Zvandiri
supporting HIV positive children, adolescents and young people in Zimbabwe through the HIV care continuum
Zvandiri: supporting HIV positive children, adolescents and young people in Zimbabwe through the HIV care continuum

is dedicated to all the children, adolescents and young people of Zvandiri
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### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
<td>MoHCC</td>
<td>Ministry of Health and Child Care</td>
</tr>
<tr>
<td>ALHIV</td>
<td>Adolescents living with HIV</td>
<td>MoPSLSW</td>
<td>Ministry of Public Services, Labour and Social Welfare</td>
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<td>ART</td>
<td>Antiretroviral therapy</td>
<td>NAC</td>
<td>National AIDS Council</td>
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<td>ARVs</td>
<td>Antiretrovirals</td>
<td>NGO</td>
<td>Non-governmental organisation</td>
</tr>
<tr>
<td>CATS</td>
<td>Community Adolescent Treatment Supporters</td>
<td>OI</td>
<td>Opportunistic infection</td>
</tr>
<tr>
<td>CBO</td>
<td>Community based organisation</td>
<td>PHDP</td>
<td>Positive health, dignity and prevention</td>
</tr>
<tr>
<td>DCWPS</td>
<td>Department of Child Welfare and Probation Services</td>
<td>PMTCT</td>
<td>Prevention of mother to child HIV transmission</td>
</tr>
<tr>
<td>HCW</td>
<td>Health care worker</td>
<td>PSS</td>
<td>Psychosocial support</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
<td>SRH</td>
<td>Sexual and reproductive health</td>
</tr>
<tr>
<td>HTC</td>
<td>HIV testing and counselling</td>
<td>UNICEF</td>
<td>UNICEF United Nations Children’s Fund</td>
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<tr>
<td>IEC</td>
<td>Information, education and communication</td>
<td>VST</td>
<td>Vocational skills training</td>
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<tr>
<td>IGP</td>
<td>Income generation project</td>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>YPLHIV</td>
<td>Young people living with HIV</td>
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Executive Summary

Introduction and background

Zimbabwe has a generalized, heterosexually-driven HIV epidemic with around 15% prevalence in the population aged 15 – 49. Vertical HIV transmission is declining as prevention of mother to child HIV transmission (PMTCT) programmes scale up and become more effective. However, Zimbabwe will continue to face widespread need for HIV services for children and adolescents born prior to widespread PMTCT or for whom PMTCT has failed, and also for those infected through sexual abuse or, as adolescents mature and become sexually active, through unprotected sex. Antiretroviral treatment (ART) has substantially increased in Zimbabwe in recent years, but many factors impede early diagnosis and successful treatment for children and adolescents. This situation urgently needs to improve.

For everyone, adolescence is a period of substantial physical, emotional and social change, the transition from childhood immaturity and dependence to adult roles, relationships and responsibilities. Children and adolescents with poor immunity because of HIV face huge additional challenges, from repeated bouts of ill-health, stunting and delayed growth and development, to multiple psychosocial stressors. These arise directly from their physical ailments and also from fear, stigma and discrimination, low self-esteem and, all too often, orphanhood and insecurity at home.

As improved care and treatment access allows more children born with HIV to survive into adolescence and adulthood, there is growing need for a holistic and long-term continuum of care. Support to address psychosocial needs, supportive and well-informed caregivers, reduced stigma and discrimination and youth-friendly health provider attitudes and facilities are essential, in addition to the availability of prophylaxis and treatment for opportunistic infections, antiretroviral medication and adherence support. These are the challenges that the Zimbabwean civil society organisation Africaid sets out to address in its Zvandiri programme.

The aims and benefits of the programme are described here in the context of the main needs and challenges facing children and young people growing up with HIV in Zimbabwe. Case studies of beneficiaries highlight selected issues and how Zvandiri has changed their lives. The
information in the booklet has come from focus group discussions and key informant interviews with Zvandiri beneficiaries, staff and partner organisations; and from literature review that includes published literature in the field, and both published and unpublished studies, in-house documentation of the Zvandiri programme, and case review.

The Zvandiri programme

Zvandiri is a complex community psychosocial and health support programme for children and young people living with HIV. It contributes to a holistic continuum of care with bi-directional referral between health clinics and the community, in close collaboration with the Ministry of Health and Child Care (MoHCC) and the Ministry of Public Services, Labour and Social Welfare (MoPSLW), other ministries and many civil society partners. Zvandiri started in Harare in 2004 with a support group of six HIV positive adolescents. Today it reaches thousands of HIV positive children and young people aged 5 – 24 in Harare, Chitungwiza, Manicaland, Midlands and Bulawayo, with plans to expand further in Zimbabwe and the region. Zvandiri has developed a theory of change approach that encourages reflection, adaptation and incorporation of new ideas and evidence into its evolving programme.

Psychosocial support and health services are provided through community support groups, community outreach and Zvandiri centres attached to health clinics.

In addition, the programme influences the home, school and overall community environment to raise awareness and reduce stigma and discrimination, and contributes substantially to training, and to policy and guideline development nationally and internationally.

At the core of Zvandiri are trained HIV positive adolescents and young people known as community adolescent treatment supporters (CATS). Supported and mentored by Zvandiri staff and supervised by primary health care counsellors, CATS provide direct psychosocial and health support services to peers living with HIV, to caregivers and to young HIV positive parents. CATS also, together with Zvandiri staff and other adolescents in the programme, propose and implement innovative ways of communicating and creating awareness to reduce stigma and discrimination, and they help develop and test training tools. CATS are powerful advocates and role models who contribute to training health care providers (amongst others) to understand the holistic needs of HIV positive children and adolescents, supporting overstretched clinic staff to address these needs. Young people in the programme have regular opportunities to share experiences, ideas and challenges and to contribute to programme modification and development.

Key areas of support

Zvandiri provides a wide range of benefits at different levels for its primary and secondary beneficiaries, benefits that often overlap and that are complementary.

Overarching objectives and benefits

- Effective bi-directional links between community and clinic to strengthen the HIV care cascade including earlier uptake of HIV testing and counselling (HTC), reduced gap between HTC and treatment uptake, and better retention in care.
- Psychosocial well-being, including improved resilience and confidence, improved mental health, earlier and supported disclosure, better adherence, better health outcomes for HIV positive children, adolescents and young people.
- Improved linkage to child protection services that prevent and respond to child protection violations including neglect, violence, stigma and discrimination.
- Support for HIV prevention, including for the next generation and for wider sexual and reproductive health, (positive health, dignity and prevention, PHDP)
- Reduced incidence of drug resistance, treatment failure and transmission of resistant virus.
- Potential for long-term cost benefits through contributing to HIV prevention, and improved sustainability of treatment and care because of reduced opportunistic infections and delayed need for second or third line ARV regimens.
- Strengthened child and youth friendly health service provision.
Benefits for children and young people living with HIV

Psychosocial and mental health benefits:
- Reduced isolation, improved psychosocial well-being and mental health, including alleviation of fear, depression and anxiety
- Increased self-esteem, confidence, motivation and capacity
- Increased HIV-related knowledge, understanding and life skills
- Greater capacity to handle stigma and discrimination and emotional violence
- Earlier identification of and response to child neglect and abuse and referral to holistic child protection services

Direct health benefits:
- Earlier diagnosis, supported disclosure, adherence and retention in care, leading to lower rates of treatment failure and better overall health outcomes
- Better sexual and reproductive health, including treatment for sexually transmitted infections, reduction in unintended pregnancy, improved uptake of prevention of mother to child HIV transmission (PMTCT) services

Indirect and long-term benefits:
- Improved education: less time lost through illness, reduced stigma and discrimination; more acceptance and understanding by peers and teachers
- Vocational training and potential for improved socio-economic status
- Direct support and social welfare referral to meet some material needs
- Improved, more youth friendly health care systems
- Reduction in HIV transmission and new infections in sexual partners

Benefits for caregivers
- Improved knowledge and understanding about HIV
- Reduced fears of infection
- Healthier children and adolescents – fewer needs, illness and costs
- More support from HIV positive child/adolescent in the home and for the future
- Improved capacity to cope appropriately
- Less isolation and stigma.

Benefits for clinic staff and health services
- Strengthened community-clinic linkages for a greatly improved holistic and comprehensive continuum of psychosocial well-being and health care
- Training opportunities for health care providers at different levels, increased understanding of adolescent needs, and skills development
- Time saving, suggestions for more efficient practice, reduced stress
- Fewer repeat visits by children, adolescents and young people for ill-health, increased counsellor contact

Benefits for children and young people

- Improved capacity of families and communities to support children and young people with HIV
- Youth empowerment as future adults, workers and parents that benefits themselves and their communities
- Expansion of the documented experience of effective approaches for children and young people with HIV
- Model for active participation with potential for sustainability and scale up that can be utilized by different organisations with other vulnerable children and young people.

- Psychosocial and mental health benefits:
  - Reduced isolation, improved psychosocial well-being and mental health, including alleviation of fear, depression and anxiety
  - Increased self-esteem, confidence, motivation and capacity
  - Increased HIV-related knowledge, understanding and life skills
  - Greater capacity to handle stigma and discrimination and emotional violence
  - Earlier identification of and response to child neglect and abuse and referral to holistic child protection services

- Direct health benefits:
  - Earlier diagnosis, supported disclosure, adherence and retention in care, leading to lower rates of treatment failure and better overall health outcomes
  - Better sexual and reproductive health, including treatment for sexually transmitted infections, reduction in unintended pregnancy, improved uptake of prevention of mother to child HIV transmission (PMTCT) services

- Indirect and long-term benefits:
  - Improved education: less time lost through illness, reduced stigma and discrimination; more acceptance and understanding by peers and teachers
  - Vocational training and potential for improved socio-economic status
  - Direct support and social welfare referral to meet some material needs
  - Improved, more youth friendly health care systems
  - Reduction in HIV transmission and new infections in sexual partners

- Improved access to PMTCT, reduced infant infections and mortality, supported parenthood
- As CATS, learning valuable skills, personal empowerment, opportunities to give back, and generate some income.

Benefits for caregivers
- Improved knowledge and understanding about HIV
- Reduced fears of infection
- Healthier children and adolescents – fewer needs, illness and costs
- More support from HIV positive child/adolescent in the home and for the future
- Improved capacity to cope appropriately
- Less isolation and stigma.

Benefits for clinic staff and health services
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involvement, suggestions for more efficient operating patterns

- Improved linkage between health and child protection services
- Support to develop youth and gender friendly health services
- Support for defaulter tracing, reducing loss to follow up
- Improved track records for successful disclosure, treatment access and adherence and retention in care
- More job satisfaction through greater engagement and better results.

