, tested, and linked to treatment. Just months later, his grandmother proudly shares the remarkable improvement in his health. (2024). © UNICEF/UNI681488/Hassam

3.3

Mwanaharusi

Going the extra mile: HIV stigma, denial and misinformation in accessing HIV services

In the rural district of Rungwe, where access to healthcare for people living with HIV is often fraught with challenges, stigma casts a persistent shadow. Fear of discrimination discourages many families from disclosing their HIV status, leading to significant delays in accessing testing and care – not only for themselves but also for their children. The interplay of stigma, denial and misinformation about HIV transmission frequently results in missed opportunities for treatment, particularly for girls and young women, who face additional vulnerabilities, due to lack of access to services, myths and misconceptions about the virus.

43-year-old Mwanaharusi, who has been a Treatment Advocate with the FCA since 2021, confronts these barriers in her daily work. “I’ve identified many children living with HIV who were undiagnosed,” she says. “Even with index testing, many parents haven’t disclosed their own HIV status, or don’t understand that HIV can be transmitted during pregnancy, so their children are born with the virus without them knowing it.”

When Mwanaharusi first visited Beatrice and her five-month-old daughter, Zuri, in March 2022, she learned that Zuri had been born at home and never been taken to a health facility. Mwanaharusi reached out to 23-year-old Beatrice, who is living with HIV, and emphasized the importance of testing her daughter, even though Zuri looked healthy. Initially, Beatrice was reluctant to agree, believing her baby was too young for an HIV test. It took multiple visits and persistent encouragement to convince Beatrice.

“Mwanaharusi told me stories of other young women who refused testing for their children, and their babies got very sick. I didn’t want that to happen to my daughter,” Beatrice says.

Treatment Advocate Mwanaharusi heads out for a check-in visit in Rungwe, Tanzania. Drawing from her own experience of living with HIV, she inspires caregivers to get their children tested and seek the care they need. (2024). © UNICEF/UNI690292/Hassam


© UNICEF/UNI690293/Hassam

Mwanaharusi has witnessed the devastating cost of stigma and silence. A few months ago, a father approached her, desperate for help, after his four-year-old son was admitted to hospital in a critical condition. Despite years of health issues, the boy had never been tested for HIV; his parents had only sought treatment for minor infections at local dispensaries. By the time the boy was given an HIV test, it was too late – he died two days after his diagnosis. After the boy's death, his mother confided in Mwanaharusi, revealing that she had been living with HIV for years but had kept her status a secret, even from her husband. To avoid disclosing her status, she collected her medication from a distant facility and hid it in a banana tree. When faced with caregivers who refuse HIV testing for their children, Mwanaharusi says she shares this story – without names – to encourage them to act before it's too late.

When Beatrice's daughter Zuri's HIV test returned positive, Beatrice was shocked. "I thought HIV was only transmitted through sex. I never imagined my child could have it," she reflects. This gap in understanding perpetuated the misconception that children are immune to the virus, contributing to her inconsistent use of antiretroviral therapy during pregnancy and her lack of awareness of transmission risks.

Limited knowledge about vertical transmission remains one of the most significant challenges faced by Treatment Advocates like Mwanaharusi. "Many mothers who know they are living with HIV don't fully understand how the virus can be transmitted to their babies during pregnancy, childbirth, or breastfeeding," she explains. This lack of understanding creates a critical gap in prevention, as mothers may unknowingly place their children at high risk of infection, underscoring the essential role of education and support in HIV care. Treatment Advocates work tirelessly to bridge this knowledge gap, offering testing referrals and linking to life-saving treatment for both mothers and their children.

Since Zuri's diagnosis, Mwanaharusi has provided ongoing support to Beatrice, offering counselling, and helping with transportation for visits to the clinic. Today, as Zuri approaches her third birthday, she is thriving – energetic, healthy and happy. "I love playing with Zuri," Beatrice says with a smile. "I hope she will grow up well, study well, and reach her dreams. When it's time, I will ask Mwanaharusi for help on how to talk to Zuri about living with HIV."

Mwanaharusi says she is determined to find every child who might be living with HIV and ensure they receive the treatment they need. When parents refuse to have their children tested, she travels between villages, searching for grandparents or extended family members who might intervene, sometimes relying on only a last name to guide her.

