

Supporting children, adolescents and young people living with HIV to start and stay on HIV treatment



About this case study

This case study has been produced by the International HIV/AIDS Alliance in partnership with Africaid Zvandiri. It is part of a series of case studies that brings together good practices from the Alliance global community-based programming to define and guide good practice in a range of technical areas including: human rights and the greater involvement of people living with HIV (GIPA), research, evaluation and documentation, HIV prevention, sexual and reproductive health and rights integration, HIV treatment, HIV programming for children, and HIV and drug use. Authors: Kate Iorpenda, Georgina Caswell, Matteo Cassolato and Cecilia Kihara.

Acknowledgements: The authors would like to thank the entire Africaid Zvandiri programme staff for providing tremendous support in collecting information and data needed for this case study. Particular thanks to Nicola Willis, Tinashe Rufurwadzo and Varaidzo Mudombi.

Design: Progression Design

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Unless otherwise stated, the appearance of individuals in this publication gives no indication of either sexuality or HIV status.

Abbreviations and Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
CATS	Community Adolescents Treatment Supporter
CYPLHIV	Children and Young People Living with HIV
HIV	Human Immunodeficiency Virus
ISALS	Internal Savings and Landing Service
MIPA	Meaningful Involvement of People Living with HIV
OSSHD	Organisation for Social Services Health and Development
READY+	Resilient, Empowered Adolescents and Young People Living with HIV
SRHR	Sexual Reproductive Health and Rights
UNICEF	United Nations International Children's Emergency Fund
Y+	Global Network of Adolescents living with HIV

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Introduction

Advances in HIV treatment have led to a decline in the number of people dying from AIDS-related illnesses in all age groups except one: adolescence (ages 10-19). HIV is the second largest cause of death for young people (ages 10-24) worldwide and the leading cause of death in Africa¹.

The need to prioritise young people, particularly adolescents, in HIV prevention, treatment, care and support has never been greater. However, numerous barriers means adolescents are far less likely to be on antiretroviral treatment (ART) or virologically suppressed than adults living with HIV. Many children (<10 years) on ART cease treatment during adolescence, falling through the gaps as they move from child to adult services.

UNICEF estimates that 72% of the 2.1 million adolescents living with HIV acquire it due to parental transmission² yet stigma can lead families to keep their HIV status secret, leaving young people no space to ask questions or voice their concerns. Global recommendations suggest children should know their HIV status before they reach the age of 12 but many young people learn they are HIV positive too late and in ways that leave them unclear about HIV transmission or the treatment they need to stay healthy.

Adolescence is a distinct time of life, a period in which people become more independent, grapple with their identity, experience many physical and psychological changes and are more inclined to take risks. Yet few HIV services acknowledge or address these distinct and diverse needs. For example, despite body image and self-esteem being of huge importance to many adolescents, young people are rarely given the space to voice concerns about the possible visible side effects of ART, such as skin conditions or the late onset of puberty, leading some to interrupt their treatment or stop it entirely.

In addition, HIV services rarely take into consideration adolescents' wider sexual and reproductive health and rights (SRHR) or their needs relating to socio-economic issues, education and mental health. Yet all of these things are fundamental to whether adolescents living with HIV are able to remain on treatment.

"I want to be a pillar of strength for my peers. I have high hopes for the future."

(CATS, 19yrs)

Purpose of this case study

This case study is suitable for those working with adolescents and young people living with, and affected by, HIV. It is informed by the experiences of Africaid, a private voluntary organisation in Zimbabwe. Through its peer-led Zvandiri programme, Africaid provides differentiated HIV prevention, treatment, care and support services for children, adolescents and young people across the HIV cascade.

The Zvandiri programme was established in Harare in 2004 in response to six adolescents living with HIV who wanted to begin a support group. Zvandiri (literally 'as I am' in Shona) aims to equip children, adolescents and young people living with HIV with the knowledge, skills and confidence to cope with their HIV status and to live happy, healthy, safe, fulfilled lives. Africaid supports more than 50,000 HIV positive children, adolescents and young people (ages 0-24) across 51 districts of Zimbabwe with peer-led differentiated services. The programme works in partnership with the Zimbabwean Ministry of Health and Child Care, the Ministry of Public Service, Labour and Social Welfare, the Ministry of Primary and Secondary Education and the National AIDS Council of Zimbabwe.

Zvandiri is setting the standard for the provision of appropriate, accessible and sustainable prevention, treatment, care and support services for adolescents and young people living with HIV. As a result, as part of its strategy to strengthen the HIV continuum of care, the Alliance is basing its model for adolescent treatment support on learnings from this programme.