Conclusions, challenges and the way forward

Despite the many benefits that Zvandiri achieves, challenges remain for its expansion and success: there is a long way to go. In Zimbabwe and the region there remain widespread stigma and discrimination against people living with HIV, including in schools, churches and communities at large. Families need continued support to overcome stigma, to change harmful traditional beliefs and to dispel myths and misinformation about HIV transmission, treatment and disease causality. Many children born with HIV are still diagnosed late, and disclosure may be delayed and poorly handled. Low self-esteem, depression and anxiety contribute to poor adherence to medication and consequently to treatment failure.

There is urgent need for wide-scale expansion of Zvandiri’s community services into under-served regions of Zimbabwe, working with government, international cooperation partners and like-minded civil society partners to support hard-pressed and understaffed clinics to provide effective, more comprehensive care. Identifying and addressing the needs of especially vulnerable children, adolescents and young people born with or at risk of acquiring HIV, such as the homeless, disabled or incarcerated, should also be a priority. To do this requires sustained and increased financing, and the capacity to expand without compromising the high quality and intensity of care and support that Zvandiri currently provides. Such expenditures now are likely to prove a cost-beneficial investment, contributing to both HIV prevention and reduced long-term expenditures on treating opportunistic infections and on second and third line ARV regimens.

With support, however, the evolving experience of Zvandiri lends itself to potentially sustainable development and wide replication, nationally in Zimbabwe and beyond its borders, and to influence programming with other cohorts of vulnerable children and young people. CATS train other CATS to take over from them; as more health providers are trained on the needs of young people, clinics become more youth friendly and aware of the importance of psychosocial support; and gradually the prevailing stigma and discrimination in schools and communities can lessen. Zvandiri’s outcomes and impacts need further quantitative as well as qualitative documentation and analysis that is currently being planned. Long-term follow up of graduates from Zvandiri will further elucidate lasting results for not just these young people, but the future, increasingly AIDS-free, generation born to HIV positive parents.
Introduction

In common with mainland southern Africa, Zimbabwe has a generalized, mainly heterosexually-driven HIV epidemic that impacts heavily on families. As well as adult infections that peak in women in their thirties and men in their forties, children are also infected – an estimated 162,900 children in Zimbabwe were living with HIV in 2010. The estimated prevalence was 15% in adults aged 15-49 in 2010/11, 7.8% in young women aged 15 – 24 and 3.6% in their male counterparts.

HIV prevalence in Zimbabwe has fallen, however, since its peak at over 24% in the late 1990s, following a decline in incidence, and it has remained stable over the past few years. This is because further incidence decline is balanced by increased survival with HIV through greater treatment access. Although by 2013 transmission from mother to child has also significantly declined through successful prevention efforts, children are still becoming infected by this route. Antiretroviral treatment has substantially increased in Zimbabwe in recent years, but treatment for children and adolescents lags behind that for adults.

Children, adolescents and young adults with HIV are increasingly being identified at health clinics throughout Zimbabwe and other East and southern African countries with generalized HIV epidemics. Many were born with HIV or acquired infection through breastfeeding. Others were infected through sexual abuse or, as they become sexually active, through unprotected sex. In the past, an estimated 50% of perinatally infected children died in the first few years of life, but some are slow progressors, and with the roll out of more effective antiretroviral treatment (ART) they may have the possibility to have relatively normal lifespans if they continue to access and adhere to medication.

Increased early childhood survival is a vital beginning, but it is followed by multiple further challenges. Many clinical and psychosocial issues arise for children and adolescents that impact on clinical and psychosocial outcomes for this group. Adolescents have their own complex needs as they transition from childhood immaturity and dependence into adulthood roles, responsibilities and relationships. If, in addition, they never had a strong immune system, they

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1 In this booklet, the age categories used broadly follow UN guidelines: children are aged under 18, adolescents are aged 10-19, and young people are aged 15-24. Therefore reference to children and young people includes the full adolescent age range.
may face multiple other challenges to their health and well-being, growth and development. Many have experienced repeated bouts of illness, hospital admissions and loss of schooling, and some have severe stunting, organ damage and learning deficits, skin disfigurement, and visual and hearing impairments because of repeated infections. Many have also faced the emotional trauma of parental deaths and are raised by other caregivers who may or may not accept their HIV status without stigma, or know how best to support them. Poverty is also widespread, and coping with chronic ill-health can drain scarce resources. With all these challenges, the death rate among adolescents on ART is higher than that in adults, reflecting late diagnosis, poor retention in care, poorer adherence and more frequent treatment failure. Chronic mental health disorders are also common in this age group.

Many challenges arise for overstretched health facilities in coping with the increasing numbers of children and young people living with HIV. Antenatal clinic care (ANC) and maternal, neonatal and (early) child health care (MNCH) are relatively well established, with dedicated staff training and clinics. Likewise, health clinics provide adult care, including for some specialist needs. However, older children and adolescents commonly fall through the cracks. Facilities are rarely youth and gender friendly, and staff commonly lack the confidence and skills to respond to the general needs of children from five through adolescence, let alone for the complexity of HIV and AIDS treatment and care in this vulnerable cohort. Time constraints, as well as lack of training and special facilities, make it difficult for hard-pressed staff to address their psychosocial needs, or to provide age-appropriate support for early diagnosis, disclosure and long-term treatment adherence. The sexual and reproductive health needs of this group are a further challenge as they grow up.

Beyond the constrained health facilities, an over-stretched social welfare system lacks the skills and experience to prevent and respond to child protection violations in this vulnerable group, such as neglect, violence, stigma and discrimination. Yet as the Department of Child Welfare and Probation Services rolls out its new national case management system, the opportunity is emerging to strengthen the linkage between health and child protection services. It is high time that denying children access to HIV testing and counselling, treatment and care is considered neglected and that stigma and discrimination are recognized as emotional violence.

In addition, cultural beliefs about disease causation and cure impact on the readiness of caregivers to pursue HIV testing and antiretroviral treatment; high mobility among young people to seek work or to stay with different relatives impedes retention in care; and widespread poverty makes it harder for people to travel to health centres or to pay for laboratory tests and administrative costs, even where actual medication is provided free. Hunger and undernutrition, of course, reduce the effectiveness of some drugs, including for tuberculosis.

This is the context in which Africaid, a Harare-based non-governmental organization, started the Zvandiri programme in 2004 with the aim of improving psychosocial and HIV outcomes for HIV positive children, adolescents and young people from five to 24 years of age. The aims and benefits of the Zvandiri programme are described here, with analysis of the main needs and challenges facing children and young people growing up with HIV in Zimbabwe. Case studies and short vignettes of beneficiaries highlight selected key issues and how the programme has changed their lives. Names and initials are changed, but the individuals’ experiences are factual. These case studies need to be understood in the context of Zvandiri’s overall programme and the ideas behind it. Also highlighted is how Zvandiri works in mutually complementary partnerships that benefit health care providers and caregivers, and that influence the home, school and overall community environment to reduce stigma and discrimination, and raise awareness. Zvandiri also has a well-developed advocacy programme and contributes to changing policy and guidelines for HIV positive children and young people.

The information in this booklet has come from a series of focus group discussions and key informant interviews with Zvandiri beneficiaries, staff and partner organisations; and from literature review that includes published literature in the field and both published and unpublished studies, in-house documentation of Zvandiri, and case review. Two tables provide quantitative data on Zvandiri’s overall programme achievements and both quantitative and qualitative information on changes in Zvandiri’s short-, medium- and long-term change results.
The Zvandiri programme

Goal, overarching objectives and benefits

Zvandiri (literally, ‘As I am’, or ‘Accept me as I am, living with HIV’) began when a group of six HIV positive adolescents approached Africaid for help to start a support group. In the 10 years since its inception, the programme has grown to reach thousands of children and young people initially in Harare and Chitungwiza, and now in Bulawayo, Midlands and Manicaland as well. It has achieved expansion to address its central goal with a full-time staff complement by 2014 of just 14 people, through extensive involvement of volunteers and HIV positive young people trained as peer counsellors, known as community adolescent treatment supporters (CATS).

At the core of Zvandiri lies the recognition that medical treatment and facility-based care alone are not enough to meet the needs of HIV positive children and young people, and that the health services do not have the resources to provide the holistic care required. Instead, Zvandiri contributes to a comprehensive care continuum through the HIV care cascade, linking clinic and community care and addressing the psychosocial and child protection needs as well as health needs of this vulnerable cohort. The programme adopts a unifying approach that brings together partners from the national health care, social welfare, child protection, education and justice systems, and numerous civil society organisations with diverse programmes for and with young people in Zimbabwe. Its central partners, in addition to the beneficiaries, are the Ministry of Health and Child Care (MoHCC), the Ministry of Public Services, Labour and Social Welfare (MoPLSW), the National AIDS Council and city health departments. Zvandiri has linked with the Department of Child Welfare and Probation Services (DCWPS) in its mandate to consolidate the diverse responses to children in need into one unified case management system and to strengthen the linkage between child protection and HIV services. Zvandiri’s overarching objectives and benefits are summarized below.

Programme Goal

To help HIV positive children, adolescents and young people to develop the knowledge, skills and confidence to cope with their HIV status and to live happy, healthy, fulfilled lives
Zvandiri model, theory and assumptions

Figure 1 depicts the Zvandiri model, with the concentric circles indicating levels of inter-related support.

Figure 1: Zvandiri model (diagram needs to be updated with changes provided by Nicola)

Overarching objectives and benefits of the Zvandiri programme

- Effective bi-directional links between community and clinic to strengthen the HIV care cascade including uptake of HTC, linkage and retention in care, and adherence
- Psychosocial well-being, including improved resilience and confidence, improved mental health, earlier and supported disclosure, better adherence, better health outcomes for HIV positive children, adolescents and young people
- Improved linkage to child protection services that prevent and respond to neglect, violence, stigma and discrimination
- Support for HIV prevention, including for the next generation and for wider sexual and reproductive health (positive health, dignity and prevention)
- Reduced incidence of drug resistance, treatment failure and transmission of resistant virus
- Potential for long-term cost benefits through contribution to HIV prevention, and improved sustainability of treatment and care with reduced opportunistic infections and need for second or third line ARV regimens
- Strengthened child and youth friendly health service provision
- Improved capacity of families and communities to support children and young people with HIV
- Youth empowerment as future adults, workers and parents that benefits themselves and their communities
- Expansion of the documented experience of effective approached for children and young people with HIV
- Model of active participation with potential for sustainability and scale up that can be utilized by different organisations with other vulnerable children and young people.

Children and young people living with HIV are at the core of the programme, requiring early disclosure, psychosocial and medical support for adherence, sexual and reproductive health and mental health services, linkage and retention in care within a supportive home, school and community environment. Collaborative efforts to provide this support come through the
health clinic, community outreach from Zvandiri and the clinic, community support groups and home visits, and four Zvandiri centres at health clinics in Harare and Chitungwiza. Their overlapping roles complement each other as indicated to provide a comprehensive continuum of psychosocial and health care with bilateral referral between clinic and community. This promotes rapid responses for children and young people needing HTC and linkage to care, those lost to follow up and for early clinic referral for those showing poor treatment outcomes. Similarly, linkages with the Department of Child Welfare and Probation Services facilitate bilateral referral between child protection and HIV services.

