Securing a future for children living with HIV

At a glance: The Aidsfonds Paediatric HIV programme



43% of children globally who are living with HIV are still untreated including 37% who are undiagnosed. There remains a huge challenge to ensure no children die from AIDS.

The Aidsfonds Paediatric HIV programme started in 2015 and is working towards "All Children aged 0-14 years living with HIV will have known status, stay in care and on antiretroviral therapy, and have achieved viral suppression and a good quality of life."

Our approach is:

- Gathering evidence on how best to find and support children with HIV
- Close collaboration with community-based partners to design programmes to deliver high quality services for children living with HIV
- Joint advocacy and knowledge exchange with partners at national and global level to increase funding, improve policies and deliver action.

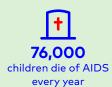
The programme's total annual budget has grown to € 2 million covering 10 countries.

As part of this initiative, together with community-based organisations (CBOs), Aidsfonds developed the <u>Kids-to-Care model</u> and <u>toolkit</u> to guide community service interventions to find, test, treat and retain children living with HIV in line with the Paediatric HIV <u>Service Delivery Framework</u>.

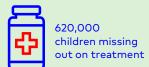


1.4 million children below 15 years live with HIV





Only 56% (780,000) of children living with HIV are on antiretroviral therapy





child transmission of HIV varies from 2.4% in South Africa to 25.5% in Congo DRC



220,000
pregnant and breastfeeding
women living with HIV
are not on ART

Why are children being left behind?

Too many children living with HIV - especially 0-14 year olds – are not being treated or are even unaware of their HIV status. In addition, children and adolescents are dropping out of life-saving antiretroviral treatment (ART), as they and their caregivers face so many challenges and barriers such as lack of transport, insufficient money for medical services and lack of confidentiality at clinics. Being particularly vulnerable, children and adolescents need age-appropriate services to access and stay on treatment. Many cannot speak out on their right to health, need for protection, and the stigma they face. Caregivers do not always disclose the HIV status to children and adolescents living with HIV. As they move into adolescence, children stop their medication, as they do not know why they need to take these and they fear stigma and discrimination in school. Often they have limited access to sexual and reproductive health and rights (SRHR) information through their peers and on social media. With treatment available for children to live a long and healthy life, the priority must be on age-appropriate disclosure, psychosocial support, HIV treatment literacy and child-friendly SRHR information.



: Brian Ssewankamk

Putting communities at the heart of the HIV response

Aidsfonds gathers evidence and advocates on the vital role of community in addressing these challenges. We convince other funders to ensure that communities are integrated into their programmes, especially if they are to reach children who are currently **underserved**. All children need to be reached, because children continue to die from AIDS.

Between 2022 and 2024, the paediatric HIV programme applied the Kids to Care model in Nigeria, Mozambique, Zimbabwe, Uganda, South Africa, Malawi, Indonesia, Tanzania, Zambia and Cameroon.

TAFU champions add social value

Towards an AIDS Free Generation in Uganda (TAFU) programme was Aidsfonds' first paediatric HIV community intervention programme co-created with Ugandan community-based partner organisations. The programme trained community resource persons and village health teams to identify children living with HIV (2567), refer them to health facilities and follow up with them after they have been enrolled in HIV care.

According to the Social Return on Investment Report 2023, TAFU generated € 1.6 million in overall social value in terms of increased wellbeing and averted costs as a result of fewer new HIV infections. This was primarily because a total of 341 mothers with HIV gave birth to children free from HIV. In addition, 3049 caregivers were engaged in village savings and loans associations, generating income for their children's medical costs, transport, nutrition and strengthening their retention on ART.

While cooperation with global organisations has been important to the success of the project, the community partners, community health workers and community structures were the real champions in developing successful approaches, strategies and smart interventions.

Kids-to-Care project results 2022-2024



59,838 pregnant and breastfeeding women tested



12,657 children supported in coping with HIV

18,800 caregivers supported to take care of children living with HIV



13,879 children supported to stay on ART

1683 returned to ART 1396 newly identified



5234
children had suppressed
their viral load



babies of HIV positive women born without HIV



"Communities continue looking after the children even after the project has closed."

