Strengthening community support to improve HIV care

Results and best practices from the Kusingata project in Mozambique (2021-2025)

Kusingata in Mozambique

Mozambique continues to face a significant HIV burden, with an estimated 2.5 million people living with HIV in 2024; the majority were adult women (1.5 million), and 180,000 were children aged 0-14.[1] Of women living with HIV aged 15 and above, 85% received antiretroviral treatment.[1] Many women do not initiate antiretroviral therapy prior to or during pregnancy because of a range of barriers. These include: lack of knowledge regarding the benefits of antiretroviral therapy; lack of support from male partners; non-disclosure of HIV status due to fear of stigma and discrimination; lack of money for transport to the health facility or to buy food; side effects from antiretroviral drugs and long waiting times at health facilities.[2]

Only 68% of all infants born to women living with HIV (HIV-exposed infants) in Mozambique received an early infant diagnosis.[1] Some of the obstacles to the use of HIV services for HIV-exposed and HIV-infected children include women seeking care outside of the conventional health system; disbelief in test results; fear of disclosure; and poor patient flow and long waiting times at the institutional level.[3] In addition, compared with adults, a clearly lower percentage of children living with HIV received antiretroviral treatment and were virally suppressed.[1] To address these gaps, Kusingata project provides community- and health facility -based HIV services. In addition, it implements community-led monitoring to encourage people living with HIV to engage with health service providers and health authorities to assess the quality of the facility-based HIV services, and to jointly create action plans to respond to the identified problems in service provision.[4]

Kusingata means "community support". The project is centred around strengthening the community structures that provide support for case finding, HIV-testing services, linkage to care and treatment, and long-term retention in care. These community structures include community health workers, community groups and leadership. Since 2021 the Kusingata project has been implemented by N'weti with support from Aidsfonds and ViiV Healthcare in Jangamo, Massinga and Morrumbene districts of Inhambane province.

From May 2024 to April 2025, Fundación Vicente Ferrer (FVF) provided additional support to existing testing, linkage and retention activities, as well as to new activities, including mobile brigades and case conferencing.

[1] https://aidsinfo.unaids.org/
[2] https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-018-0644-7
[3] https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-14-1240
[4] https://phia.icap.columbia.edu/wp-content/uploads/2023/10/201023_INSIDA_ENG_RR4.pdf

The Kusingata project's goal is that "children and mothers living with HIV and/or affected by HIV in Inhambane province can live healthy lives in which they can reach their full potential". To achieve this, the programme has the following main objectives:

- Establish an enabling environment for increased provision, demand, uptake, and ownership of quality community-based and clinical HIV services among pregnant and breastfeeding adolescents and women, and children living with HIV.
- Identify and link children, adolescents, pregnant and breastfeeding women living with HIV to care and treatment.
- Support retention in care and adherence to treatment of children, adolescents, and pregnant and breastfeeding women living with HIV, towards achieving viral suppression.
- Document the results and the implementation model for advocacy and sustainability.

Who is N'weti?

N'weti is a Mozambican non-governmental organisation working towards the vision that individuals and communities adopt healthy behaviours and have access to universal, equitable and quality public health services. N'weti is a pioneer in social and behaviour change communication in Mozambique and builds community-based initiatives to support HIV testing, linkage and long-term adherence and retention.

Kids to Care model

The Aidsfonds Kids to Care model empowers communities to strengthen the links between communities and health facilities to find, test, treat and retain children, and pregnant and breastfeeding mothers, living with HIV. The Kids to Care model is built on the following foundational principles:

- Community-owned and community-led
- Builds on existing community structures
- Child and family centred
- Builds on government frameworks and policies
- Key stakeholders are meaningfully involved from the beginning
- Interventions are informed by data
- Committed to sustainability and long-term support

Kusingata project interventions

The Kusingata project is built on the premise that strong, informed and active communities can drive sustained improvements in health outcomes. The project mobilises and capacitates a diverse network of community actors and community leaders to extend services beyond the health facilities. The community actors provide a comprehensive package of services that are tailored to the needs of individuals and families. The interventions work at individual, family and community levels, to provide holistic support to people living with HIV. The project also supports and works in collaboration with the health system to improve HIV services at health facilities. The interventions are built on the Kids to Care model stages to find, test, treat, and retain.

