



# Supporting caregivers to care for children living with HIV



Results and best practices from the KidzAlive@Home programme in South Africa

## KidzAlive@Home in South Africa

UNAIDS reported that 320,000 children aged 0-14 years were living with HIV in South Africa in 2016. However, 45% of those children are not enrolled in antiretroviral therapy.<sup>1</sup> The majority of HIV infection in children is the result of vertical transmission from mother to baby which has prompted government action to prevent this mode of transmission. Despite some successes from the initiative, a high number of children are lost to follow up after 12 months of age.<sup>2</sup> HIV disclosure in South Africa is hindered by significant stigma and discrimination associated with HIV, leading to fear of rejection, isolation, and bullying for children and their families. In addition, children and their caregivers often lack accurate knowledge about HIV, including its transmission and treatment, making effective disclosure challenging. Therefore, age-appropriate communication is crucial when disclosing HIV status to children as younger children struggle to comprehend complex medical concepts. Caregivers should be supported with information and tools to disclose the HIV status of their children in an age-appropriate way to them.

KidzAlive@Home is an innovative approach to improving identification, testing, treatment and retention in care for children living with HIV in South Africa by supporting caregivers to access comprehensive services in a child-friendly environment. The programme was implemented by Zoë-life South Africa with support from Aidsfonds from 2019-2022, and focused on two communities in eThekweni and uMgungundlovu districts in KwaZulu-Natal province.



<sup>1</sup><https://www.unaids.org/en/regionscountries/countries/southafrica>  
<sup>2</sup>ibid

## The programme aimed to achieve the following objectives:

- ✓ Create a community environment that is supportive for enabling comprehensive service provision related to HIV, tuberculosis, malnutrition, child abuse and other health related issues pertaining to children, adolescents, and their caregivers in two targeted communities in eThekweni and uMgungundlovu districts in KwaZulu-Natal province.
- ✓ Diagnose children and adolescents living with HIV as early as possible and link them to care and treatment and ongoing psychosocial support effectively and sustainably.
- ✓ Improve the quality of HIV services (child-friendly care) and health outcomes (adherence, disclosure, viral suppression and mental health, nutrition) of HIV-infected and affected children and adolescents.
- ✓ Provide capacity building and training to healthcare workers on the provision of child-friendly disclosure to enhance their knowledge, skills, and confidence in effectively.
- ✓ Share evidence of the KidzAlive@Home community intervention model.

## What is the 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





## KidzAlive@Home project interventions

KidzAlive@Home is based on identifying children living with HIV through engagement with community-based organisations and community structures building on the Kids to Care model stages which include find, test, treat and stay.

To first find children living with HIV (stage 1 of the Kids to Care model), KidzAlive@Home works with community structures to create an entry point into the community, as well as a pathway to work with families through the trust and relationship that community structures already have with many families. KidzAlive@Home works with community-based organisations, faith-based organisations, churches and other religious institutions, ward AIDS committees, community councils and other structures as relevant. These community structures play a key role in identifying and reaching untested children as a means of increasing HIV testing rates, early diagnosis and access to age-appropriate care and support. They know the children and are trusted by the communities that these children live in.

As KidzAlive@Home began to identify children living with HIV and help them enrol in antiretroviral therapy or return to care if they were lost to follow up, they learned that although many caregivers are provided with support on treatment literacy, many are actually overwhelmed with all of the information. KidzAlive@Home worked to create easy to understand working tools (job aids) and these helped caregivers translate knowledge into practical action so that they could more easily care for their children and support their retention on HIV medication.

The foundational approach in the KidzAlive@Home model is to connect with caregivers and help translate treatment literacy information into actionable steps with support from health facility and community-based health workers.

KidzAlive@Home has produced a number of child-friendly resources that are used by community healthcare workers to provide health education, to translate treatment literacy information and create action plans for their children's care. This links with stage 3 and 4 of the Kids to Care model (treat and stay) and includes:

1. **The KidzAdherence support group curriculum** is a **structured curriculum** accompanied by a job aid with child-friendly stories that address different aspects of adherence, as well as an activity template flip file. Healthcare workers at the facility and community health workers are trained using this curriculum. These resources can be used within home visits and clinic visits.
2. **KidzAlive Foundations of working with children HIV Testing Services, Disclosure and Adherence (FHDA)** is a **comprehensive course** for healthcare providers that work with children. It provides training on how to test children for HIV, provide family-centred disclosure support and manage adherence in children 0-14 years living with HIV in a child-centred and age-appropriate way. This empowers the child to take ownership of their health and ensures that they do not merely survive but thrive. The programme also teaches play therapy techniques and teaches healthcare workers how to use the KidzAlive job aids (including the KidzAlive Talk Tool Job Aid pictured below) to support HIV testing services.
3. **KidzAdherence clubs** are a key intervention for the KidzAlive@Home programme where kids can come together and learn about HIV, sharing their experience in a safe space and reducing stigma and fear. KidzAlive@Home offer two types of KidzAdherence clubs:

- ✓ Nginamandla clubs support children who are virally suppressed and are adhering to medication at time of enrolment.<sup>3</sup>
- ✓ Ngisekele clubs are intended for children who have an unsuppressed viral load and have a reported history of poor adherence to treatment as well as those who are at high risk of defaulting at time of enrolment.