Africaid own in-depth assessment³ of Zvandiri informs this case study, as do observations from a visit to Zimbabwe by the Organisation for Social Services, Health and Development (OSSHD), an Ethiopian Alliance Linking Organisation and Alliance technical advisor.

Community Adolescent Treatment Supporters: a peer-led model

Since 2009, Africaid has been developing a globally recognised, peer-led model for supporting children, adolescents and young people living with HIV. This approach centres on Community Adolescent Treatment Supporters (CATS), who are young people (ages 18-24) living with HIV who support 0 to 24-year-olds living with HIV to begin ART and remain on treatment. The model takes into account adolescents' broader health and social welfare needs, and differentiates between the needs of individual adolescents, as well as younger and older clients, in recognition of the changes that occur as people move through adolescence.

¹ UNAIDS (12 August, 2015) 'Update: Active involvement of young people is key to ending the AIDS epidemic by 2030'

² UNICEF (2016) 'The State of the World's Children'

³ Africaid (2015) 'Zvandiri: Supporting HIV positive children, adolescents and young people in Zimbabwe through HIV care continuum' (<http://www.africaid-zvandiri.org/v3/wp-content/uploads/2015/06/Zvandiri-Supporting-CAYPLHIV-in-Zimbabwe-1.pdf>)



In their work, CATS utilise index case finding to identify and link adolescents and young people to HIV testing services. Those who are diagnosed as HIV negative are then linked by CATS to prevention services, while those who are HIV positive are linked to treatment and care, including initiation on ART. CATS then support HIV positive adolescents and young people to adhere to treatment by providing peer-led, adolescent-focused information, counselling and support. They provide this support during home visits, group meetings, visits to clinics, and by sending SMS clinic and adherence reminders. Any adolescent or young person experiencing challenges with adherence, as well as those facing poor physical health, mental health challenges, disability, pregnancy or child protection risks, will be referred by CATS for enhanced support. They then provide this support in partnership with the adolescent's health facility and other community cadres.

CATS facilitate support groups for adolescents and young people living with HIV and run adolescent-friendly corners in health centres. These are spaces where adolescents and young people can ask confidential questions and gain a better understanding about HIV, as well as finding support for other issues such as SRHR.

CATS train health service providers, social welfare officers and Ministry of Health and Child Care officials to build a better understanding of the needs of adolescents and young people living with HIV and are involved in local, national and global advocacy work.

Factors for success

HIV positive adolescents and young people are at the heart of the Zvandiri programme. The way Africaid train, mentor and supervise CATS is supportive rather than directive. As a result, CATS actively participate in all aspects of programme planning, implementation, monitoring and evaluation.

The personal experiences of adolescents and young people living with HIV also form a central part of the CATS training curriculum, which is currently being used in Zimbabwe, Mozambique, Tanzania and Swaziland.

The Ministry of Health and Child Care and the Zvandiri Mentors are responsible for identifying and selecting new CATS. New CATS receive two weeks of theoretical and practical training before beginning and continuous mentoring while in the role.

Most CATS fit their work around education or vocational training and are paid a stipend every month and transport reimbursement every week.

Individual CATS support a caseload of between 60 and 80 clients from their own or neighbouring communities. CATS offer each client

either a standard or enhanced level of support according to the individual's clinical and mental health needs.

Some clients may be seen each week, especially if they are new or facing particular issues, while others are seen less frequently on a one-on-one basis but will be monitored through support groups.

Within health facilities, CATS provide their clients with information and counselling on disclosing their HIV status, ART initiation and adherence. CATS also participate in refill visits and register adolescents and young people for community follow-up at home and in support groups, as well as referring those who need it to services for SRHR, mental health and child protection.

CATS are supported through Zvandiri's 'Care for CATS' scheme. This includes clinic-based CATS supervisors providing CATS with on-site mentorship, weekly visits from Zvandiri Mentors and monthly CATS co-ordination meetings.

Interventions

Supporting treatment adherence and disclosure

CATS' core work is supporting adolescents and young people living with HIV in their homes. At times this can be challenging as family members may be wary about older adolescents meeting privately with their children. As a result, CATS often have to build a family's trust and confidence in order for them to give the adolescent family member the privacy they need to discuss their issues. CATS are trained in how to deal with difficult or hostile situations and are also very aware of the need for confidentiality. In some situations, other family members or neighbours might not know about an adolescent's HIV status. For this reason, CATS do not come to their clients' houses with programme-branded materials, rather they visit as 'friends'.