Even after a child tests positive for HIV, some caregivers resist treatment, choosing instead to rely on faith or deny the diagnosis entirely. "One girl's aunt, who was her caregiver, refused to believe she had HIV," Mwanaharusi recalls. "She insisted that prayers at church would heal her, and that medication wasn't necessary." For Mwanaharusi, however, no distance is too far and no obstacle too great when it comes to securing testing and life-saving care for these children. "I keep trying. It can take many attempts, and it's often very challenging, but I don't give up."

3.4

Bahati

No child left behind: the urgent need for a whole-child agenda

26-year-old Bahati has lived openly with HIV for more than a decade and has been working as a Treatment Advocate in Mbeya District for three years. “I’ve seen many cases where children grow up sick because their parents don’t know they are living with HIV, and the children are never tested,” Bahati explains.

In 2022, Bahati was approached by a concerned community member about a five-year-old boy named Joseph, who always seemed to be sick. Initially healthy, Joseph began to develop severe skin blisters, high fevers, and recurrent diarrhoea at the age of two. His mother, 30-year-old Joyce, had taken him to several clinics but, even as his health deteriorated, no healthcare provider suggested an HIV test. Unaware of her own HIV status, Joyce was left searching for answers.

Despite Joyce’s efforts to seek medical help, it still took several visits from Bahati before Joyce agreed to an HIV test for Joseph. “She was in denial at first,” Bahati recalls. “She couldn’t imagine her son could be HIV-positive, but I kept telling her, ‘Don’t wait too long. If we delay, he might not get the help he needs in time.’” After much persuasion, Joyce finally consented, and the test confirmed Joseph was living with HIV. Joyce also tested positive. Joyce recalls having an HIV test, with a negative result, during her first antenatal care visit. She believes she contracted HIV later in her pregnancy and cannot recall if Joseph was tested at birth.

Following Joseph’s diagnosis, Bahati provided support to help Joyce disclose her HIV status to her new husband, who tested HIV negative. Joseph’s younger siblings, born after Joyce started antiretroviral therapy, are also HIV-negative. Today, Joseph is a healthy seven-year-old who takes his medication alongside his mother every evening. He has yet to be told he is living with HIV. Bahati will support Joyce in disclosing Joseph’s status to him at an appropriate age.

Treatment Advocate Bahati, preparing to visit a house. (2024).
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Joyce, a 30-year-old mother of three living with HIV, is pictured with her youngest child, 10 months old, who is not living with HIV. (2024).
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The persistent fear of HIV stigma and disclosure

In a neighbouring village, Bahati also met 14-year-old Faraja, who had been sick for most of his life. Like Joseph, Faraja's frequent illnesses were never linked to HIV, despite multiple visits to healthcare facilities. He was prescribed antibiotics repeatedly, but no HIV test was ever recommended. Faraja's grandmother, 63-year-old Mary, was relieved when Bahati referred Faraja for an HIV test. The test confirmed that Faraja was living with HIV, and he was also diagnosed with tuberculosis.

"He was always sick, not growing like the other children," Mary explains. "I thought maybe it was the food, but he wasn't improving. I was relieved to finally have an answer and medication that could help him." Faraja's mother, who rarely visits him, has not shared her own HIV status with her family, contributing to the silence and stigma surrounding the disease. "People don't want to talk about it. There's still too much guilt," Mary says.

"Disclosure of HIV status is one of the hardest parts," Bahati explains. "It can take a year or more of counselling before people are ready to discuss their status openly, even with their families."

Despite the significant improvements in Faraja's health since starting treatment, Mary has yet to tell him that he is living with HIV, fearing his reaction. "I've heard stories about children who take the news really badly." Mary says.

Bahati says harmful myths and fears, such as these, reinforce the need for more support to help caregivers talk to children about HIV. He emphasizes that disclosure is essential for helping children take ownership of their health and treatment in the future. "When we go for his treatment, little by little, I hope Bahati can start to tell him," Mary adds.