Photo credit: N'weti

To find people living with HIV, especially children, adolescents, women of reproductive age, pregnant and breastfeeding women (stage 1 of the Kids to Care model), the project establishes an enabling environment. The aim is to increase demand, uptake, and community ownership of community- and health facility-based HIV services of high quality. Through training and supervision, the project strengthens the capacity of community health workers to support prevention of mother-to-child transmission, HIV testing, early antiretroviral treatment initiation, adherence to treatment and retention in care.

The trained community health workers sensitise and mobilise the community on the same topics through meetings with community leaders and influencers, as well as through structured community dialogues. The community dialogue activity is a key strategy for N'weti to **create demand for HIV testing and to mobilise community support for people living with HIV**, by improving understanding of HIV and reducing stigma and discrimination. Through seven weekly interactive community dialogue sessions that focus on sexual and reproductive health, antenatal care, HIV prevention and other topics related to HIV[5], participants engage in discussions aiming to increase awareness and shift perspectives. In addition, the trained community dialogue facilitators offer private one-to-one discussions with the participants to identify their health concerns and need for services, and provide referrals to relevant services, with a focus on HIV counselling and testing. The Kusingata lay counsellors visit the community dialogue groups to provide community-based HIV-testing services to eligible participants.

> Of all the themes of the community dialogue sessions, I liked most the ones about sexuality and family planning. This allowed me to break the taboo to talk about these topics, and I was motivated to discuss with my daughter, because I had a bad experience with my older daughter, who had an unintended pregnancy. She was abandoned by her partner, and as I did not want the same to happen with Marta, I decided to advise her to use contraceptive methods. I want to make sure my daughter has a healthy life, advising her to prevent early pregnancy, HIV and sexually transmitted infections.
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> **Isaura**

N'weti implements **community-based HIV testing, supports testing at remote health facilities** (stage 2 of the Kids to Care model) and, since the beginning of 2023, has distributed HIV self-test kits. Trained lay counsellors carry out all these activities. They provide community-based HIV-testing to sexual partners and children of people living with HIV (index testing approach), their family and household members. Mobile testing is offered to community dialogue participants and through integrated mobile brigades to remote communities. Besides pregnant and breastfeeding women, the project tests other adolescent and adult women as well as their partners, to ensure they know their HIV-status and can either prevent getting HIV, or initiate antiretroviral treatment already before they get pregnant.

The lay counsellors refer all those tested at the community who have a positive test result to the health facility so they can **initiate treatment as soon as possible (**stage 3 of the Kids to Care model). They accompany the newly diagnosed individuals to the health facility and follow up through home visits and phone calls, ensuring rapid linkage to care and treatment. Those who receive a positive test result at the mobile brigades or at health facilities, can initiate treatment immediately. Health providers from the health facilities also provide other health services, such as antenatal care, during the mobile brigades. Those who have a negative test result are counselled on and referred to HIV prevention services.

To create an enabling environment for HIV testing and retention in care at the health facility level, the project **empowers and engages the community to demand accessible and high-quality health services**, with a focus on antiretroviral treatment and prevention of mother-to-child transmission services (stage 3 of the Kids to Care model). Kusingata implements community-led monitoring by using the community score card tool to encourage people living with HIV to engage with health service providers and health authorities to assess the quality of the services, and to jointly create action plans to respond to the identified service gaps. To improve sustainability and ownership of this process, the project also trains community-based organisations and key local actors such as health facility co-management committee members, to advocate for improved quality of HIV services.