A key part of the CATS' role is helping adolescents and young people understand their HIV diagnosis. Often, the parents or caregivers of young people who have acquired HIV as children, most commonly through parental transmission, will be reluctant to tell them they have HIV or will not have enough knowledge about HIV to be able to explain it to their children. As a result, the problem of partial disclosure, even amongst older adolescents and young people, is a common occurrence. Often, young people will know they need to be on lifelong treatment but will not know what for, or they will think it relates to something different such as a heart condition or the need to 'keep flu at bay'. (See the resources section at the end of this case study for further information on supporting disclosure.)



Explaining HIV: the ‘Our Story’ game

The way many adolescents and young people living with HIV find out from their families about their HIV status leaves them unclear about their diagnosis, treatment or hope for the future. To address this, CATS use a tool called ‘Our Story’, an interactive card game suitable for all ages, based on a book of the same title written by the CATS. The game provides clear messages about HIV and some of the physical and biological impacts it can have. It also shows how ART, when taken effectively, enables people to live healthy lives. CATS also teach the game to clients so they can use it to help articulate their status to others.

CATS have particularly observed how the ‘Our Story’ game has provided children, adolescents and young people with a vocabulary to explain HIV to others, with some using it to give confident explanations about HIV to friends and family.

The game is also used with clients who are not yet aware of their HIV status in order to explore partial disclosure and the importance of adhering well to medication.



CATS also support treatment adherence during home visits. Because of their own experiences, CATS understand that adhering to treatment is a daily struggle for adolescents. Adolescents often face confusing messages, as some faith healers and churches talk about curing HIV. They may also feel isolated if they are the only person in the family on ART. CATS discuss all these issues, as well as advising on how to store medicines, count pills and use pill boxes correctly.

Zvandiri Mobile Database Application (ZVAMODA)

ZVAMODA, the Zvandiri database, is a management information system which has been developed by Africaid to track the progress of each child, adolescent and young person registered in the Zvandiri programme. ZVAMODA is a digital application that allows CATS and their Zvandiri Mentors to enter real-time data, collected during every contact with a client. It is also used for sending adherence and clinic visit reminders and providing e-mentorship to individual CATS in different locations.

CATS also remind clients about support groups and will accompany young or nervous clients to these events themselves. They are also trained to offer advice around issues within the family and identify any wider concerns relating to a client’s well-being, for instance they will

report concerns about mental health, school exclusion or family conflicts. They do this by filling out a referral form, which is then referred to programme or clinic staff, resulting in the client being connected to family care workers in the local area if needs be.

Working with clinical service providers

CATS provide the link between adolescents and health facilities. This is critical for ensuring that adolescents and young people are retained within HIV treatment services. They also play a crucial role in linking adolescents to other SRHR services and support.

CATS provide a valuable perspective on the needs and preferences of adolescents and young people living with HIV, and the challenges that affect their attendance in clinics or adherence to treatment. They also help clinics trace non-attenders, something service providers report they were previously unable to do.

The expertise of the CATS, coupled with the important partnership Africaid has established with the Zimbabwean Ministry of Health and Child Care and others, has enabled CATS to inform and deliver training for health workers and government staff on adolescent-tailored services.

Under the Zvandiri programme this has been supported through a formal government agreement. But it has been crystallised through regular contact between CATS and clinical staff, through which an understanding of the strengths CATS bring to client experience has developed, building a strong working relationship. This relationship is supported by the ongoing training of health workers to address attitudes, actions and behaviours relating to adolescents and young people.

CATS also help local clinics attract more people in the community to get tested for HIV through index case finding and mobilisation activities at high volume events such as music galas, exhibitions and commemorations.

Young people’s national and international advocacy work

Nationally, Zvandiri has supported government campaigns on HIV testing, as well as developing its own campaigns (see the section on stigma reduction below). CATS have also partnered with organisations such as the Elizabeth Glaser Pediatric AIDS Foundation in provincial HIV testing and counselling campaigns and community dialogues.

Zvandiri has also built the capacity of young people living with HIV to become powerful advocates in the national and international sphere.

In Zimbabwe CATS represent young people living with HIV in the Technical Working Group of Young People and HIV, the Child Protection Committee, AIDS Action Committees and the HIV Partnership Forum.



Globally CATS are active in the Global Network of Adolescents Living with HIV (Y+), the Adolescent HIV Treatment Coalition, the Global Fund Community Delegation, the Youth Engage Network, the Meaningful Involvement of People Living with HIV (MIPA) forum and the Young People’s Network on Sexual Reproductive Health HIV & AIDS.

Using their personal experiences and learnings from the programme, young advocates have become key players in campaigns to demand better services and support for adolescents and young people living with HIV.