Addressing missed opportunities and strengthening paediatric HIV care

The stories of Joseph and Faraja underscore the urgent need for integrated HIV services that address the specific needs of children. Missed opportunities for early diagnosis, driven by a lack of routine HIV screening for symptomatic children, continue to leave many undiagnosed until their health has significantly deteriorated. The failure to link recurrent illnesses and growth delays to HIV diagnosis remains a critical gap in the healthcare system. Furthermore, the pervasive stigma and fear surrounding HIV disclosure continue to delay access to care and support, leaving families isolated and children without the knowledge they need to manage their health.

Treatment Advocates like Bahati play an indispensable role in bridging these gaps, but more systemic support is required to ensure that children like Joseph and Faraja are diagnosed and treated early, and that families receive the counselling they need to navigate disclosure. As Bahati continues his work, he remains committed to ensuring that children are not left behind. “Other HIV related projects that have been implemented in this area have only focused on adults, and children have been forgotten,” he says. His persistence and dedication are essential to closing the treatment gap and ensuring that every child has access to the care they need to thrive.

Mary, 63-year-old, stands outside the home she shares with her 14-year-old grandson, Faraja, in Mbeya, Tanzania. (2024).
© UNICEF/UNI681609/Hassam

4

A promising practice:

How the Family-Centred Approach is reaching undiagnosed children living with HIV in Tanzania

The Family-Centred Approach (FCA) focuses on reaching children and adolescents living with HIV, especially in hard-to-reach* communities. The initiative goes beyond traditional index testing to locate children who might otherwise be overlooked, particularly those not living with their biological parents. The programme aims to help more children living with HIV access the diagnosis and treatment they need, with UNICEF Tanzania working with the Ministry of Health and the National Council of People Living with HIV and AIDS (NACOPHA) to provide technical guidance in designing an innovative programme in two high-burden districts, Mbeya and Rungwe, in the Mbeya Region.

The FCA has recruited and trained 120 Treatment Advocates across the two districts. However, Treatment Advocates do not have the authority to conduct HIV testing. Instead, they refer children to healthcare facilities or practitioners for testing.

The first phase of the FCA, which ran from December 2021 to April 2022, trained 60 Treatment Advocates to cover 20 out of 57 wards in these two districts. In June 2024, an additional 60 Treatment Advocates were recruited to expand coverage to 20 more wards. The second phase of the FCA is still ongoing. However, 17 out of 57 wards in the district have not yet been covered by either phase of the initiative.

Treatment Advocates, who are themselves living with HIV, collaborate closely with district coordinators and healthcare workers to deliver a range of essential services. In addition to connecting people to HIV testing and treatment, Treatment Advocates play a pivotal role in promoting an integrated family-centred approach, using HIV testing as an entry point to deliver comprehensive wellness checks. These include assessing immunization status, providing Vitamin A supplementation, de-worming and nutrition screening, while also raising awareness about preventing and reporting violence against children. Additionally, the project emphasizes birth registration for children under five. By adopting this integrated approach, the initiative ensures children access a range of health services, extending beyond HIV epidemic control to support broader health and well-being outcomes.

Treatment Advocates receive a three-day face-to-face training focusing on several key communication areas including building relationships within communities, maintaining confidentiality and showing respect for all. They are also trained on using culturally appropriate and clear language to facilitate effective communication.

Each Treatment Advocate is assigned a target of referring at least 30 children per month for HIV testing. To support their efforts, they receive a monthly stipend of TZS 70,000 (approximately US$ 27) to cover travel expenses, including transportation of children to health facilities when needed.

See Annex 2 for the main delivery approaches used to identify children for HIV testing and other details of the project.

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* Hard-to-reach in this context refers to communities that have limited access to essential HIV and general health interventions largely due to geographical (nearest health facility is far or terrain makes mobility a significant challenge).

Mbeya map

Mbeya has a total population of 2,343,754, according to the 2022 Census. It has an area of 37,700 km^2, resulting in a population density of 62.17 people per km^2. The region's annual population growth rate is 3.2 per cent. Within Mbeya, the Mbeya District Council has a population of 305,319, while the Rungwe District Council has a population of 321,713.