The scale up in other provinces replicates this model with the added dimension of support from Harare with training, mentorship, provision of resources and monitoring of progress. The provinces build on the experience of Harare adapted to address priorities in their own particular context. In 2015, Zvandiri is expanding support for training CATS and setting up support groups in every province of Zimbabwe through collaboration with the MoHCC and MoPSLSW, and also in four nearby countries.

Capacity building at all levels is undertaken to strengthen the coping mechanisms of the children and young people, and to improve the quality of support from caregivers, health providers, faith organisations, schools and other community groups. Zvandiri undertakes widespread advocacy and participates actively in policy and guideline development.

Ongoing monitoring by Zvandiri includes regular review of the psychosocial status of beneficiaries utilizing several self-reflection tools, notably: ‘Ask the Expert’ that addresses measures of interpersonal and intrapersonal coping, safety, and social interaction; a tool measuring confidence; a ‘Promising Quality’ checklist; and the Shona Symptom Questionnaire, a screening tool for depression. Adherence self-report measures are also used to assess children and young people’s levels of adherence and the support they require. Thus individual case management includes regular opportunities to assess how well beneficiaries feel they are doing and provides an additional avenue...
to identify and address problems early.

Zvandiri has evolved through developing a theory of change to unpack emerging assumptions and, learning from experience, to achieve short-, medium- and long-term changes. It is a complex programme within which multiple pathways can lead to results at different levels. The programme activities, ranging from direct service support for improved health and psychosocial well-being to training service providers, advocacy and policy development, feed into immediate, short-term positive changes for children and young people, their caregivers and families, the wider community and for multi-sectoral service provision. These in turn feed into medium- and long-term changes as outlined.

In its evolution over time, the programme has espoused the following broad assumptions or guiding concepts:

- Children with HIV have the right to access HIV testing and counselling, treatment and care, to information about their own health, to be involved in matters that affect them and to live in safe, supportive environments that protect them (in line with the United Nations Convention on the Rights of the Child)
- Children and young people with HIV face multiple psychosocial and health challenges; increased confidence, self-esteem and overall mental health will contribute to treatment adherence in children and young people, and to better sexual and reproductive health
- Early diagnosis and disclosure of HIV status are important preludes to effective long-term treatment, HIV prevention and positive mental health
- Functioning health services (and basic laboratory services) are necessary but insufficient to address the full needs of children and young people to ensure early detection of HIV status, disclosure and treatment adherence
- Support groups for children and young people with HIV and for caregivers, sustained counselling and home visits by peers promote knowledge, skills, confidence and self-esteem, reduce isolation, and improve coping and adherence
- Maximising the active participation of beneficiaries at all levels and stages of the programme is a cost-beneficial and effective way to achieve continued psychosocial support (PSS) and health benefits for them and for other beneficiaries, building on the concepts of participatory development
- Multiple stakeholders, including families, communities, health and welfare services and children and young people with HIV themselves, all stand to benefit from the programme and will buy into it; this will lead to programme expansion, replication and further evolution
- As the programme demonstrates being cost beneficial, cost effective and efficient, resources and funding will continue to be available.

The key principle throughout the development of the programme has been that it must be driven by the beneficiaries – through the insights they provide as to their specific needs, the gaps in existing service provision and support, and barriers in their home, school and social environments to coping with their HIV status and related concerns; and how they think these can best be addressed.

The HIV care continuum and Zvandiri structures and approaches

Zvandiri defines the continuum of care for children and adolescents with HIV as incorporating the following:

- HIV testing and counselling (HTC) and linkage to OI/ART services
- Disclosure and follow up counselling and psychosocial support
- Pre-ART monitoring, care, treatment and support
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Starting antiretroviral treatment (ART)

Adherence and retention in treatment, care and support

Addressing long-term mental health and psychosocial well-being; sexual and reproductive health services and relationships

Transiting into adult care

Zvandiri recognizes that the care continuum must be supported through an integrated facility and community-based approach for optimal health and psychosocial outcomes. Beneficiaries have depicted the continuum as a generic ‘river of life’ roadmap and individuals are encouraged to map their own experience as a therapeutic exercise.

Zvandiri supports children, adolescents and young people to access the continuum of HIV care through several complementary structures and approaches. The structures are outlined below in the chronological order in which they were first established.

Community support groups: From 2004, the first initiative that gave rise to Zvandiri was the adolescent support group noted earlier. This approach gradually expanded into other monthly community-based support groups run by trained facilitators (including YPLHIV), providing structured activities to build resilience, confidence and self-esteem, to develop knowledge and skills related to HIV, and to promote adherence as well as broader sexual and reproductive health. These support groups provide opportunities for sharing experiences and developing friendships and support networks, and an opportunity for informal review of beneficiaries’ well-being. Wider youth groups and young parent groups are also being run to respond to the evolving needs of these young people with HIV.

Community outreach was developed early on and has now expanded into a multidisciplinary team including an HIV clinician, nurse, counsellors, a social worker and a network of community adolescent treatment supporters (CATS). This team provides home-based clinical monitoring, counselling, adherence support and ensures linkage and retention in care. The team identifies and refers back to the clinic children requiring ART, laboratory investigations, management of opportunistic infections (OIs), possible ARV-related toxicities and treatment failure. Young people with depression and anxiety are supported in partnership with the government’s child and adolescent psychiatry unit. Sexual and reproductive health services are also provided. Children at risk of neglect, violence, stigma and discrimination are case managed and linked in to the Department of Child Welfare and Probation Service’s national case management system.

Community based HTC is available to improve the uptake of HTC services for this age group, particularly for hard to reach groups such as young people living on the streets or in resettlement areas. CATS conduct information sharing sessions with community groups and in schools, advocating for early testing and treatment for children.

Community adolescent treatment supporters (CATS): The CATS initiative was established in 2009. YPLHIV who are coping well with their own HIV have been trained and supported to become counsellors for their peers, through clinics and home visits. CATS have personally experienced many of the issues around ill-health, anxiety, guilt, fear, shame, rejection, depression and hopelessness, and also the personal growth and transformation through Zvandiri that enables them to support others effectively. This lived experience makes them particularly credible to others struggling with a new HIV diagnosis or with treatment, with their unique value as normative role models.

Since 2009 Zvandiri has trained adolescents who are coping well with their own HIV to become supporters for their peers: the community adolescent treatment supporters (CATS), who are now the central players in Zvandiri’s delivery of psychosocial and health service support. These young people living with HIV wanted
to assist their peers systematically and professionally and, quite correctly, felt they had a lot to give. CATS have experienced many of the issues around ill-health, anxiety, guilt, fear, shame, rejection, grief, depression and hopelessness themselves, and also the personal growth and transformation through Zvandiri that enables them to support others effectively. This lived experience makes them particularly credible to others struggling with a new HIV diagnosis or with treatment, with their unique value as normative role models.

Starting with 10 HIV positive adolescents in 2009, by late 2014 there were 35 trained CATS in Harare and Chitungwiza conducting an average of 283 home visits each month for children and young people on ART, and 100 more CATS trained in eight districts in Manicaland, Midlands and Bulawayo. CATS are supervised by Ministry of Health and Child Care primary counsellors, with additional Zvandiri support, and new recruits are gradually being taken on board. The induction of new CATS is undertaken largely by experienced CATS who will shortly graduate from Zvandiri at age 24.

CATS undergo an initial four-week hands-on training programme that includes two weeks’ clinical attachment. They have ongoing training as part of their supervision, and quarterly refresher training workshops. In 2014 new supervision guidelines were developed, and at weekly meetings CATS receive training and supervision, report on their work, seek advice on challenging issues, and provide mutual support. Once trained, CATS provide direct support services to peers, caregivers and young parents living with HIV; they propose and implement innovative ways of communicating and creating awareness; they help develop and test training tools; they are powerful advocates and role models; and they contribute to training of health staff to understand the holistic needs of HIV positive children and adolescents, and then support overstretched health staff to address these needs. CATS have regular opportunities to share experiences, ideas and challenges and to contribute to programme modification and development, and they contribute to policy and guideline development nationally and internationally. Demand is growing rapidly from clinics throughout Zimbabwe to have CATS linked with them, and Zvandiri plans to expand its programme under the MoHCC as funds and resources are available.

CATS’ roles have evolved and expanded as they gained experience, training and capacity. To fulfill their roles, the main activities within the continuum of holistic care are:

- Holding monthly support groups for HIV positive children and adolescents, either at clinics or in a community venue, with opportunities for individual counselling as needed
- Since 2012, holding support groups also for caregivers, after it was recognized that a major problem lay in poor understanding and support from caregivers
- Undertaking home visits when health providers refer cases of loss to follow up or suspected poor...
adherence, and also for assistance in disclosure, and to provide information and support to caregivers. They see children commencing ART or defaulting on a daily basis for as long as necessary to ensure adherence and the resolution of associated problems, providing an invaluable bi-directional link between clinic and community.

- Initiating referrals to clinics when their attention is brought by friends or others to a child or adolescent in the community who appears chronically unwell.

**Zvandiri centres**: Clinic-based Zvandiri centres were established in 2013 in four clinics in Harare. These centres provide an adolescent-focused environment for young people to access HIV and SRH related information, counselling, peer support, life skills training, and recreational activities. Trained and mentored YPLHIV from Zvandiri run the centres, supervised by clinic staff. The centres also refer young people to other services including HIV testing and counselling, family planning, treatment for sexually transmitted infections (STIs), prevention of mother to child HIV transmission, mental health and child protection services.

**Literacy materials and tools**: In addition to direct service support, CATS and other beneficiaries have

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**CATS roles and responsibilities**

- Identification and linkage of children and young people with HIV to HTC, OI/ART, SRH, Mental Health and Child Protection Services
- Disclosure support and counselling
- Home visits (adherence monitoring, counselling, tracing those lost to follow up, supporting those moving elsewhere)
- Identification and referral of those at risk (e.g. children and adolescents not tested, not on ART but eligible, non-adherent, sick, exhibiting possible treatment failure, possibly abused, with SRH and mental health needs and other social challenges)
- Intensified daily adherence support for those initiating or failing ART
- Intensified counselling for adolescents with depression
- Facilitation of Zvandiri support groups
- Facilitation of Zvandiri centres
- Information sharing and counselling for caregivers
- Training of health workers, communities, teachers, church leaders
- Participation in Child Protection Committees

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‘Being a CATS is a platform for me to understand myself better. It has empowered me a lot... I have gained a lot of confidence and I know there is more to life. I can speak about my status to anyone’ (CATS, 21 years old)

‘(Being a CATS) helps me cope with my own status and makes me realize that I have something greater in me that I can share with my peers. I still have hope and dreams that need to be fulfilled.’ (CATS, 19 years old)
produced various materials to promote the continuum of care, including posters, publications of their personal stories, DVDs, and developing awareness campaigns. Fourteen Harare support groups of HIV positive children and adolescents aged 8 – 18 collaborated to produce an engaging publication called ‘Our Story’. This combines essential information about coping with HIV and AIDS with many personal quotes and monitoring charts, and it is designed to assist children and young people living with HIV and also health practitioners and other carers to understand their needs. Health workers in 54 clinics across Zimbabwe and the region received 21,000 copies of the publication between 2006 and 2014. Zvandiri has also distributed a game version of ‘Our Story’ to 28 clinics in four provinces, a tool to assist HTC, disclosure and counselling for ART. More recently, Africaid has developed the Zvandiri Toolkit, 200 sets of which will be distributed to health facilities and community organisations working with Africaid. In these and other ways – through training health providers, posters and other materials and, most of all, through the participation of CATS – Zvandiri contributes to making clinics more child and adolescent friendly, and hence more effective in addressing HIV and AIDS.