[5] **These topics include:**

1) Gender norms and equality; communication within the family
2) Rights and responsibilities related to health and health care, focusing on sexual and reproductive health
3) Prevention of HIV and sexually transmitted infections; HIV counselling and testing
4) Family planning and planning for pregnancy, including use of contraception
5) Prevention of mother-to-child transmission and adherence to antiretroviral treatment
6) Delivery and taking care of a child exposed to or living with HIV, including the importance of early infant diagnosis (EID)
7) Participation in community-based monitoring of the quality of health services

Photo credit: N'weti

Once antiretroviral therapy has been initiated, people living with HIV are supported in adherence to treatment and **retention in care** (stage 4 of the Kids to Care model). Trained mentor mothers (who are themselves mothers living with HIV and adherent to antiretroviral therapy) conduct preventive home visits and phone calls to support retention of children exposed to or living with HIV (≤ 5 years of age), and of pregnant and breastfeeding women living with HIV. The mentor mothers provide education on HIV, adherence, prevention of mother-to-child transmission, early infant diagnosis and nutrition, among other topics. If a pregnant or breastfeeding woman, or a child under 5 years interrupts treatment, the mentor mothers conduct reintegration home visits and phone calls, during which they counsel the mothers and families on the importance of returning to care and treatment. After reintegration, the beneficiaries continue to receive home visits supporting their adherence and retention.

Mentor mothers also facilitate mother-to-mother support groups where mothers living with HIV and other caregivers of children exposed to or living with HIV can share experiences, support each other, receive information on and discuss the above-mentioned topics. In addition, Kusingata improves age-appropriate disclosure of the child's HIV-status with support from Zoë-Life and in coordination with PATA - Paediatric-Adolescent Treatment Africa, through training and supervision of community actors and use of child-friendly tools.

The project also implements case conferencing with children, pregnant and breastfeeding women living with HIV who had unsuppressed viral loads, meaning that the antiretroviral treatment does not have the desired effect, most often due to lack of adherence to antiretroviral treatment. During case conferencing sessions, the beneficiaries (or their caregivers in case of children), the community actors, and health facility providers, jointly identify the reasons for unsuppressed viral loads (including wrong/no dosage of antiretroviral treatment given to children due to lack of a steady caregiver or non-acceptance of the child's diagnosis by the parents, non-adherence due to non-disclosure of HIV status to partners/family members caused by fear of stigma and discrimination, side effects of medication, lack of nutrition, etc.) and make a plan to address these reasons which is jointly implemented and monitored.

Children over five years, women who are not pregnant or breastfeeding, and men, who are recently diagnosed to be living with HIV or who have interrupted treatment, receive retention support from lay counsellors, who conduct similar preventive and reintegration home visits and phone calls as mentor mothers. As a complimentary activity, N´weti supports local authorities and health providers in improving the quality of viral load monitoring, by providing on-the-job training to community actors and health providers, strengthening coordination between health facilities and the district laboratory, and transporting viral load samples and results when visiting the health facilities.

As an additional strategy to support retention, N'weti has established village savings and loan groups as well as income generating groups to **strengthen economic opportunities and to ensure sustainable livelihoods for pregnant and breastfeeding women living with HIV**, and for families of children living with or exposed to HIV. In the village savings and loan groups, members come together on a regular basis to contribute savings and take rotating loans to invest in income-generating activities through, for example, small businesses. The groups are facilitated by trained facilitators, and besides improving the participants' financial literacy, they provide information on diverse health topics. In addition, the facilitators have individual discussions with the participants and provide referrals for the needed health services. The groups often continue to a second savings cycle, which they conduct independently, although the facilitators continue supporting them when needed to ensure sustainability.

The project also facilitates income generating groups that train members in sewing, agricultural farming or raising chickens, for example. The increased income these activities generate can be used to cover medical expenses, healthier food, and improving the quality of life and living conditions of pregnant and breastfeeding women living with HIV and their children.