Enike, a grandmother, stands beside the cacao fields near her home in Rungwe district, Mbeya Region, Tanzania. Living with HIV for 18 years, she actively distributes prevention tools like condoms and advocates for lowering the legal age for HIV self-testing in Tanzania from 18 to 15, ensuring adolescents can access life-saving testing and treatment services. (2024). ©UNICEF/UNI685726/Hassam

5

A whole-child agenda:

Overcoming barriers

5.1

How stigma, disclosure and structural barriers fuel missed opportunities in HIV healthcare

HIV-related stigma and discrimination, including self-stigma, are key barriers to accessing healthcare and treatment at multiple levels. Stigma prevents caregivers from seeking HIV testing for children, fosters misconceptions about HIV transmission, and creates barriers to disclosure. This continues to hinder opportunities for timely diagnosis, treatment and care, perpetuating the cycle of delayed intervention and worsening outcomes for children and adolescents living with HIV.

Stigma is pervasive and manifests not only in community discrimination but is internalized as self-stigma by individuals living with HIV. Stigma, including self-stigma, profoundly shapes decision-making around HIV testing for children, particularly under the care of non-index caregivers, such as grandparents or extended family members. The stigma that continues to surround HIV leads many to feel fear and shame, often deterring adolescents and caregivers from seeking HIV testing even for themselves, perpetuating a cycle of silence, and a culture of secrecy and denial.

Stigma further complicates the issue of disclosure. Self-disclosure is closely intertwined with stigma in communities where fear of discrimination and social exclusion runs deep. For young women and adolescents, the act of disclosing their HIV status is fraught with anxiety, as it can lead to social isolation, rejection and the dissolution of marriage. HIV stigma extends beyond personal relationships, influencing how people living with HIV are treated in schools, healthcare settings and within their broader communities. Neema's reluctance to disclose her HIV status, even to her own sister, underscores how pervasive this fear can be.

Unless this stigma is addressed – both externally, through community education, and internally, by supporting those living with HIV – the treatment gap for children and adolescents will continue to widen.

For many caregivers, disclosing a child's HIV status is an extremely challenging process. Fear of rejection or judgment keeps caregivers like Mary from telling children like Faraja that they are living with HIV. This reluctance, driven by stigma, leaves adolescents in the dark about their own health, preventing them from taking ownership of their treatment and care.

Without structured support systems to guide families through this challenging process, disclosure remains a significant barrier to effective HIV management. Treatment Advocates like Bahati play a critical role in offering counselling and support, but a formalized framework for disclosure is essential to ease the emotional burden on caregivers and ensure that adolescents are fully engaged in their own healthcare. Tackling stigma is critical to ensuring that individuals feel empowered to disclose their status, seek care and access the life-saving treatment they need.

Deep-rooted denial that children might have HIV, compounds missed testing opportunities. The lack of routine HIV screening in healthcare facilities exacerbates the treatment gap, as children with persistent symptoms often remain undiagnosed. Neema and Flora's grandmother repeatedly sought care for minor infections, without healthcare providers considering HIV as an underlying cause. By the time the Treatment Advocate, Daina, intervened, Neema and Flora were severely ill with undiagnosed HIV. Similarly, Joseph's mother, Joyce, took him to numerous clinics, but none suggested an HIV test.

Missed opportunities for HIV testing often stem from inconsistent implementation of systematic protocols for children, but equally from systemic denial that children could be living with HIV. This denial not only prevents early diagnosis but prolongs suffering and increases the risk of severe health complications. Without addressing the stigma that fuels this disbelief, many children will continue to go undiagnosed and untreated, leading to prolonged suffering and increased health risks.

Stigma exacerbates critical gaps in knowledge of vertical transmission of HIV from mother to child. Antenatal care programmes designed to prevent vertical transmission often fail to re-test women during pregnancy, leaving a window of vulnerability for HIV transmission. Joyce, who tested negative at her initial antenatal care visit, was not re-tested, missing a crucial opportunity for early intervention to reduce the risk of HIV transmission to her child and denying children like Joseph the chance to be born HIV-free.

Stigma can exacerbate these gaps, as many mothers, unaware of the risks of vertical transmission, do not seek consistent antenatal services or follow-up care. Joyce's story highlights the critical need for regular HIV testing throughout pregnancy and a system that ensures both mothers and their babies are monitored closely. Without this, children are left exposed to preventable transmission.