David Bitira, Community Health Alliance Uganda, about the TAFU programme Source: Aidsfonds 2022-2024 data

Kids to Care countries 160,000 **†** 15,000 Uganda **2**9,000 **№** 72,000 **⊘** 77% **†** 3,200 † (no data) Tanzania **2** 68,000 **†** 3,800 Zambia **№** 58,000 Malawi **†** 2,300 **№** 50.000 72%+ 1,400 Zimbabwe **?** 70,000 Mozambique **63% †** 2,300 **?** 150,000 **†** 7,800 South Africa **№** 160,000 **№** 63% **†** 1,500

- Number of children living with HIV (0-14) in 2023
- Children living with HIV (0-14) treatment coverage in 2023
- ↑ AIDS-related deaths among children (0-14) in 2023

Source: UNAIDS 2023 *UNAIDS 2022



Find, test, treat

Finding and supporting children living with HIV starts with community dialogues¹ and engaging with the entire community - caregivers, peers with lived experiences, mentor mothers, traditional midwives, lay counsellors, children clubs, religious leaders and young adolescent peer supporters. It can also include reaching out to the private sector (pharmacists), networks of people living with HIV and local structures like village health teams, community health workers and village leaders. Partners pilot various testing approaches and explore which (combination of) testing approaches are best suited for case finding in their context. Once the children living with HIV have been identified, the community and Aidsfonds partners ensure that children and adolescents are connected with health facilities, which provide good quality services² like testing based on advanced risk-stratification tools and early infant diagnosis. Then they follow up on the children and their families in cooperation with community health workers. Aidsfonds and partners are also exploring closer cooperation with traditional birth attendants (TBAs)³ in Nigeria⁴, Malawi and Tanzania and collaboration with schools and children's clubs in other countries. In Zambia, Uganda and Malawi young mothers and sex workers are closely involved, volunteering as community health workers to support case identification. Initial research in eight local government authorities in Taraba State, Nigeria shows that TBA's have doubled referrals of mothers for HIV testing services and their children living with HIV. This means TBA's can be an efficient link between households and health facilities for testing services.



"We have increased the number of children in care more than 10 times."

Harriet Ijongat, assistant nursing officer in Soroti District (Uganda)

Retain in care

Aidsfonds' partner, ZoeLife has developed effective treatment adherence approaches based on ageappropriate disclosure⁵ for children, adolescents and caregivers. This contributed to the successful rollout of the Nigeria national guideline on disclosure. Retention and viral load suppression is stronger in paediatric HIV programmes with psychosocial support through adherence clubs for children and adolescents (SFH publication, 2023, Nweti Narrative Reports 2023). Evidence also shows that treatment adherence among children is stronger when caregivers have greater financial stability through village savings and loans associations and food security through kitchen gardens or nutritional support. TAFU partners in Uganda⁶ reached over 3000 caregivers of children living with HIV and adolescents living with HIV with economic empowerment through village savings and loans associations⁷, (TAFU SROI report 2023). Through VSLAs and by providing nutritional support and treatment literacy, the Kids to Care programme supported 18,800 caregivers with taking care of their children living with HIV in 2022-2024.

Collaborate with government at all levels

Strong cooperation with national AIDS control councils and district health authorities in Uganda, Mozambique and Indonesia increased government investments in support for children living with HIV and joint monitoring visits with District Health authorities ensured active engagement and better record keeping at government health centres. In Uganda joint sustainability plans are now being rolled out with village health teams. Advocacy of partners in Uganda led to the District Health authorities stepping up during the on-going stockouts of HIV self-testing kits which resulted in a sufficient supply of tests. Meanwhile in Zimbabwe, SAfAIDS successfully advocated for the national roll out of Paediatric Dolutegravir⁸, after the government committed to paying community health workers to do this work. In Nigeria, the National AIDS Council offered our partner the Society for Health office space for the Paediatric HIV Breakthrough Partnership.