Zvandiri is well respected among influencers and has resulted in Africaid playing a key advisory role to government. In addition, founder and executive director Nicola Willis sits on the World Health Organization’s (WHO) technical reference group for adolescent treatment and the Adolescent Treatment Coalition among others. Young people from Zvandiri have also influenced policy and guidance by contributing to the development of WHO’s global ART guidelines and guidance on differentiated service delivery for adolescents, developed by WHO and the International AIDS Society.

Addressing stigma

Within any treatment support programme it is fundamental to address community stigma, and this starts by assessing where it is most prevalent in both private and public spaces, how it manifests itself, and how it can be challenged.

Beneficiaries from the Zvandiri programme devised their own stigma-reduction campaign *Bury stigma, resurrect love*. This targeted churches, schools and the community to raise awareness about HIV-related stigma in places where it is most prevalent.

For children and younger adolescents, family clubs and events were held where the impacts of HIV-related stigma were discussed and linked to the concept of emotional abuse.

Support, mentoring and career progression for CATS

The CATS occupy a central role within the programme and demonstrate extensive knowledge and understanding, as well as confidence and self-assuredness in their work. The work can be challenging at times; at debriefing sessions CATS have highlighted extreme cases of self-harm and suicide amongst clients as well as violence and abuse. The programme staff is aware of the psychological impact this could have on the CATS and provide support in the form of debriefing and counselling sessions.

The work can also be time-consuming and the balance with school and work can be a difficult one for CATS to maintain. Adolescents and young people are

often expected to contribute to their family, so a monthly stipend is provided to CATS to help address this issue. Some report that it helps them to provide food for the family or at least gives them the means to buy personal items without relying on family members. Others use this to pursue their studies.

Mentorship within the programme creates a constantly evolving cadre of peer leaders. Older CATS support younger CATS and also shadow prospective CATS. CATS also attend public lectures, workshops, conferences and district meetings to sharpen their skills and keep their knowledge up-to-date. In addition, some older CATS become provincial mentors. This is a full-time, paid role that involves supervising larger numbers of CATS over wider geographical areas and liaising with case care workers and multiple service providers.

Holistic support

As Zvandiri developed, a training-and small-business grants programme was introduced to extend support to the CATS and Zvandiri clients. Partnerships with local colleges and business, who provide training and apprenticeships in subjects such as bakery and mechanics, support older clients and ‘graduating’ CATS to take on new challenges and develop their skills, experience and careers.

With support from funding partners, Africaid is also implementing an Internal Savings and Landing Service (ISALS), which focuses on CATS and young mothers.

A young mothers’ group has also been established in recognition of the challenges facing young women living with HIV around conception, pregnancy, feeding and parenting. The group supports young mothers living with HIV to deal with issues that arise within family and romantic relationships and with in-laws, and in relation to parenting and early childhood development. It also provides somewhere for these young women to socialise with their peers and share experiences.



Results

The Zvandiri peer-based model has proved to be an extremely powerful approach for supporting children, adolescents and young people living with HIV with their daily, lifelong medication.

As at September 2017, a team of 860 CATS were actively providing adherence support for more than 45,000 HIV positive children, adolescents and young people in Zimbabwe. Moreover, in 2016, the CATS model began being scaled up in Mozambique, Tanzania and Swaziland under the READY+ programme, led by the Alliance.

By giving adolescents and young people living with HIV an opportunity to develop their own counselling tools, skills and experience of care and support, Zvandiri has helped many of them find education and job opportunities within the health system and the non-government organisation sector, with many of them developing professional careers.

In 2017, Africaid created employment for 13 former programme beneficiaries and CATS who are now responsible for leading and supporting the scale up of the Zvandiri model in various districts, with continued mentoring support from health service providers.

Lessons learnt and key recommendations

Peer-led interventions are extremely effective for adolescents

Peer relationships are key to the success of the Zvandiri model, particularly because many CATS have previously been clients and deal with the daily realities of living with HIV. The opportunity to talk to someone who has had similar experiences - and understands the priorities, influences, pressures and changes an adolescent faces – is the most effective way to enable young people living with HIV to orientate through services.

Services that are accountable to adolescents and young people are more effective

Making services accountable to adolescents and young people can be done in a number of ways. For instance, they can act as mystery clients or lead service assessments and accreditation processes. Involving adolescents and young people in the evaluation of services is the best way to test whether those services truly meet their needs.

The relationship between programme staff and CATS is critical

The Zvandiri Mentors, affectionately referred to as ‘Aunties’ and ‘Uncles’, are professionals from various fields including nursing, counselling, social work, disability, monitoring and evaluation, communications, finance and mental health, who can provide on-going training, mentorship and additional support when the CATS need specific advice.