In rural communities in Tanzania, a prevalent misconception is that HIV is transmitted exclusively through sexual contact. This widespread belief among women discourages many from testing their children, as the risk of vertical transmission is not well understood. Beatrice, for example, was unaware of the possibility of HIV transmission during pregnancy or breastfeeding until her daughter, Zuri, tested positive for HIV. Such gaps in knowledge delay timely diagnosis and treatment while perpetuating stigma and reinforcing the false perception that children are not vulnerable to the virus.

"In regions like Mbeya, the FCA has been instrumental in reaching children and adolescents, bringing us closer to the 95-95-95 targets," says Emmanuel Petro, TACAIDS Coordinator. "The dedication of our government and UNICEF reflects our shared commitment to a brighter, healthier future for children living with HIV."

5.2 Beyond the call of duty: Locating and Linking children to care

Treatment Advocates are indispensable in addressing the barriers that hinder access to life-saving HIV care for vulnerable children. Working under difficult conditions, Treatment Advocates are the crucial link between underserved families and formal healthcare systems, bridging the gap between vulnerable children and essential HIV services. They tackle the fear of stigma and the discrimination that often follows, providing education and emotional support to help families confront the reality of HIV. Their commitment and determination, along with their persuasive efforts to ensure that a sick child is eventually tested, are key to the success of reaching children living with HIV whose status is unknown, through the FCA.

Treatment Advocates are deeply embedded in their communities, using their own experiences of living with HIV to build trust and advocate for testing and treatment. Daina's determination to test all Nasta's grandchildren, traveling to distant villages to ensure they received care, underscores the indispensable role of Treatment Advocates, who are also problem-solvers, navigating systemic barriers to ensure that no child is left behind. By persistently engaging with caregivers and following up on cases, Treatment Advocates act as the critical link between community members and healthcare services, often making the difference between children receiving life-saving care and being left untreated.

More than just facilitators, Treatment Advocates fill critical gaps in knowledge, ensuring caregivers understand the importance of testing and treatment. In remote areas where healthcare facilities are far away, Treatment Advocates often go beyond their usual duties, arranging transportation and logistics for families who may not have the means to access care. In doing so, they prevent delays in diagnosis and treatment, which are often exacerbated by denial or disbelief that children could be living with HIV. Treatment Advocates confront the challenge of HIV stigma head-on, building trust within their communities and providing a lifeline to families hesitant to seek care.

Despite their efforts, Treatment Advocates face systemic challenges, such as shortages of HIV testing kits in remote areas, which can result in children being turned away without receiving care. Nevertheless, they persist, often using their own limited resources to ensure that children receive the testing and treatment they need.

To end AIDS for children and adolescents, who are most vulnerable, formal recognition and investment in Treatment Advocates and other community health workers, are essential. They must be empowered with the necessary tools, resources and capacity to carry out initial testing and follow-up care. Strengthening their ability to operate effectively is crucial to closing the treatment gap for children living with HIV and ensuring that stigma, misinformation, and logistical barriers no longer prevent children from accessing the care they need and deserve.

"The FCA highlights the power of community in child health, especially in reaching children with non-biological caregivers," says Dr Zeye Nkomela of NASHCoP, Tanzania's Ministry of Health. "This model has potential for sustainable scale-up across Tanzania's 184 districts, with plans to extend it with support from The Global Fund."

6

Policy recommendations

1. **Integrated, multisectoral *whole-child* agenda:** Advocate for implement a comprehensive, whole-child agenda, integrated across all health services and extended to include protection, education and economic empowerment initiatives. This approach is critical to providing children and adolescents with consistent, sustained care – particularly for HIV– supporting their overall health and well-being. Strong referral and linkages between health, protection and education systems, as demonstrated by the Family-Centred Approach to reaching children, can facilitate access to testing, help keep girls in school, and support ongoing HIV behaviour change programmes.

2. **Empowering community health workers:** Formally recognize and invest in Treatment Advocates and other community health workers as vital contributors to HIV response efforts, establishing a sustainable, community-driven model of care. To enhance their impact, ensure fair compensation aligned with WHO 2019 guidelines and provide essential resources such as self-testing or home-testing kits and transportation support. These provisions would enable Treatment Advocates to reach underserved communities, facilitate timely referrals, and expand access to HIV testing and care. Empowering Treatment Advocates with these resources would improve service delivery, address access barriers, and strengthen community engagement in HIV prevention and treatment efforts.