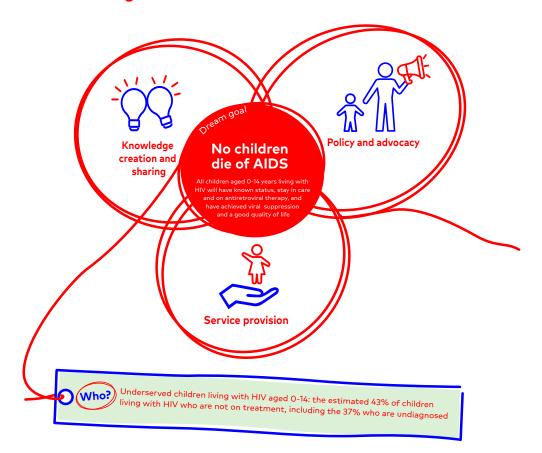
"The Kids to Care model has revealed, and further strengthened the need for us to support the communities more. This will strengthen what we are doing there as the Ministry of Health, working with the different partners that support us to implement our HIV program."

Dr. Eleanor Namusoke Magongo, Lead National HIV Program for Children and Adolescents of the Ministry of Health in Uganda

Develop lasting partnerships

The programme has led to enduring partnerships in each country, building strong leadership skills in our community partners. Community organisations in Uganda and Nigeria, for example, now play a leading role in country planning, reporting and proposal writing within the Paediatric Breakthrough <u>Programme</u>. In addition, the <u>Paediatric HIV Advisory</u> Panel established in 2023, co-decides on grant allocations and competently advises Aidsfonds on its direction in paediatric HIV. Aidsfonds' partners frequently link up to learn about pressing new developments in the paediatric HIV sector. We share best practices and jointly develop toolkits and other resources, and share our expertise in international spaces. Together we support advocacy initiatives of global networks and the Global Alliance to End AIDS in Children. In addition, we are continuously exploring new pathways in finding, testing, treating and retaining underserved children.

The way ahead: Securing a future for children with HIV



The Aidsfonds paediatric HIV programme has a strong evidence-base and applies all available resources to continuously learn, exchange and develop in collaboration with community partners. The achievements over almost 10 years enabled Aidsfonds to roll out the Kids to Care model in five new countries in 2024 - Malawi, Zambia, Tanzania, Indonesia and Cameroon.

While funding for paediatric HIV has changed drastically over the years Aidsfonds continues to invest in community-based programming. In the upcoming years we will prioritize sustainability and integration of community models with governments, and encourage projects to establish strong paediatric coalitions at country level.

In the past years community structures were strenghtened and the linkages with health facilities was improved which changed the way paediatric HIV services are deliverd.

To meet new and persistent challenges like gaps in paediatric HIV services, stigma, climate change and recent reductions in funding for children with HIV, funders need to step up:

- 1. Invest in communities, community structures and community-based organisations for effective programmes and for sustainability.
- 2. Accelerate programming for children with HIV to bridge the gaps before more young lives are lost.

- N'weti Factsheet <u>Kusingata Mozambique factsheet2023 final.pdf</u> (aidsfonds.org)
- 2 In close cooperation with EGPAF/PATA, as part of the ViiV Paediatric HIV Breakthrough Programme in five countries.
- 3 Traditional Birth Attendants (TBAs) are skilled village midwives with little or no official status in national health systems. Many women give birth with the support of a TBA, but they do not always access PMTCT (prevention of mother to child transmission) services.
- 4 Effectiveness of community mobilisation models in improving HIV testing services uptake among women and children in Nigeria: A quasi-experimental study
- 5 <u>KidzAlive_SA_factsheet2023_RGB_final.pdf (aidsfonds.org)</u>
- 6 National Network of people living with HIV in Uganda (NAFOPHANU), Community Health Alliance Uganda (CHAU), HealthNeeds Uganda (HNU).
- 7 Village Savings and Loans Associations contributed Euro 2,4 million overall direct value and 1,1 million overall long-term value and directly 87,000 and 50,000 social value, according to SROI 2023.
- 8 https://aidsfonds.org/vp-content/uploads/2024/02/FTT_Zimbabwe_factsheet2023a_final.pdf