Zvandiri links with different partner initiatives to share ideas, training, mentorship and experience and with organisations supporting HIV positive children and adolescents already in special care for other reasons or with special needs in addition to HIV. To date these include physically or mentally disabled children and adolescents, those who are deaf, children in residential care (usually orphaned) or living on the street or in detention centres. Other vulnerable young people at high risk for HIV, such as those drawn into sex work, involved in male-to-male sex, or who have been sexually abused, will also need particular attention to access testing and to benefit from a continuum of

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**Quotes from Our Story Book**

One of my relatives told me that I was going to die and there is no life for me at all but he had already seen that I was positive before I was tested. I spent the whole day crying, wishing to die and never see the light again.

Before I was told that I had HIV, I felt sick and helpless but I did not know what it was. I had big tonsils and I felt lonely when people laughed at me.

I was scared of my status. I was frightened and felt so alone, like I am going to die. All my thoughts were about dying. I didn’t realise that I was going to live for many years.

I felt so relieved to know my status as I was worried what was going on in my life. Finding out my status made me cry for a long time, thinking “where did I actually did get this disease?” but I did not have an answer.

I am happy starting these ARVs because they make me strong by fighting against the disease in my body. Now I am going to feel better for the first time in my life after a long time of sickness without hope.

I now feel very strong and my skin is now clear. I now feel like other children. When I was sick, no one would play with me. But now I am well and have lots of friends. We play together all the time.
Core areas of Zvandiri support

Overview

Zvandiri secures multiple benefits for its young beneficiaries and also for their caregivers and for overstretched health professionals, with potentially much wider benefits for managing the HIV and AIDS epidemic as a whole. The programme contributes towards reducing the HIV testing and treatment gap for children and adolescents. It helps make health services more efficient and effective by taking extensive responsibility for linkage and retention in care, loss to follow up and adherence monitoring, as well as changing health provider attitudes and building their skills, through training and exposure to CATS, to provide strong youth friendly services.

By strengthening uptake of HTC, disclosure, treatment access and adherence and retention in care, Zvandiri contributes substantially to HIV positive health, dignity and prevention, PHDP, as part of wider sexual and reproductive health benefits and improved mental health. In turn, these can generate substantial cost benefits and cost savings over time through fewer new infections, earlier access to testing and treatment, reduced occurrence of drug resistance and hence lower rates of treatment failure. Strengthened linkages with child protection services also promote better, more holistic case management to deal with issues of neglect, discrimination and stigma, and child abuse. More broadly, Zvandiri contributes to advocacy, raising awareness and challenging stigma and discrimination in schools, churches and the community at large. Finally, Zvandiri also contributes substantially to policy and guideline development and training.

Benefits for children and young people living with HIV

The benefits of Zvandiri for children and young people living with HIV are complex and overlap.

Psychosocial and mental health benefits:
- Reduced isolation, improved psychosocial well-being and mental health, including alleviation of fear, depression and anxiety
- Increased self-esteem, confidence, motivation and capacity
- Increased knowledge, understanding and life skills
Greater capacity to handle stigma and discrimination and emotional violence

- Earlier identification of and response to child neglect and abuse and referral to holistic child welfare services
- Improved family communications and parenting, happier home life
- Opportunities for regular involvement in activities and group events – fun, uplifting, involving, inspiring, developing skills and information, making friends

**Direct health benefits:**

- Earlier diagnosis and linkage to care, earlier supported disclosure, adherence and retention in care, leading to better health outcomes
- Improved sexual and reproductive health, including treatment for sexually transmitted infections, reduction in unintended pregnancy, early linkage to and improved uptake of PMTCT

**Indirect and long-term benefits:**

- Improved education: less time lost through illness, reduced stigma and discrimination; more acceptance and understanding by peers and teachers
- Vocational training and potential for improved socio-economic status
- Direct support and social welfare referral to meet some material needs
- Improved, more youth friendly health care systems
- Reduction in HIV transmission and new infections in sexual partners
- Improved access to PMTCT, reduced infant infections and mortality, supported parenthood

As CATS, learning valuable skills, personal empowerment, opportunities to give back, and some income.

Children and young people engaged with Zvandiri gain multiple short-, medium- and long-term benefits that are mutually reinforcing. Improved psychosocial well-being and mental health improve treatment adherence, for example, and improved health in turn strengthens a sense of hope for the future, lifts depression and anxiety and enables children and young people to engage more actively in all areas of life. The next sections delve further into the overall continuum of care, into specific challenges within it and how Zvandiri addresses them, and into the needs and benefits provided to caregivers.

**Comprehensive care**

The case study is an example of a boy born with HIV and suffering with significant delayed growth and development who, after being orphaned early, was taken into residential care. The study highlights the impacts of linkage to successful early treatment adherence interventions with long-term Zvandiri support, and how he was assisted to get back on track after a lack of confidentiality and consequent stigma in a new home led him to default ARV treatment. Work with the school and home environments was critical, as well as with the boy and the clinic to strengthen his psychosocial coping and skills.
Case Study 1: The need for comprehensive care

CM is a double orphan from the age of six, who was born with HIV. He spent his childhood and adolescent years in children’s homes, together with his younger sister who is HIV negative. As a child, he suffered from chronic ear infections that did not respond to repeated cycles of antibiotics, leaving him with significant hearing impairment. He was informed of his HIV status at the age of 10, shortly after testing HIV positive. The staff at the children’s home were initially reluctant to disclose to him as they were not sure how to talk about HIV and whether he would cope. However, with support from clinic staff and complementary follow up visits to the children’s home by Zvandiri, he was informed of his HIV status. Further support was provided for the staff at the children’s home so that they were equipped with knowledge and skills to support CM, including for adherence to ARVs.

At the time of diagnosis, CM’s CD4 count was 104 and he was commenced on ART. He was then referred by his clinic to a Zvandiri support group for peer support, recreational activities and sustained counselling and life skills training. On joining the group, he had stunting and pubertal delay and had many concerns and questions about HIV and his future.

CM was an enthusiastic member of the support group as he felt comfortable in the company of friends who were also small for their age. He commented that he had lots to say and contribute at school, too, but no one would listen to him because they thought he was younger than his classmates. He also explained that he struggled to participate in conversations as he could not hear well. In the support group he felt valued and listened to.

Initially, CM’s adherence to ART was good. His height increased, he gained weight and his CD4 count increased to 386. His ear infections finally cleared once his immune system strengthened. However, at the age of 14 years he moved to a different children’s home and, within six months, his CD4 count began to drop, he stopped gaining weight and height. Psychologically, he was withdrawn and anxious.

Following counselling, CM revealed that he was unhappy at his new home as the house mothers had disclosed his HIV status to everyone. The other boys in the home were now stigmatising him, particularly at 7.00 am and 7.00 pm when he was publicly called for his medication. He informed the Zvandiri counsellor that he did not want to take his ARVs any more and, even though the staff gave him the tablets each day, he never swallowed them. At the same time, his school perceived CM to be less able than his actual ability due to his growth delay and hearing difficulties and he was being held back in school. This distressed him greatly as he wished to progress at school along with his peers.

The Zvandiri team and clinic staff met with the headmaster at CM’s school, an assessment was conducted and he was able to progress to high school. The team also found that the staff at the children’s home had never received any training or support to look after children with HIV. Zvandiri provided training and then regular visits to CM at the home. Working together with CM’s clinic nurse and the Zvandiri support group leader, adherence support in the home was intensified. Subsequently, his CD4 count, height and weight increased. Although CM continued to experience stigma from particular boys in the children’s home, overall the home was more supportive. CM became more resilient with coping skills and improved self-esteem gained through attendance at the support group.
CM is among 130 beneficiaries that Zvandiri, in partnership with Newlands Clinic, has supported to attend various vocational skills training courses at Harare Polytechnic. The wide-ranging courses include, for example, auto electric, welding, cosmetology and graphic design, and run for approximately one year. In both Harare and Gweru Zvandiri has also assisted some young people with HIV to establish income generating projects such as peanut butter making, candle production and other activities.

HIV testing and counselling and disclosure

The point of disclosure, when children or adolescents living with HIV are informed of their HIV status, can be particularly challenging. Zvandiri assists disclosure through counselling from Zvandiri staff and CATS for children, adolescents and caregivers. Clinic staff are also trained on the benefits of disclosure, the process of disclosure and on how to handle likely responses. For children and adolescents, the processing of new information and understanding its implications is an individually tailored process, rather than a one-off event. Caregivers often delay disclosing to children and adolescents their HIV status for fear of upsetting them, because they are themselves unsure what it means or how to inform them, for fear of loss of confidentiality and for other reasons. Clinic staff can only disclose the information to children with the consent of the caregiver and may not have the time, confidence or skills to provide an extended process of disclosure and support. The Zvandiri outreach team and CATS support disclosure jointly with caregivers at home or in the clinic, and provide ongoing daily support to the family afterwards. Both the caregiver and the child or adolescent are invited to the appropriate support groups.

Disclosure is essential at some point, and early, gradual disclosure is preferable so that children from an early age can ask questions and begin to understand their condition and the importance of treatment adherence as they grow up. However, the point of disclosure can

A qualitative Harare-based study found that clinic staff preferred that caregivers undertake initial disclosure with staff providing supporting information on the next clinic appointment. This lessens their risk of upsetting a child and having to spend too much time providing counselling. Adolescents in the same study, however, reported that they preferred disclosure by clinic staff who could immediately answer related questions. In practice, Zvandiri supports a combined approach that is led by caregivers but with optimal support from the clinic and/or Zvandiri.
Case Study 2: HTC and disclosure

RM was six years old when her mother died and she went to live with her maternal aunt. Her aunt suspected that the mother had died of AIDS and she was concerned that RM might also be HIV positive. She visited several clinics but struggled to get RM tested for HIV. One clinic explained that they were not testing children. Another informed her that they needed more confirmation that she was the legal guardian for consent purposes. The aunt did not know what to do until she met a Zvandiri CATS during a community awareness raising event. The CATS explained about the services on offer and referred the aunt to Zvandiri House.