3. **Lowering the age of consent, decentralized and differentiated approaches to HIV testing for HIV self-testing to 15 years:** Lowering the age of consent for HIV self-testing to the age of 15 years would provide adolescents with a confidential and empowering tool, and help structural barriers associated with clinic-based services. This policy shift would likely promote earlier diagnosis and support Tanzania's commitment to ending AIDS among young people by 2030, advancing a more inclusive, rights-based healthcare framework for adolescents. Currently, in Tanzania, adolescents aged 15 years and older can consent to HIV testing at health clinics but must be 18 to perform a self-test. Adjusting this policy would allow young people greater autonomy in managing their health and facilitate a more youth-centred approach to HIV prevention and care.

4. **Breaking the silence – Disclosure guidelines:** Creating a supportive environment where HIV can be discussed openly and without fear is vital to empowering children and adolescents to manage their health while dismantling stigma. Community health workers, caregivers, and healthcare providers play a critical role in fostering a culture of openness, trust, and acceptance. Evidence-based guidelines that equip parents, health workers, and community cadres to facilitate HIV disclosure to children and adolescents are essential in promoting positive living with HIV. Such guidelines not only enhance health outcomes but also positively impact other critical aspects of life, including education, protection, and overall well-being. Empowering young people to live positively with HIV paves the way for a healthier, stigma-free future.

5. **Addressing HIV stigma through awareness and behavioural change programmes:** Government investment in comprehensive public awareness and social and behaviour change programmes is essential for addressing HIV stigma. Developed in collaboration with Networks of People Living with HIV, these programmes aim to dismantle persistent misconceptions, reduce fear and discrimination, and combat social isolation. Schools and community settings serve as key focal points, fostering supportive environments that empower affected families, encourage early testing and treatment, and provide critical support for children and adolescents living with HIV.

7

Conclusion

To achieve programme effectiveness and close the treatment gap for children and adolescents living with HIV, a more supportive policy environment must be fostered.

Current HIV policies and primary health care systems frequently overlook the specific needs of children and adolescents, leading to inadequate and restrictive HIV testing, suboptimal treatment outcomes, and infrequent retention in care. It is imperative to introduce a child- and adolescent-centred policy framework, asking bold questions and responding to the demands/needs of children and adolescents. Young people would like to see key areas of focus include eliminating age-related barriers, such as the age of consent, implementing gender-responsive approaches to healthcare, addressing stigma and discrimination, strengthening social protection systems, and integrating comprehensive services – including sexual and reproductive health alongside HIV care (10-10-10) – to optimize outcomes.

Progress in diagnosis, treatment and viral suppression depends not only on biomedical advancements and ensuring access to optimal treatments, but also on empowering and enabling children, adolescents, young women and their caregivers to access these services.

Thousands of children and adolescents like Neema, Flora, Baraka, Zuri, Joseph and Faraja rely on the global AIDS community to uphold their rights – the right to health, access to information and dignified care. The Global Alliance to End AIDS in Children by 2030 urges countries to prioritize these rights through targeted policy reforms and the delivery of differentiated services that ensure every child, adolescent and young woman receives the care they need.

Annex 1: Methodology: how the stories were collected through the Family-Centred Approach

UNICEF engaged a consultant who worked closely with UNICEF Tanzania's programme team, alongside the Global Alliance Community Champions for Children in Tanzania, Bahati Haule and Pudensia Mbwiliza, and regional and district health officials, to document the stories of those impacted by the Family-Centred Approach.

In August 2024, the team met with a group of 20 Treatment Advocates, all living with HIV, to understand their critical advocacy roles and learn about the children and adolescents who have benefited from the FCA. The interviews aimed to understand what motivates Treatment Advocates to go beyond their formal duties to find children living with HIV who are undiagnosed and not receiving treatment.

The Treatment Advocates introduced the UNICEF team and consultant to beneficiaries from both phases of the FCA. This included children, adolescents, parents, grandparents and other caregivers with whom the Treatment Advocates had built trust over time. Through these interviews, conducted in August and September 2024, the beneficiaries shared how the FCA has transformed their lives and helped overcome social and structural barriers to HIV testing and treatment.