<sup>3</sup> Viral suppression in the South African 2019 ART Clinical Guidelines for the Management of HIV in Adults, Pregnancy, Adolescents, Children, Infants and Neonates is defined as being under 50 copies/mL.





**Community healthcare workers conduct home visits** to provide health education and support caregivers in understanding treatment literacy. Importantly, they also provide **age-appropriate disclosure support and counselling**. This guides caregivers through the challenging process of disclosure, helping them work through the barriers they face which are most often emotional or psychological.

"The most critical thing to remember is that caregivers, children living with HIV and healthcare workers are all just people. People who are afraid, feeling guilt or shame, or facing other barriers to accessing care, disclosing their status, supporting a child living with HIV. Zoë-life believes that when we can see people as human and remember that in the same situation, we might respond in the same ways, we can support people to live more positively and to thrive."

- Nokuthula Heath, KidzAlive@Home Maternal and Child Health Programme Manager

To strengthen the continuum of care, the KidzAlive@Home programme works with health facilities and community-based organisations to create **child-friendly spaces** for children living with HIV. Healthcare workers based at the facilities use learning resources, such as those mentioned above, and innovative technology to help children understand HIV and support their retention in care. Health facilities create child-friendly spaces where the children and their caregivers feel relaxed and comfortable, where they can share health information in a way that is engaging and can also be easily understood and actioned. The child-friendly spaces are equipped with toys, colourful posters and other items that encourage play and interaction. The area is designed to be safe and inviting, providing an environment where children can have fun and enjoy their time.

KidzAlive@Home invests a lot of time and energy in **quality assurance and quality improvement** by conducting routine quality assessments with community structures on a bi-monthly basis to identify gaps in the provision of comprehensive services to children, adolescents, and their caregivers. KidzAlive@Home develops and tracks the implementation of quality improvement plans based on the gaps identified in the quality assessment process. The project team uses a tool called the "Ideal Community" to enhance community leadership structures, community organisations and networks so that they can improve their HIV response for children and adolescents.



## Impact of KidzAlive@Home

Zoe-life's success with the KidzAlive@Home project has led to their inclusion in the Department of Health technical working group, where they advocate for child-friendly paediatric HIV services. The government has endorsed the KidzAlive@Home approach as an intervention to improve children's health outcomes.

### The project has had numerous impacts during the implementation period – from 2019 to 2022:

- 192 healthcare workers were trained in the KidzAlive Foundations of working with children HIV Testing Services, Disclosure and Adherence (FHDA)
- 147 healthcare workers were mentored on KidzAlive@Home family support activities
- 15 child-friendly spaces were created at health facilities
- 5,329 children were tested for HIV, of which 201 tested positive
- 235 children were linked to care and initiated HIV medication (34 returning to care who were lost to follow up)
- 1,097 caregivers received disclosure support and 748 children received age-appropriate disclosure
- 22 KidzAdherence clubs were started supporting 157 children and 157 caregivers

Siyabonga, a nine-year-old boy and his caregiver joined a Nginamandla KidzAdherence support group in 2021. His HIV status had not been fully disclosed to him. Through the sessions, Siyabonga's caregiver prepared for full disclosure to Siyabonga. The boy was able to understand how the HIV virus affected his body and how he could take care of himself through the KidzAdherence sessions. By the end of the sessions, Siyabonga was advocating for himself, reminding his healthcare worker to test his viral load so he could monitor his health and wellbeing.



## Lessons learned and best practices

- ✓ Knowledge must be translated into action. It is not enough to provide caregivers with treatment literacy information; they must be supported to translate that knowledge into actionable plans which requires the use of child-friendly and easy to use tools by community healthcare workers.
- ✓ Creating comfort in child-friendly spaces is critical to engaging caregivers and children themselves in their own care. Caregivers and children living with HIV must feel comfortable with their healthcare worker within a space that is accessible and child-friendly. Creating child-friendly spaces in clinics and conducting household visits creates trust and security so that healthcare workers can alleviate fears, support disclosure and help to translate knowledge.
- ✓ KidzAdherence clubs help children understand their diagnosis and reduces their fear through connection with other children living with HIV. Children living with HIV need to know they are not alone and be given the opportunity to understand their diagnosis. KidzAdherence clubs and the resources created by Zoë-life help children feel less afraid and to be more involved in their own care.

## What's next for KidzAlive@Home?

KidzAlive@Home have learned the importance of psychosocial support for caregivers and resources that can improve their mental health. As Zoe-life move forward with the KidzAlive@Home programme, a key focus will be moving beyond treatment literacy with caregivers to build their resilience and support positive parenting. Its work with community-based organisations will include implementing more support groups and building capacity within community-based organisations to provide one-to-one sessions for caregivers who need additional support.

Alongside this, Zoe-Life wants to continue to provide support with quality assurance and quality improvement for community-based organisations, strengthening the structures that operate closest to where families are so that care can be accessible and effective for the long term.

Zoe-life also works regionally, providing training on age-appropriate disclosure and improving paediatric HIV services.

## Who are Zoë-life?

Zoë-life is a non-governmental organisation supporting the wellbeing of children, youth and families. To achieve this, Zoë-life develop **tools** to fill the gaps in systems that support children and share this knowledge to contribute to widespread change. Zoë-life work with community-based organisations and health facilities to increase case finding, antiretroviral therapy initiation and viral suppression among children aged 0-19 years of age.

## 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.



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