Three days later, at the age of eight years, RM was brought by both her maternal and paternal aunt for HIV testing. They asked RM to leave the room but she was curious about what was being discussed and kept returning. The Zvandiri counsellor explained to the aunts that RM was demonstrating that she needed more information and wanted to know what was going on. However, the two aunts disagreed on whether RM should be tested. Following counselling, they did agree to the HIV test, which was positive.

After continued counselling, both aunts agreed RM should be informed of her HIV status and asked the Zvandiri counsellors to assist. Zvandiri’s Our Story game was used as a visual, interactive method for explaining HIV and ARVs. On hearing her HIV status, RM was extremely distressed, asking why she had not been informed earlier. She asked wider-ranging questions from whether she would be able to go back to school, to would she ever get married? The Zvandiri counsellor asked a CATS to join the session. When RM was informed that the CATS was also HIV positive, she could not believe it and said, ‘I would never have known you are positive. So can I also grow up like you?’ The CATS counselled her and encouraged her and they agreed to meet at the support group the following weekend.

RM soon returned to boarding school and commenced on ART. Ten years later, she remains on first line ART, has a CD4 count of 622 and is virologically suppressed.

Treatment adherence

A core purpose of Zvandiri’s support programme is to promote and monitor ART adherence. Many reasons for non-adherence have been documented, including the following eight reasons identified in a multi-study systematic review by Vreeman et al.: poor socioeconomic environment, negative caregiver characteristics and problematic child-caregiver communications, stigma, HIV status disclosure, and complex drug regimens with side effects and high costs. Zvandiri endorsed these and also highlighted the practical barriers of distance to clinics, difficulties precipitate despair, fear of imminent death, and feelings of shame and guilt. Sustained counselling after disclosure as the child grows through adolescence is critical and is a major focus of the Zvandiri programme through its community support groups, CATS, Zvandiri centres and multidisciplinary outreach team of doctor, nurse, counsellors and social worker.

Sometimes children or adolescents find out inadvertently that they have HIV – for instance, one beneficiary described seeing her medication on television as treatment for AIDS; another found his father’s hidden ARVs and looked them up on line. He then suspected that his mother, who had died of an unexplained illness, might have had AIDS, and that HIV might explain his own ill-health. The case study highlights how barriers may be raised against testing and disclosure, but that even a young child can be aware that there is something wrong and needs the reassurance of information sharing combined with the right counselling and support.
renewing prescriptions during school hours, fears of loss of confidentiality and the resultant desire to conceal medication. Religious and cultural factors, depression and anxiety (common mental health disorders) are increasingly seen to challenge adherence.

CATS cited repeated examples of children and adolescents despairing for the future, of isolation, and non-supportive caregiver attitudes – often because of lack of understanding of the importance of life-long adherence. Keeping medication hidden at boarding school is frequently a problem, as well as taking it on a strict schedule every day. Several CATS had experienced these problems personally. As children grow into adolescence their adherence may also decline, as discussed earlier. If they are being looked after by grandparents, as many are after their parents die, further challenges arise as the elderly increasingly have their own problems of poverty, immobility, various health needs and perhaps failing memory, all making it more difficult for them to provide support for adherence to specific treatment regimens. In the first case study, CM stopped adhering to medication because of negative peer attitudes.

Zvandiri has found that adolescents may continue with clinic appointments and collect new prescriptions, but carefully remove the right number of tablets from their remaining prescription to indicate to the clinic nurse that they are adhering well. They fear an angry reaction from the health staff. Others simply default and are lost to follow up, in which case CATS can undertake home visits to bring them back into care.

Health clinic staff in busy clinics traditionally renew prescriptions, and are required to undertake clinical examination, and to authorize CD4 counts on a six-monthly basis. The CD4 test may require separate queuing, however, to see a counsellor or nurse aide, and Zvandiri beneficiaries reported this as a deterrent. Thus, if the health provider is too busy and does not undertake a thorough clinical examination, treatment failure through poor adherence (or other reasons) may not be recognized for a considerable time. The MoHCC has adopted the WHO recommendations for routine viral load testing but this is not yet widely available or implemented. CATS are providing back up support to clinic staff in ensuring CD4 counts or viral load testing is done, as well as detecting declining health and poor adherence early, even in the absence of routine laboratory monitoring.

CATS promote adherence in many ways, through the support groups, daily home visits as long as they are needed, counselling and by their own example as peers living healthily and successfully because of their adherence to medication. They unpack the reasons for non-adherence and help build the beneficiary’s sense of self-worth, confidence and hope for the future. Without blame or judgment, they explain why a high level of adherence matters and help resolve practical barriers to achieving this. For instance they suggest ways to keep medications private, including the provision of discrete pill boxes, or explore changing the timing of medication so that it is least disruptive. They use WhatsApp technology to message the beneficiaries they support at the times of day they need to take their medication and to remind them of clinic review dates.

CATS also discuss the issues with caregivers or other family members as indicated, and try to establish better on-going support at home.

Another facet of support is engaging health providers to understand the psychosocial challenges and experiences faced by this group in general. Zvandiri engages CATS and shares counselling tools and approaches including their own games, books and films to promote support for adherence.

Other supportive changes resulting from CATS advocacy and awareness creation with health providers include changed opening hours in some clinics so that children and adolescents can have appointments out of school hours, and even the establishment of children’s review days. The provincial hospital in Mutare has dropped administrative charges for some children and adolescents after CATS informed staff that this was deterring them from accessing their review days.

Zvandiri has also introduced digital storytelling as a therapeutic tool to help HIV positive adolescents reflect
on what has happened in their lives, how HIV affected them and how they have learned to cope and turn their lives around. To date 12 adolescents have made short films narrating their life experiences, films that some keep private or share with caregivers, while others approve their use in training health providers and even for showing publicly to generate awareness and understanding. These films illustrate issues around disclosure and treatment adherence, stigma, and barriers to care and how these obstacles have been overcome. Importantly, all young film makers described the transformative effect of engaging in peer-led interventions.

The case study below illustrates challenges to adherence and how Zvandiri has assisted one beneficiary; in particular it highlights how an HIV positive peer can be instrumental in generating openness, hope for the future and successful adherence when, despite regular clinic attendance, this adolescent girl had given up.

Case Study 3:
Adherence and treatment failure

KM is a 17-year-old girl with perinatally acquired HIV infection. She is a double orphan brought up by her maternal aunt and attends boarding school. KM was receiving HIV treatment and care at a central hospital. She commenced ART at the the age of 13, following admission with pneumonia and subsequent diagnosis of HIV. At ART initiation her CD4 count was 46 and although this initially rose to 202, it later dropped to 47 after two years on treatment. She reported to her clinic team that she had been adhering well. She was switched to a second line regimen, she began to gain weight and her CD4 increased to 198. Regular adherence monitoring was recorded in her medical notes and she reported she was adhering well.

Two years later, KM rapidly lost weight, she was emotionally withdrawn and her CD4 count had dropped to 21. A private sponsor assisted with a viral load test and this was 1 million copies/ml. When counselled by the HIV clinician, nurse and counselor, she confirmed that she was adhering well to her medication. Her clinic team planned to switch to a third line regimen and she was referred to Zvandiri for counselling prior to switching treatment regimen.

On arrival at Zvandiri, KM was quiet and reluctant to talk about her experiences. She was introduced to a community adolescent treatment supporter (CATS) and, within 30 minutes, she was describing her reluctance to adhere well owing to treatment fatigue and loss of hope for her future. In agreement with KM’s clinic team, KM and her aunt, the Zvandiri team of HIV clinician, nurse, counsellors and CATS initiated an intensified adherence support programme for one month involving daily home visits, SMS notification when it was the time for medication, and support group attendance. KM transformed into a more confident, cheerful young woman who confirmed her commitment to engaging in treatment, care and support.

After one month the viral load was repeated, demonstrating virological suppression to 1100 copies/ml. KM was delighted with her progress. She began gaining weight and she was able to return to boarding school.
**Case Study 4:**
**Delayed diagnosis, poor adherence and treatment failure**

BM has grown up in a high density suburb of Harare with his maternal grandparents following the death of his parents as a child. He was born with HIV and his childhood was characterised by repeated admissions to hospital with diarrhoea, pneumonia and, later, tuberculosis (TB). He was diagnosed with HIV at 16 years, commenced on ART and informed of his HIV status.

BM was referred to the Zvandiri support group in his community by his local clinic. When he first came to the group, he was quiet and found it difficult to interact with the others. Over the following months, the Zvandiri team and support leader visited BM in his community and found that he was drinking alcohol and using glue on a regular basis. He had dropped out of school and spent little time at home, preferring instead to engage with local gangs. He reported that he did not really want to take his ARVs and that he struggled to remember to take them in any case.

He was visited weekly at home by the outreach team and was encouraged to attend life skills training programmes at Zvandiri House. He exhibited a real interest in the creative arts, so he was engaged in a digital story telling project through which he learned photographic and media skills. With his permission, his film has now been used in the training of health workers and as an advocacy tool. He was then recruited into the Zvandiri vocational skills training programme where he pursued his interest in photography. Following entrepreneurial training, he then began establishing his own small photographic business. His support group leader mentored him as a youth leader and he began assisting with the running of the support group.

At the age of 22 he met his girlfriend TM, also HIV positive, through the Zvandiri Youth Group. They married and, in 2013, had a baby boy. Home visits and regular liaison with the clinic team were provided for the couple to ensure optimal adherence, antenatal care and infant feeding support. Their son is HIV negative.

Last year, BM’s grandfather died and, at the age of 22, he is now the head of the household for seven other household members. The Zvandiri community outreach team noticed he was beginning to lose weight and, when following up at his clinic, established that his CD4 count was dropping. He was tested for TB with a negative result. The outreach team assisted BM at clinic visits and, through discussions with his clinical team, established treatment failure. BM has now been switched to a second line regimen and the couple are being closely monitored and supported, including for adherence and condom use. Both partners are now doing well.

As a result of experiences such as in case study 3, clinic teams now routinely refer adolescents who are struggling with adherence or with treatment failure, and CATS follow up through home visits and counselling, and introduce them to support groups.

The following case study is of a boy who slipped through the net and, although born with HIV and being a double orphan with repeated bouts of ill-health, was not diagnosed with HIV until the age of 16 – when he had AIDS-defining infections. As a consequence of late diagnosis, poor support and poor adherence, this talented young man failed on first line treatment by age 22. Now, with Zvandiri support, his life is coming together despite the many challenges he still has to face.

