Strengthening community support to improve HIV care

Results and best practices from the Kusingata project in Mozambique (2021-2023)

Kusingata in Mozambique

Mozambique had an estimated 2.4 million people living with HIV in 2022; the majority were adult women (1.5 million), and 150,000 were children aged 0-14.[1]
Of women living with HIV aged 15 and above, 83% 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]
About a quarter of all infants born to women living with HIV (HIV-exposed infants) in Mozambique did not receive a virological test for HIV within two months of birth (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 lower percentage of children living with HIV received antiretroviral treatment, were virally suppressed, and retained in care.[1,4] 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. [5]

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.

[1] https://www.unaids.org/en/regionscountries/countries/mozambique
[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://www.state.gov/wp-content/uploads/2022/09/Mozambique-COP22-SDS-.pdf
[5] 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, pregnant and breastfeeding adolescents and women living with HIV, towards achieving viral suppression.
- Document the results and the implementation model for advocacy and sustainability.

Who are 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 lactating 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 implements a comprehensive package of interventions that work towards achieving the project objectives. Individuals and families receive multiple services that are adjusted to their needs, and reinforce the same messages. The interventions work at several levels, to support the individuals and their families in a holistic way. Family and community support are mobilised, and the project works in collaboration with the health system to improve services at health facilities, to promote HIV testing, treatment and retention in care. The interventions are built on the Kids to Care model stages to find, test, treat, and retain.

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 for increased provision, demand, uptake, and ownership of quality community and health facility-based HIV services. Through training and supervision, the project strengthens the capacity of community health workers to support prevention of vertical 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,[7] 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"

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 other community members. 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.

[7] **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 vertical 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

The lay counsellors refer all those who have a positive test result to the health facility so they can initiate treatment immediately (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 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 vertical 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. People living with HIV 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.

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 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 vertical 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 do a 'reintegration home visit', 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 can share experiences, support each other, receive information on and discuss the above-mentioned topics. 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.

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 to provide referrals for 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, 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 first two years:

- 24 mentor mothers, 41 lay counsellors, 42 community dialogue/community-led monitoring facilitators, and 19 village savings and loan group/income generating group facilitators were trained to support people living with HIV in the communities.
- 10,477 participants (55% women) 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% participants responded correctly to statements about HIV; this increased to 96% by the end.
- 2,152 referrals were provided for HIV testing and 1,466 for other health services through the community dialogues and other project activities.
- 14,593 individuals (19% of them children) were tested for HIV and 1,074 (6% children) tested positive.
- 24% of adults (42% of women and 13% of men) and 2% of children tested through community-based index testing activity, were found to be living with HIV.
- 1,170 HIV self-test kits were distributed to community members during five months.
- 98% of those who were diagnosed as living with HIV, were successfully linked to care and treatment.
- 1,152 children and adults received home visits to improve antiretroviral treatment literacy and retention, including 382 pregnant and breastfeeding women living with HIV and 192 HIV-exposed children visited by mentor mothers.
- 179 pregnant and breastfeeding women living with HIV participated in mother-to-mother peer support groups.
- 387 people living with HIV who had interrupted treatment were returned to care and treatment through reintegration visits.
- 630 beneficiaries participated in village savings and loan groups to improve their economic resilience and quality of life, including 138 pregnant and breastfeeding women living with HIV, and 306 caregivers of children living with HIV or other people living with HIV.

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 activity create an important avenue for referrals.** Community dialogue 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, 42% of adult women and 13% of adult men were diagnosed as living with HIV.
- **Mobile testing provides increased likelihood of completing referral for 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.
- **Home visits support linkage and retention.** 98% of those diagnosed as positive by lay counsellors were linked to care and treatment. Of those supported by the project through home visits by mentor mothers and lay counsellors, 91% were reintegrated to care after interrupting treatment.
- **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, improve 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 were developed to resolve the identified problems in services.

What's next for the Kusingata project?

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. To measure the effect of different interventions on retention, socioeconomic status and quality of life of the beneficiaries, N'weti will continue to develop improved monitoring and evaluation models. The results will be used to identify gaps and opportunities for improvement, and to advocate for scale-up of the community-based service package. The project will also initiate new collaborative activities, such as implementing mobile testing in hard-to-reach communities together with a clinical partner that can also provide community-based antiretroviral treatment distribution and other health services. In addition, N'weti and the partners will intensify their outreach to adolescents through provision of community dialogues and health services near schools, and by training teachers to create a better understanding of paediatric HIV and how to refer adolescents for support when needed.

n'weti aidsfonds

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, to accelerate and strengthen efforts to meet this goal, ending deaths from AIDS and ending new HIV infections. A critical component of this is to improve paediatric HIV and prevention of vertical transmission services. Aidsfonds together with community partners, co-created the **Kids to Care model** as a key strategy toward their goal to see the end of AIDS by 2030.