Project impact

Through the Kusingata project, particularly by participating in the community dialogues, community members have significantly improved their knowledge and understanding of HIV and sexual and reproductive health. They have learnt to assess and demand high quality health services through engaging in community-led monitoring of HIV services. The Kusingata project developed strong community-clinic collaboration and effective two-way referral systems between community and facility-based services. Through provision of HIV counselling and testing services by the project's lay counsellors, people living with HIV including children, pregnant and breastfeeding women were identified, tested and successfully linked to care. The Kusingata project strengthened community structures to support adherence, retention, treatment literacy and reduced stigma through preventive and reintegration home visits, mother-to-mother support groups, case conferencing, village savings and loan groups as well as income generating groups. Through the comprehensive community-based service package, the Kusingata project achieved the following results during the last four years:

- 35 mentor mothers, 49 lay counsellors, 42 community dialogue/community-led monitoring facilitators, 19 village savings and loan group/income generating group facilitators, and 8 linkage facilitators were trained as community actors to support people living with HIV in the communities.
- 17,182 participants (58% of them were women and 29% adolescents aged 15–19 years) completed the seven-week community dialogue activity to sensitise and mobilise the community about HIV and prevention of vertical transmission, and to improve health-seeking behaviour. At the start of the community dialogue sessions, 51% of the participants responded correctly to statements about HIV; this increased to 96% by the end.
- 4,642 referrals were provided for HIV testing and 4,036 for other health services through the community dialogues and other project activities. 87% of these referrals were completed.
- 36,756 individuals (65% of them were females, and 16% children aged 2-14 years) were tested for HIV, and 2,052 (68% of them were females and 5% children aged 2-14 years) tested positive.
- 25% of adults (44% of women and 13% of men) and 2% of children tested through community-based index testing activity, were found to be living with HIV (positivity rate).
- 14,235 HIV self-test kits were distributed to community members since 2023 (20% to adolescents aged 15-19 years).
- 99% of those who were diagnosed as living with HIV, were successfully linked to care and treatment.
- 2,981 children and adults received home visits to improve antiretroviral treatment literacy and retention, including 417 pregnant and breastfeeding women living with HIV, 347 HIV-exposed children, and 188 children living with HIV visited by mentor mothers.
- 262 pregnant and breastfeeding women living with HIV, and 12 caregivers of children living with HIV, participated in mother-to-mother peer support groups.
- 1,134 people living with HIV out of 1,276 who had interrupted treatment and received a reintegration home visit, were returned to care and treatment through reintegration visits, corresponding to 89% reintegration rate.
- 30 pregnant, breastfeeding women and children living with HIV with unsuppressed viral loads benefitted from case conferencing during the past year. Of those whose viral load was controlled after support from the project, 77% had a suppressed viral load.
- 32 community actors, 11 healthcare providers, and 8 provincial-level project staff were trained by Zoë-Life on age-appropriate disclosure of HIV-status to children, and they supported the disclosure to 91 children during the past year.
- 332 community members using health services (including 106 pregnant and breastfeeding women living with HIV) and 74 health care providers participated in community-led monitoring. 79% of the problems in health care that were possible to solve locally, were solved.
- 1,467 beneficiaries participated in village savings and loan groups to improve their economic resilience and quality of life, including 343 pregnant and breastfeeding women living with HIV, and 488 caregivers of children living with HIV or other people living with HIV.
- 113 individuals benefited from income generating activities, of whom 24 were pregnant and breastfeeding women living with HIV, and 66 were caregivers of children living with HIV or other people living with HIV.
- An average of 7 community leaders and other influential community members participated in 128 meetings to engage them in raising awareness and mobilising the community members, and to increase ownership of the project activities.

Lessons learned and best practices

- **Community dialogues are effective in improving knowledge and attitudes.** As mentioned above, when the sessions started about half of the participants responded correctly to statements about HIV, while after completing the activity, almost all responded correctly.

- **Private discussions as part of the community dialogue and village savings and loan activities create an important avenue for referrals.** Community dialogue and village savings and loan group facilitators have one-to-one discussions with the participants after the sessions to identify health concerns and needs and where relevant, provide referrals for HIV testing and other health services.

- **Community-based index testing is effective in case-finding, especially among women.** Of the sexual partners of people living with HIV who were tested by the project, 44% of adult women and 13% of adult men were diagnosed as living with HIV.

- **Mobile testing provides easy access to HIV testing.** Some community dialogue participants fail to complete referrals for HIV testing and other health services due to a range of barriers. N'weti initiated mobile testing outreach by lay counsellors to provide HIV testing services to eligible community dialogue participants. This significantly increased their access to this service. In addition, integrated mobile brigades implemented by project lay counsellors and health providers, proved to be an effective strategy for expanding access to HIV testing, same-day treatment initiation, and other health services in remote and hard-to-reach areas.