**Sexual and reproductive health and parenthood**

As children become adolescents, and adolescents transition into adulthood, the issues around sexual and reproductive health, partnerships and child bearing become increasingly pressing. Many children and adolescents have despaired of ever having a sexual partner, let alone having a baby or family of their own, prior to Zvandiri support. They thought they had no future and, even if they survived, either no partner would want them or they felt it wrong to get involved let alone to become a parent. One adolescent girl said: ‘Before I started attending these sessions (support groups) I never thought I would ever consider to have
This case study is a girl who ‘just wanted to be normal’ like her peers but, having overcome her reluctance to continue ART, and having disclosed to her supportive partner, faced further trauma when she became pregnant and had her first baby.

As well as supporting the transition into adulthood with regards sexual and reproductive health and child bearing, Zvandiri assists many young people with vocational skills development, as noted earlier and in this and the first case study. By 2014, there were seven income generating projects being run by Zvandiri beneficiaries. One or two others joined Zvandiri as staff. Maintaining treatment adherence and retention in care into the future, and promoting partner disclosure, are ongoing challenges, but the strong basis provided by years of counselling, encouragement and life skills development at Zvandiri stands the beneficiaries in good stead. Likewise, the training and skills development of health providers in the public and private sectors enhances their capacity to address their patients’ needs as adults, sexual partners and parents preventing onward HIV transmission.

Zvandiri: Supporting HIV positive children, adolescents & young people in Zimbabwe through the HIV care continuum
Case Study 5:
Family challenges

EG, who acquired HIV perinatally, was first diagnosed with HIV when she was 10. Her mother died when she was eight years old, probably of HIV, and she did not know her father. She lived with her maternal aunt. EG was referred to Zvandiri following her diagnosis, and she was assisted with payment of school fees and school uniform. She was an active member of the Zvandiri support group in her local community and was committed to doing well at school.

EG did well on ART initially and was healthy and growing well, attending the clinic every three months until the age of 16. At this point she dropped out, missing clinic reviews and not collecting her ARVs. The clinic nurses contacted Zvandiri because they could not reach EG by phone, and they knew she had been attending a Zvandiri support group. The Zvandiri outreach team visited her home and learnt that she had left and moved in with her boyfriend. The team located her and established from EG that she did not want to take ARVs any more as: ‘I have been taking these for too long and I am bored. I want to be like my friends who don’t take medication.’ She wished, like her peers, to get married and have children. She had not disclosed her HIV status to her boyfriend and was terrified he would leave her if he found out. ‘There is no way I can tell him, he will leave me. He loves me. I can’t tell him.’ She said that this was the first time in her life that someone had loved her.

EG was counseled by the Zvandiri team, working in close collaboration with her clinic. With support, she disclosed her HIV status to her partner and, with regular couples counselling, they remained together. She committed to adhering to her ARVs for her own health and to prevent transmission to her partner. They were counseled about condom use and PMTCT and she was treated for genital warts. Her viral load was monitored and, when undetectable, they stopped condom use and she became pregnant. She was supported through pregnancy but the couple experienced considerable pressure from the partner’s mother who refused to accept the relationship. She said her son should not be with an HIV positive girl and described their child as a curse. Traditional medicine was brought to the couple to be used to cleanse the baby of HIV. EG struggled to breastfeed and daily home visits were conducted to assist her with feeding, adherence to her medication and to cope as a new mother. However, she was also under considerable pressure from her partner’s mother who provided conflicting advice. EG would try to breastfeed at Zvandiri but then go home and be expected to use milk formula and traditional fluids. The formula was supplied by the partner’s mother, but EG was instructed to dilute it to make it last. EG’s partner was very supportive and tried to do the right thing, but he felt trapped between his mother’s and the clinic’s contradictory advice.

The baby became malnourished and suffered from burns to the legs, following an accident with the traditional ‘muti’ which required steaming. She developed diarrhoea and, at eight weeks of age, sadly passed away. Her DBS result was negative, confirming that PMTCT had been effective. A combination of community and clinic interventions had assisted her in preventing HIV transmission. However, the myriad of social pressures had still led to tragedy for this couple and their infant.

The Zvandiri team continued to work with EG’s clinic to support her with grief and bereavement counseling, family planning and adherence support. She was recruited into the vocational skills training programme and the couple then tried for a second child. Zvandiri also provided information and counseling for the partner’s mother. She is reported to be supportive now and to accept the new baby. The couple remain happy together and, at the time of writing, they have a healthy, HIV negative two year old girl. Zvandiri is working with EG to assist her to set up her own income generating project.
Caregivers and the family

Benefits for caregivers include:
- Improved knowledge and understanding about HIV
- Reduced fears of infection
- Healthier children and adolescents – fewer needs, illness and costs
- More support from the HIV positive child/adolescent in the home and for the future
- Improved capacity to cope appropriately
- Reduced isolation and stigma.

Many caregivers are loving and supportive throughout, even if they may lack information or insight as to how best to assist a child or adolescent with HIV. They may hide the HIV diagnosis to spare the child from experiencing stigma and maintain strict confidentiality to avoid risks of discrimination. In the resource constrained environment of Zimbabwe, however, meeting extra financial costs of school fees, clothes, food and ongoing health costs are serious issues for many families. Caregivers also need to see that investing in children and adolescents with HIV is not so much a long-term drain on scarce resources till the child or adolescent dies, but a contribution to young people with a future. In a group discussion with adoptive caregivers, several commented that one valued result of Zvandiri support was that their charges were now fit enough to contribute effectively to household chores. Although there could be risk of exploitation, the benefits of reciprocity by the HIV positive adolescent in return for family care is clear. The adolescents do not want to be perceived as, or to see themselves as, a family burden, and it is important for both their self-respect and for acceptance that they are able to contribute. For the caregivers, reducing costs in kind and in money, seeing their charges grow up healthy, knowing the family will not be infected by them, and feeling confident in how they cope, are substantial benefits. They know CATS value them highly.

CATS and other beneficiaries have described positive family experiences but have also described deeply painful experiences of stigma and discrimination first hand. They cited having been made to eat from different plates and being banned from playing with other children in their adoptive families, being bullied or rejected by other children at school, and even being treated as if they were dying and, as a consequence, not worthy of proper feeding or visiting by relatives. One young woman noted: ‘I was staying with my father’s brother’s wife whom I call mother, as usual (in Shona culture). (People) put cat faeces in my glass, in my clothes, in my pants and in my bed. It turned out to be the aunt who instigated it.’ Such experiences led to feelings of isolation, shame, guilt and despair, including suicidal ideation. One, now highly competent and confident young woman commented that before joining Zvandiri, ‘I was not allowed to touch (my adoptive family’s) things – their brooms, dishes, or the tins they used to pour water for fear of contamination. My HIV status was continually thrown in my face and in the end I believed I had no place on this earth, no reason to be alive and I seriously contemplated killing myself. I had no reason to believe I was worth anything. I had lost all my confidence, I was empty.’

‘Because of my status I didn’t have hope in my life and I thought that I couldn’t achieve anything big. These thoughts have gone now because of my experiences with the VST’ (Vocational Skills Training Student, 19 years)

Caregivers commented that the CATS provide information, encouragement, love and respect for them as caregivers, motivation to their charges and that they greatly appreciate both support groups and home visits.

about HIV and AIDS, stigma and discrimination are still fueled by ignorance and unrealistic fears of transmission – such as by shaking hands, sharing seats, blankets or eating utensils, or any scarring on the skin – and ignorance of the treatment now available.

Perpetual denigration, rejection and other psychological or physical violence are likely to have long-term consequences on children’s self-esteem and self-efficacy and their negotiating capacity and decision-making as they grow up. This can negatively affect not just negotiating safe and supportive sexual relationships but also all other areas of competency in adulthood, including parenting and employment. The children and young people at Zvandiri, however, in developing confidence to cope with their own infection and to speak out against stigma and discrimination, develop skills that will stand them in good stead in much wider areas of life than simply coping with HIV infection. The previous case study highlights problematic family relations and the results of ill-informed advice despite Zvandiri and clinic support – but ultimately, with a positive outcome.
Wider needs and benefits

Capacity strengthening for health care providers and the health system

Benefits for clinic staff and health services include:

- Improved track records for successful disclosure, treatment access and adherence and retention in care
- More job satisfaction through greater engagement and better results.

It is clear that support for psychosocial needs, supportive and well-informed caregivers, reduced stigma and discrimination and supportive, youth-friendly health provider attitudes matter greatly for health outcomes, in addition to access and uptake of medication for opportunistic infections and ARVs. Improved treatment outcomes of children and adolescents with HIV are signs that the combined health and psychosocial services are functioning well. The immediate benefit is for the young people, but these improved health results are also meaningful to staff who care about their work and their patients. Zvandiri support through the CATS and the outreach team enables public and private health providers to save time, to work more efficiently and effectively, and to get more job satisfaction through enhanced engagement, skills development and insight.

Health staff training for HIV and AIDS, and particularly for children and young people living with HIV, is essential.
Zvandiri has assisted in the development of five national training curricula, and ALHIV have contributed extensively to training programmes. These include training health providers nationally in: HTC for Children; the National Integrated HIV Curriculum; the two-week Advanced HIV Management course run periodically by the MoHCC (810 nurses, doctors and counsellors from the public and private sectors were reached by end of 2013); Adolescent Sexual and Reproductive Health, and Zvandiri’s three-day ALHIV training. The latter reached 168 nurses and primary counsellors from MoHCC who now supervise the 40 trained CATS in Manicaland, Bulawayo and Midlands.

As part of the training, CATS share their personal stories and perceptions, their lived experience of growing up with HIV, and discuss their work as CATS. Using group discussion, short video clips and other media they are able to highlight how they have coped themselves, and how they have addressed issues such as disclosure, loss to follow up, adherence support and retention in care, including their experience in support groups for beneficiaries and caregivers. Anecdotally these sessions are reported to be transformative introductions to the multiple stressors HIV positive children and young people face and the type of support they need, changing health providers’ perceptions, understanding and commitment to act. One doctor commented, ‘This opened my eyes. What we have been doing is not nearly enough’. End-of-course evaluations also indicate positive learning and attitudinal outcomes. Follow-up in-service training and review would corroborate if these are lasting results over time and indicate where further reinforcement is needed.

The benefits of health provider training and mentorship are also visible in concrete changes in practice, with clinics becoming more youth friendly through, for example, changed provider attitudes, changed clinic opening times, and use of materials disseminated by Zvandiri. In Gweru, training led to the initiation by staff of review days for children and adolescents, an approach that could be replicated widely in the country. They then went on to establish support groups linked to each clinic and a CATS team has been trained and mentored in Gweru.