To be effective, the support that adult professionals provide must genuinely respect the role the CATS play by valuing the CATS’ contribution and potential, and allowing them to take ownership of the programme and lead activities. It is important for programme staff to guide the CATS in problem solving and facilitation in a very equal way, rather than trying to direct them. Providing a space for autonomy and self-determination is a key principle of the programme and is instrumental in its success.

Enabling autonomy leads to strong leaders and role models

Enabling young people’s autonomy is an essential part of the programme’s success. The CATS are confident adolescents and young people whose knowledge has been deepened by their own experience and training. Within the programme, they have been given permission to do their best and to lead, and they are not afraid to make mistakes and learn from them. This approach has resulted in the CATS having a tangible self-assuredness in their work, with strong content knowledge, humility and pragmatism, plus strong cultural values around education and ambition for the future. These qualities have seen them become effective advocates, role models and leaders.

Designate a physical space that is welcoming and safe

It is important to create a physical space where adolescents and young people can meet, hold activities and be listened to. Africaid has been running the Zvandiri House Training and Support Centre in Harare since 2005. This is a welcoming and open drop-in centre with an atmosphere that balances between professional and informal, where young people can be creative and feel safe. HIV positive children, adolescents, young people and their caregivers come for information, counselling, clinical assessments and SRHR services. Life-skills training programmes are run for children, adolescents and young people, and young people come to use the library and information technology lab where they are trained in IT skills. It is a busy place, each room is often filled with young people running their own training workshops, counselling sessions, IT trainings, creative arts programmes, team meetings and innovative programmes.

Focus on strength and hope

Many adolescents and young people have negative associations with HIV as a result of a poor disclosure process, often linked to the death of a parent. Due to this association, many are unable to see positive opportunities or hope in their situation and some display high levels of anxiety and fear. There is a need



to change the understanding of the virus, to provide a more positive, strengths-based perspective for these young people. For example, the Our Story game, which CATS use to help clients understand HIV and the role of ART, talks less about fighting the virus, and more about maintaining strong immunity. The message here is more positive: it encourages the understanding that ART is about maintaining health.

The CATS themselves are a great example of this strengths-based, positive approach as they have strong identities, confidence and knowledge, and are people who their peers can both admire and relate to.

Differentiate between ages

Zvandiri works with children, adolescents and young people and has developed responses that are age differentiated. At times, this is not explicitly stated but there is a recognition of the specific challenges that affect younger and older adolescents. For younger clients, the dependence on adults and the need for supportive caregivers and strong relationships are key. Here, working with a client's support network is a critical part of understanding their progress and addressing any adherence issues. As children become adolescents they are likely to want more autonomy in managing their treatment, while being less ready to interact with adults, and this is where the CATS, as their peers, can play a powerful role.

Systems to track progress

Tracking progress on treatment is important for measuring the programme's impact but, to do this effectively, data that can be triangulated (verified by two or more sources) need to be collected. Viral load is the best indicator for the effectiveness of treatment but, in its absence, pill counts, adherence reports and CD4 counts are all important things to measure. This can also help to measure the impact of a specific intervention (for example, whether adherence improves after a support group or CATS has been introduced).



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Additional resources from the Alliance

Good Practice Guide: Adolescent HIV Programming (2017)

Information, strategies and resources to help programmers implement HIV programming for adolescents.

Link Up: Key Resources (2016)

These key resources have been developed to help those looking to enable young people most affected by HIV to understand and claim their SRHR and access youth-friendly, integrated services.

What's so different about adolescents? (2016)

Lessons from Link Up about the unique challenges and opportunities in engaging 10-19 year-olds in integrated HIV and SRHR services.

Safeguarding the rights of children and young people (2014)

A guide to facilitating a workshop for those working with vulnerable children and young people.

Find all of these resources at www.aidsalliance.org/resources.

About the International HIV/AIDS Alliance

We are an innovative alliance of nationally based, independent, civil society organisations united by our vision of a world without AIDS.

We are committed to joint action, working with communities through local, national and global action on HIV, health and human rights.

Our actions are guided by our values: the lives of all human beings are of equal value, and everyone has the right to access the HIV information and services they need for a healthy life.

About Africaid Zvandiri

Africaid is a community based organisation in Zimbabwe which, through its Zvandiri programme, provides community and health facility based prevention, treatment, care and support for children, adolescents and young people living with HIV. Zvandiri aims to support national HIV systems to provide a comprehensive package of care for children, adolescents and young people living with HIV which is responsive to their clinical and psychosocial needs and experiences. HIV positive children and adolescents are at the heart of the programme, whereby they take the lead in designing, implementing, monitoring, and evaluating Zvandiri activities.