- **Age-appropriate disclosure of HIV status can improve treatment adherence among children.** Training and mentorship provided by Zoë-Life and PATA to the project's community actors strengthened their clinical and psychosocial counselling skills to support age-appropriate disclosure.

- **Home visits support linkage and retention.** 99% of those diagnosed as positive by the project lay counsellors were linked to care and treatment. Of those supported by the project through home visits by mentor mothers and lay counsellors, 89% were reintegrated to care after interrupting treatment.

- **Case conferencing improves viral suppression rates.** The case conferencing sessions brought together people living with HIV who had unsuppressed viral loads (or their caregivers in case of children), the project's community actors, and health facility professionals, to jointly analyse the challenges of each individual patient and develop a jointly agreed action plan to overcome the problems.

- **Strengthening economic opportunities and supporting household needs holistically promotes retention in care.** Linking families to village savings and loan groups and income generating groups offers the chance to improve household economic status and in turn, to improve retention through increased knowledge about the importance of adherence to antiretroviral treatment, improved affordability of transport for consultations and antiretroviral treatment refills, as well as better household nutrition.

- **Community-led monitoring of HIV services empowers and engages the community to demand for improved quality of care.** The quality of services at the supported health facilities was evaluated by people living with HIV and health providers, and joint action plans developed to resolve the identified problems in services improved the quality of care at health facilities. Through this activity, the communities transitioned from being beneficiaries, to co-designers of local solutions to improve HIV services.

- **The adaptation and use of the DHIS2-based Tracker enhances timely monitoring and data-driven decision-making.** The tool enables the project team to monitor and discuss the results daily and to remotely identify gaps and plan targeted technical support, ensuring that decisions are guided by real-time evidence from the field. This innovation also reduced the reliance on paper-based forms contributing to environmental sustainability, and improved timely reporting.

Photo credit: Andreas Scheibenreif

What's next for the Kusingata project?

As shown by the results above, the project has created a comprehensive package of HIV services that supports pregnant and breastfeeding women living with HIV, and children exposed to or living with HIV, while preventing new infections. To ensure continuous and closeby support to these target groups, their families, communities, and health facility providers, have also been involved.

The project participants confirmed the value of providing comprehensive community-based services for vulnerable people living with HIV, including mobilisation of community support and socioeconomic strengthening activities.

Towards the end of the project, the focus will be on sustainability of the activities, as well as on advocacy for the scale-up of the created model of services. At the community level, Kusingata will ensure the gradual transfer of successful practices to community workers and local structures. They will continue to support the target groups through home visits to individuals identified by the health providers as needing adherence support. In addition, the participants of the village savings and loan groups and income generating groups have been capacitated in continuing the activities without supervision, thus providing social and financial support for families affected by HIV.

At health facility level, the health providers have committed to continuing paediatric disclosure sessions, integrating them into the work plans of the health facility. The district authorities have agreed to adopt case conferencing as a routine practice to be implemented at the facility level, as well as to conduct monthly supervision.

Furthermore, N'weti has presented the Kusingata intervention model and its results to district- and provincial level health authorities as a best practice that could be replicated in other locations. The authorities recognised the relevance of the model, especially the importance of community-level activities, the close community-clinic collaboration, and expressed interest in scaling up key elements of the model such as family-based psychosocial support through home visits, case conferencing and community-led monitoring.

During these meetings, the legacy of Kusingata was discussed not only through its direct results, but as a model of involving and empowering communities in planning and monitoring of the health services. The commitment of the local authorities and communities to continue the Kusingata approaches constitutes a key factor in the sustainability of the model.

About Aidsfonds

Aidsfonds is a non-governmental organisation based in the Netherlands that is working to end AIDS by 2030. Aidsfonds works with community partners in regions most affected by HIV and AIDS, committed to ensuring that those who are in a most vulnerable position are not left behind. Improving paediatric HIV interventions and prevention of vertical transmission services are a key strategy toward achieving these goals.

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