‘Most important is the role of CATS in training doctors and nurses in the National Advanced Training Course at Newlands. Their eyes open. One doctor on the course stated: ‘I never realised that’s what children think. I never realised that my manner was so important when treating children.’”’ (Trainer, Newlands Clinic)

‘Zvandiri brings in a change of attitudes among service providers…. In some hospitals… the doctors allow CATS to visit their peers in hospital – professionals are seeing the value of peer participation.’ (Health Care Provider, Manicaland)

Operations research in Gokwe District, Manicaland
An operations research study is currently being conducted in a rural community in northern Zimbabwe in order to demonstrate more rigorously the effectiveness of the CATS intervention on linkage and retention in care, adherence and psychosocial well-being amongst adolescents with HIV. Additionally, research is needed into the cost effectiveness and cost benefit of clinic-linked community support groups and home visits by CATS. Zvandiri could research rates of loss to follow up, treatment adherence and transition to second-line drugs among adolescents in Zvandiri-supported clinics and matched unsupported clinics. A significant difference would indicate likely increased treatment success and measurable cost savings for treatment and HIV prevention over time.
Zvandiri staff, adolescents and young people have contributed extensively to policy and guideline development at international, national and local levels, including participating in an expert panel of the World Health Organization (WHO) to develop international testing, counselling, treatment and care guidelines for adolescents. The guidelines describe best practice models from around the world, of which Zvandiri is one. Zvandiri is at the forefront of demonstrating how young people living with HIV can actively contribute to holistic care, the benefits of community-clinic bilateral referral, and the importance of psychosocial well-being and mental health for effective HIV and AIDS management.

At national level Zvandiri adolescents and staff have contributed actively to several national strategies and guidelines, attending national paediatric and adolescent fora, stakeholder meetings and inputting into draft documents. In 2008 they supported MoHCC to develop HIV testing and counselling guidelines for children and the subsequent revision of these in 2014, and in 2010 psychosocial support guidelines for adolescents living with HIV (ALHIV). They have contributed to life skills, sexuality and education guidelines and the teacher training curriculum within the education sector; to adolescent sexual and reproductive health guidelines; and, in 2014, they supported the revision of the National Treatment Literacy Manual and the National Operational and
Weekend children’s review days in Gweru clinics

After Zvandiri training for staff in 2012 and 2013, Gweru City Council co-organized regular support groups and children’s review days during school holidays and weekends at three clinics. The Senior Nursing Officer reported: ‘Children have a day of fun when they visit the clinic, they get involved in games, face painting with Donna Donna the clown, drama, poetry, music and dance, then they are served with refreshments before they collect their drug supplies…. The (children) have become friends of the clinics and all the fear and anxiety of visiting the clinic has been removed.’ The children make friends with each other, their caregivers have a chance to ask questions and to share experiences, and the nurses provide more individualized care without the pressure of seeing other patients.

The indirect benefits of these review days include garnering the interest of other organisations that can contribute funding and other support, and a general raising of awareness in the community. Local counsellors have attended special days and promised support for future activities and potential support from the Mayor’s Christmas Cheer Fund. Local NGOs such as MASO (Midlands AIDS Support Organisation) and All About Love Trust (that works with youth) are now engaged with the clinics to provide additional psychosocial and other support.

Service Delivery Manual. They have also produced their own guidelines on counselling adolescents regarding relationships and families, training curricula on prevention, treatment, care and support for adolescents with HIV, counselling tools and the Zvandiri Toolkit. Members of both health institutions and community organisations have undergone training on its use, and 200 copies of the toolkit are being distributed to those working with Africaid.

The MoPSLSW is finalising a national case management system to strengthen coordination between various systems of support, such as education, social welfare, health and child care. Zvandiri, UNICEF and other partners have been involved in developing this system and Zvandiri will contribute to its effective functioning in line with its own aims of well-coordinated support to address multiple needs. In 2014, Zvandiri is providing technical support to the MoPSLSW in mentoring its community case care workers and probation officers with the aim of strengthening the prevention and response to child protection violations amongst children with HIV. This echoes the importance Zvandiri accords to a holistic approach specifically to care for children and young people with HIV. An empowering approach is also widely applicable to other vulnerable children and young people with wide-ranging needs, and whose self-esteem and coping capacity are low. Zvandiri is reaching out to HIV positive young people with HIV-related impairments and disability, those living on the streets and those in conflict with the law, including those in juvenile detention, remand or prison.

Advocacy and creating awareness

Zvandiri undertakes public awareness work and advocacy in many different fora and through imaginative channels. For example, Zvandiri adolescents are involved in Junior Parliament and in youth networks, appear on radio and television programmes, and undertake awareness work with diverse community organisations. From 2011-2013 a national advocacy team of 40 was established comprising 10 youth members each from the four provinces that Zvandiri covers. This team produced advocacy ideas that led to national and international advocacy campaigns including for HTC for children, disclosure, treatment adherence and reducing stigma.

Zvandiri has developed many examples of innovative awareness creation and advocacy. Beneficiaries have turned drug packaging into art by making plastic flowers from their recycled ART bottles that are used on a sculptured tree of life in Zvandiri centres. They have contributed to articles for Zimbabwe daily newspapers and other publications highlighting their

‘As teachers, I feel we are also the perpetrators of stigma and discrimination… through these information sharing sessions and advocacy efforts, I am beginning to appreciate how I have contributed to stigma in my school… let’s continue working together and bury this stigma for good!’ (Teacher, Harare)
personal experiences, in addition to producing their own publications including ‘Zvandiri News’ magazine. Jointly with the ‘Superband of Zimbabwe’, and using the funds from the Auxillia Chimusoro Award, they have produced a song and dance DVD called ‘How to Dance’, submitted to the International AIDS Conference, Melbourne, in mid-2014. This was performed at the Harare International Festival of the Arts, HIFA, in April the same year and the song is available on YouTube: by May 2014 it had had over 10,500 hits. The DVD has also been shown internationally, for instance at WHO Geneva on World AIDS Day 2013, and at the 2013 ICASA Conference in Cape Town. Five hundred copies have been distributed to raise awareness amongst schools, clinics, communities and policy makers.

In addition to ‘Our Story’ mentioned in an earlier section, another publication, ‘Red Ribbons and Roses’ provides personal anecdotes and insights in rhyme and text of beneficiaries’ experiences in relationships and families, illustrated by beneficiaries with artistic skills.

In 2010, Zvandiri mounted an exhibition in the National Art Gallery, Harare, the Audacity of Hope. The aim was to strengthen people’s understanding and awareness of the needs of HIV positive children and adolescents in Zimbabwe and to advocate for continued access to treatment, care and support. The exhibition displayed HIV positive children’s art and stories and was seen by 146 service providers and nearly 700 children. The contributors shared their stories of how HIV testing and counselling, disclosure and access to treatment, care and support had affected their lives, turning despair into health and hope for the future. The exhibition and linked commentary are captured in a DVD that has had wide showing.

In 2011/12 Zvandiri beneficiaries and other school children designed an advocacy campaign to challenge stigma and discrimination in schools. In 2013, with Ministry approval, the Bury Stigma, Resurrect Love campaign reached nearly 43,000 students and 45 teachers in 34 schools across 16 districts of Harare, Manicaland and Midlands. As well as aiming to reduce stigma and discrimination, the campaign encouraged early HIV testing and promoted adherence to medication, giving hope to those living with HIV.

In 2011, a movable ‘children’s graveyard’ display was developed for the National HIV Conference. An area was set aside for numerous placards on which delegates wrote the names of children and adolescents who have died of AIDS, and related messages as
on a tombstone. This created a powerful visual image of loss, drawing attention to the need for improved paediatric and adolescent HIV and AIDS care.

In 2013, Zvandiri joined in the launch of the national consolidated treatment guidelines. A beneficiary was on the panel alongside the Deputy Minister of Health and Child Care. She advocated for HTC, treatment, care and support for children, adolescents and young people living with HIV before launching ‘How to Dance’. The Deputy Minister commented, ‘Zvandiri, you have really shown us how to dance in the storm’.

Zvandiri beneficiaries have addressed a number of leaders and dignitaries including Graça Machel, the First Lady of Zimbabwe Grace Mugabe, Government ministers, the Executive Director of UNICEF and the Former President of Ireland, Mary Robinson.

These and other awareness and advocacy initiatives are helping put Zvandiri on the map and flag the urgency of providing holistic care for HIV positive children and young people throughout the country – and the region. Gradually they impact on entrenched stigmatising attitudes and behaviours and promote support and enlightened approaches in health facilities, schools, churches and communities at large, although more is needed.
How to Dance

In 2013, Africaid was awarded the PEPFAR-funded Auxilla Chimusoro Award. This enabled Zvandiri adolescents and young people to create their own song and dance video describing their life experiences growing up with HIV and how they have learned ‘to dance in the storm’. Led by Zimbabwean musician Rina Mushonga, and joined by other world-class Zimbabwean artists, they created a vibrant product. This is the first time that young people in Zimbabwe, perhaps globally, have spoken out about their HIV status in such a way.
Conclusions, challenges and the way forward

Zvandiri secures multiple benefits for its young beneficiaries and also for their caregivers and for over-stretched health professionals, with potentially much wider benefits for managing the HIV and AIDS epidemic as a whole. The programme helps make health services more efficient and effective by strengthening uptake of HIV testing and counselling and linkage to services, reducing loss to follow up and ensuring intensive adherence monitoring, as well as changing health provider attitudes and building their skills to provide strong youth and gender friendly services. By strengthening disclosure, treatment access and adherence and retention in care, Zvandiri contributes substantially to HIV positive health, dignity and prevention as part of wider sexual and reproductive health benefits, as well as improvements in mental health. In turn, these can generate substantial cost benefits and cost savings over time through fewer new infections, and reduced occurrence of drug resistance and subsequent treatment failure. More broadly, Zvandiri also contributes to advocacy, raising awareness and challenging stigma and discrimination in schools, clinics, churches and the community at large, as well as developing and contributing to policy and guidelines and training. Nonetheless, many challenges remain to be addressed, including bringing the present services and support to scale with continued high quality and intensity.

The evolving experience of Zvandiri lends itself to ongoing development and wide replication, with potential to expand nationally in Zimbabwe and beyond its borders, and to influence programming with other cohorts of vulnerable children and young people. Its outcomes and impacts need further quantitative as well as qualitative documentation and analysis that is currently being planned. Long-term follow up of graduates from Zvandiri will further elucidate lasting results for not just these young people, but the future, increasingly AIDS-free, generation born to HIV positive parents.