Caregivers and adolescents expressed their gratitude for the Treatment Advocates' dedication and the vital role they are playing in improving the health of children in their communities.

Annex 2: The main delivery approaches used to identify children for HIV testing

Non-index-based testing (house-to-house visits): Treatment Advocates map out households eligible for inclusion, focusing on households with children, including children living with non-biological caregivers. They then go house to house across villages, meeting with caregivers of children who are frequently ill and whose HIV status is unknown. In an urban area, a Treatment Advocate may be responsible for visiting up to 300 households within a five month period, with relatively short distances between them. In contrast, in rural areas, there may be fewer households, but they are spread out over much longer distances. After building a rapport and learning whether the child has been tested for HIV recently, Treatment Advocates provide referrals for testing. With the guardians' permission, if they are unable to take the child themselves, the Treatment Advocates assist in bringing the child to healthcare centres for HIV testing.

Index-based testing: Treatment Advocates identify children whose parents are known to be living with HIV and refer them for testing. Support groups for people living with HIV are used as an entry point, as some of these children have not yet been tested. Health workers help by giving Treatment Advocates information, with a client's consent, about people on HIV treatment, especially new patients, where their child's HIV status is unknown.

Community sensitization and voluntary testing solicited by caregivers: Treatment Advocates utilize community meetings and faith leaders to deliver messages about the importance of knowing a child's HIV status and how it relates to their health, development and survival. As a result, Treatment Advocates are approached by community members who are concerned about children who are not growing well or are often sick.

Key components of the Family-Centred Approach

Key providers and support system

Who?
Treatment Advocates

How are they selected?
People living with HIV, Community-based, Eligibility criteria

What do they do?
Awareness-raising on HIV prevention, testing, referrals and treatment

- Capacity building (trained by health workers)
- Financial support (monthly stipend)
- Tools (reference materials, e.g., forms, letter of support from district, client listing)

- Work plan done per village
- Village leaders provide support to TAs
- Allocated geographical location for accountability

People living with HIV cluster

Social welfare office

Child-centred

Household/Family

District council

The information and service delivery platform

Implementation modalities in community

- Home visits: house-to-house visits
- Mapping people living with HIV as index for index testing
- Direct observation (e.g., cases of children failing to thrive)
- Sharing information with other Treatment Advocates
- Use their knowledge of the community
- Community meeting
- Accompanied referral from community to facility

↕

Implementation modalities within facilities and linkages

- Direct referral based on TA note
- Mobile outreach to communities for services (HIV testing, other essential health services)
- Health facilities call TAs on potential follow-up cases and provide client listing

Scope of services TAs provide

- HIV prevention services (awareness and promotion of testing for HIV-exposed infants, condom distribution, awareness on HIV prevention)
- Identify children for potential HIV testing and linkage to facility
- Education and awareness raising on HIV prevention, care, support
- Support provision of psychosocial support
- Identify and link to essential health interventions (immunization and growth monitoring, nutrition, child protection, social protection, birth registration)

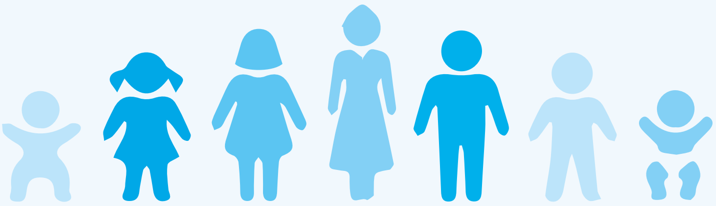
Community level

Social protection

Data from the initial phase of the FCA

(December 2021 – April 2022)

10 wards in Rungwe District • 10 wards in Mbeya District



393 index-based tested
(of these, **75 children** HIV positive)

473 non-index-based tested
(of these, **46 children** HIV positive)

Total 866 tested
(of these, **121 children** were HIV positive – a **14 per cent positive rate**).

All 121 children who tested HIV positive started on treatment

A **14 per cent** HIV positivity rate far exceeds other HIV testing modalities for children in the country.

The FCA has shown that, in addition to index testing, identifying children living with non-biological caregivers can be highly effective.

Beyond reaching and testing children whose HIV status was unknown:

164 children referred for missed vaccinations

16 cases of violence against children identified and linked to social welfare services

Critical links: Healthcare facilities and Treatment Advocates


A health facility in Kyimo, Rungwe, Tanzania. (2024).
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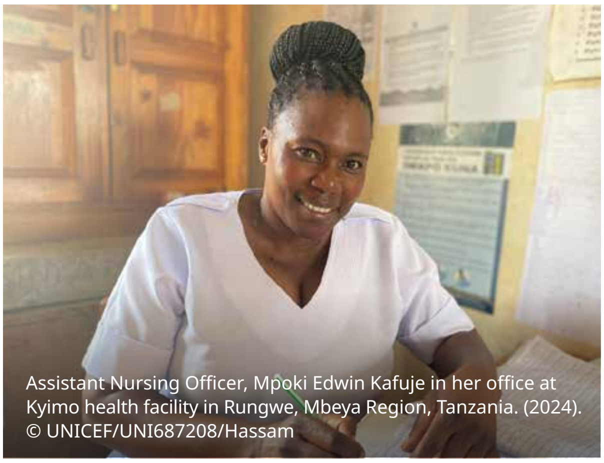
This health facility in Kyimo, in Rungwe District Council, serves around 6,250 people. The clinic offers youth-friendly HIV services, prevention of mother-to-child transmission (PMTCT), and family planning. In September 2024, 339 people (5 per cent of the clinic's patients) were receiving HIV treatment. This included 84 men, 255 women, and only nine children. Four of the nine children were located through the Family-Centred Approach.

"Recently, a mother tested positive for HIV, and she had one child with her who tested negative. The mother told us she didn't have any other children at home, but we didn't believe her. We asked one of the Treatment Advocates to go to her house, and she found two more children living there. The Treatment Advocate managed to convince the mother to bring the other children for testing and one of them tested positive for HIV." – Mpoki Edwin Kafuje, an Assistant Nursing Officer at the facility.


Assistant Nursing Officer, Mpoki Edwin Kafuje in her office at Kyimo health facility in Rungwe, Mbeya Region, Tanzania. (2024).
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Mpoki Edwin Kafuje speaking to Treatment Advocate, Mwanaharusi. Health workers have established strong partnerships with treatment advocates, who are able to follow up with caregivers of children they are concerned about. (2024).
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Key qualities of a Treatment Advocate

Living with HIV

All 120 trained Treatment Advocates are living with HIV and were selected through regional, district and local HIV networks. Treatment Advocates must feel comfortable being open about their HIV status and be adherent to treatment, showing positive health outcomes they can share with others.

"I start by telling them that I am living with HIV. I tell them that I take medication and that I am healthy and well." – Mwanaharusi, Treatment Advocate, Rungwe District

Previous experience in peer support

Nearly all Treatment Advocates have prior experience in peer support or community advocacy, with emotional intelligence and empathy being key components of their success. Their adaptability allows them to provide more than just HIV testing and treatment information, including referrals for other health services like immunizations.

"I explained that their grandmother didn't know about the different health tests. I said that if she had known, she would have taken them to be tested earlier so that they would be able to get better." – Daina, Treatment Advocate, Rungwe District.

Passion and persistence

Treatment Advocates play a vital role in overcoming barriers by engaging repeatedly with caregivers to ensure that children at risk of HIV receive the necessary testing and care. Their dedication to connecting HIV-positive children to life-saving treatment forms the backbone of the initiative.

"I had to visit her house several times, urging her not to wait too long to test her child. I said that without treatment, he could become seriously ill." – Bahati, Treatment Advocate, Mbeya District.

Trusted and accepted by their communities

Treatment Advocates can build trust within communities where they are known for their peer support work and are accepted by community members. Their understanding of community systems, structures and dynamics is crucial in identifying HIV cases in children.

"It's easier to convince caregivers to test their children in villages where people already know me. It's often more challenging when I travel to new communities." – Queen, Treatment Advocate, Rungwe District.

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UNICEF is deeply grateful to all the children, adolescents, caregivers and Treatment Advocates in Tanzania who shared their personal stories and agreed to be photographed for this report, helping to influence the agenda for children living with HIV impactfully, not just in Tanzania, but around the world. Without their courage and willingness to speak out, these important stories would remain untold.

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