Several significant lessons can be drawn from the Zvandiri experience.

a) The theory of change has proved a useful framework for the development of the Zvandiri programme, encouraging flexibility to respond to underlying and evolving assumptions about how change happens and how to overcome the barriers impeding progress towards the programme goals.
Continuing challenges

- Meeting the needs of especially vulnerable children and young people born with or at risk of acquiring HIV – e.g. juvenile offenders, children with disabilities, children living on the streets, child-headed households, those who are orphaned, mobile, displaced, homeless, abused or trafficked; sex workers, the poorest, addicted, boys or young men having sex with other males, children in residential or other institutional care

- Health system constraints: in staffing, facilities, provider attitudes, lack of youth and gender friendliness, access, fees, supplies, waiting times in crowded facilities

- Limited availability of antiretroviral treatment options for those failing first and second line regimens

- Continued widespread stigma and discrimination

- Continued information gaps and some traditional beliefs, myths

- Education system insensitivities and discrimination

- Judgmental attitudes by some churches, faith organisations and others

- Depth of psychosocial impairments, chronic depression, anxiety, grief and bereavement and low esteem; and of physical impairments and disabilities

- Long-term tracking and providing evidence of results

- Finance for nationwide expansion and sustained programming with continued high quality of service.

b) It appears feasible, cost beneficial, and sustainable to develop a holistic continuum of psychosocial and clinical care for HIV positive children and young people in resource constrained settings, leading to multiple health and psychosocial benefits and greatly improved treatment outcomes. The long-term sustainability of these findings needs to be carefully assessed.

c) Peer-led initiatives are of substantial direct benefit to the young people providing the services (e.g. CATS) as well as to the children and young people they support, the caregivers, health staff and wider communities.

d) Providing low level finances widely among young people as CATS is a cost-effective and potentially cost-saving investment because of the earlier identification of HIV positive children and adolescents and their enhanced retention on treatment as they grow up. Reduced treatment failure and delayed need for second-line drugs (let alone third-line) represent enormous cash savings over time as well as contributing to HIV prevention as HIV positive young people become sexually active. These outcomes need to be more closely quantified and evaluated over time.

e) The MoHCC and health providers in public and private practice have shown strong interest in engaging with the Zvandiri programme, responding positively to training and mentorship opportunities. They appreciate how trained HIV positive young people can address psychosocial and monitoring
needs of their peers to promote HTC, linkage to care, disclosure, treatment adherence and retention in care, psychological and mental health and also lead to wider sexual and reproductive health benefits.

f) Clinic-community-clinic bilateral referral for a holistic continuum of care has proven mutually beneficial, both reducing time demands on busy health staff and leading to more efficient and effective practice, while providing many benefits for their young patients, including linkage to child protection services.

g) The peer-led approach is a model that can potentially be expanded into many other areas of child and adolescent need, including for those with disabilities, street children, survivors of abuse and those in juvenile detention centres, remand homes or prison and other especially vulnerable children and adolescents.

Support is needed for sustained livelihoods for young people living openly with HIV in severely resource constrained environments; this could lead to multiple benefits not just for them, but also in the normative value of positive role models and advocates to reduce stigma and discrimination. Retention of graduated CATS might be one cost-effective opportunity to expand the programme and make optimal use of their unique capacity to contribute to effective treatment, HIV prevention and psychosocial support, as well as training, co-supervising and supporting new CATS.

Finally, more systematic quantification of results over time is needed to demonstrate further the cost benefits of Zvandiri’s holistic approach, and to elicit sustainable funding for scale up, including investigating the potential to reduce reliance on donor funding in the long run.
### Community Support Groups

- **2004:** One support group for 6 young adolescents (beneficiaries) with HIV in Harare
- **2005:** 14 community groups (beneficiaries: n=70) in Harare
- **2006 onwards:** 20 community support groups across 8 districts in Harare and Chitungwiza, meeting monthly (beneficiaries: 2006 n=160; 2007 n=368; 2008 n=440; 2009 n=413; 2010 n=507; 2011 n=589; 2012 n=994; 2013 n=1,172)
- **2011:** Provincial scale up – 10 support groups established across 10 districts in 3 provinces outside Harare (new support groups: 2011 n=3; 2012 n= 5; 2013 n= 2)

  112 (70%) of the 160 YPLHIV attending in 2006 still attending the groups by 2014; drop outs: death 9; moved out of Harare 13; graduated with age 16.

  Overall 200 YPLHIV have moved out of Harare; 5% have since joined support groups elsewhere as provincial scale up developed

- **2013:** Support group in Harare for HIV positive young parents enrolling 19 mothers and 2 fathers, ages 16-23

### Community Outreach Team

- **2005:** One volunteer counsellor for support groups and home visits: 155 home visits for 48 YPLHIV
- **2006 – 2010:** Part-time team expanded to 9 staff: 2,631 home visits for 1,200 YPLHIV

  By 2011: A full time, multidisciplinary community outreach team of HIV clinician, paediatric/adolescent HIV nurse, two counsellors and one social worker: 9,617 home visits for 2,503 YPLHIV in 2011, 2012 and 2013

### CATS

- **2009:** First 10 CATS recruited and trained in Harare and Chitungwiza increased to 20 CATS by 2013
- **2013:** 40 CATS trained in 3 additional provinces (Bulawayo, Manicaland and Midlands) and a system for peer to peer support, remote monitoring and supervision established

  From 2009 to 2013 CATS have conducted 14,074 home visits in Harare, of which 12,248 were for adherence support or follow up

### Zvandiri centres

- **2006:** Zvandiri House first training and support centre established

  By 2013: 4 clinic based Zvandiri centres. Average of 117 children and adolescents make at least 2 visits to the Zvandiri centres every month

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**Annex 1: Zvandiri programme data**

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| **IEC materials production** | 2006: Our Story – a book by children and adolescents describing personal experiences and providing information for YPLHIV: 21,000 copies distributed 2006 – 2014 Our Story books distributed to clinics, schools, communities, stakeholders across all 10 provinces. 2nd edition currently in development; available online for download in 2014  
2010: Our Story game (card game relevant to HTC, disclosure, ART counselling), 300 copies distributed, used in 28 clinics in 4 provinces 
2011: Red Ribbons and Roses, personal stories, sketches and poems: 600 distributed to YPLHIV, organizations, health institutions, donor agencies and government departments in Zimbabwe (Manicaland, Harare, Midlands and Bulawayo) and Lesotho 
2012: 12 My Story ‘digital story telling’ films by 12 HIV positive young people as a therapeutic intervention 
2014: 200 sets of the Zvandiri Toolkit produced for distribution to partners including health institutions and CBOs working with Africaid |
| **IGPs**                 | 2011 to date: 140 youth trained in a vocational skill and being mentored to establish their own IGPs. To date, 7 IGPs have been established |
| **Advocacy teams and events** | 25,243 children (male: 12,122, female: 13, 121) have been reached with comprehensive information sharing sessions on HIV/AIDS prevention, testing, treatment and care 
2010: Audacity of Hope Exhibition held in the National Art Gallery, Harare, to celebrate World AIDS Day, reached 146 service providers and policy makers and 692 children; launched by the Zimbabwe Minister of Health and Child Welfare 
100 Audacity of Hope DVDs produced and distributed to funding and technical partners using various platforms 
2011-2013: National Advocacy Team – comprising young people selected for 3 years to represent their peers on the Africaid national advocacy platform. Campaign ideas converted into national and international campaigns including: series of newspaper articles for the national press: The Herald (readership: 2,791,597) and The Daily News (readership: 1,395,798) as precursors to campaigns, focusing on e.g. HTC, stigma, SRH and ART 
CATS are involved in 5 national networks and fora: 2 for young people and HIV including the Junior Parliament (Zvandiri has provided training on ALHIV for Youth Parliamentarians since 2009); one for prevention, treatment and care; one for adolescent sexual and reproductive health; and one for child protection 
2013: Bury Stigma, Resurrect Love campaign reached 42,941 (male: 20,697, female: 22,244) students and 45 teachers in 34 schools across 16 districts in Harare, Manicaland and Midlands, focusing on stigma reduction and creating more supportive environments in schools |
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<td>2013: How to Dance DVD released on YouTube with 10,243 hits by May 2014, launched at Harare International Festival of the Arts (HIFA) April 2014; 500 DVDs distributed to artists, service providers, funding partners and relevant government departments; shown at launch of Zimbabwe’s 2013 National ART Guidelines, on World AIDS Day 2013 at WHO Geneva and at the 2013 ICASA conference in Cape Town, South Africa</td>
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**Capacity development**

Africaid was integral to development of 5 national curricula: HTC for Children; Adolescent Sexual and Reproductive Health; Adolescents Living with LHIV; Integrated HIV/AIDS Curriculum; Advanced HIV Management Course

Training 235 health care workers in HTC for Children; 180 HCWs in the National Integrated HIV Curriculum; 810 HCWs from the public and private sectors on the Advanced HIV Management Course, training 34 institution heads and probation officers from residential care homes, including for children with disabilities, and correctional services on care and support for children and adolescents with HIV

Training 77 religious leaders from different denominations on prevention, treatment, care and support services
### Direct benefits

#### 2.1 Improved morbidity and mortality, sexual and reproductive health, psychological well-being (including resilience, confidence, self-esteem, self-efficacy)

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<th>Quotes</th>
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<tr>
<td>KI 12 (HCW): ‘Support groups have been very important in getting kids back into clinic care and medication adherence.’</td>
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<td>FGD 1 (CATS): ‘When attending the support groups, seeing peers like me was a motivation to take my medication.’</td>
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<td>C: ‘Thank you so much (Zvandiri) for accompanying me to Marlborough Clinic for counselling and collecting my medication. I had already given up on this… thought I was going to die.’</td>
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<td>KI 7 (health care provider): ‘CATS are an effective means of changing mind sets because they are building a positive attitude to life in the youngsters, and positive values…. Nurses see the change in better adherence, less fear.’</td>
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<td>KI 10 (pastor): ‘The Zvandiri model is a very good approach, it increases confidence and adolescents are helped… (particularly) with disclosure, adherence.’</td>
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<td>KI 1 (ALHIV): ‘I want to have children, I want to take care of children who are HIV positive, I don’t want them to feel like I did. I grew up an orphan and it was tough.’</td>
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<td>KI 2 (CATS): ‘Zvandiri gave me the knowledge of how to live positively, how to disclose to partners when the right time comes; it also helped me to realize that I am not alone.’</td>
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<td>FGD 7 (MoPSLSW, UNICEF): ‘The model is part of a wider approach to child protection in general…. The Ministry … (wants) national systems and scalable models… seven thematic areas that include HIV, but the strength and resilience needed for HIV are the same as all children need to survive.’</td>
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#### 2.2 Improved children’s agency

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<tr>
<td>FGD 7 (MoPSLSW and UNICEF): ‘Zvandiri has inadvertently become an intervention that tackles some of the structural drivers of HIV…. The kids who have HIV have no power and they are getting it back through (Zvandiri), and that power is going to help them throughout all aspects of their life.’</td>
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<td>C: ‘Because of my status I didn’t have hope in my life and I thought that I couldn’t achieve anything big. These thoughts have gone now because of my experiences with the VST (Vocational Skills Training) Programme.’</td>
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<td>A: ‘I used to be so shy and intimidated by talking to other people, but now I can talk to anyone without fear.’</td>
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<td>KI 13 (CATS) ‘I am a motivator for other people’s lives…. Being a CATS is helping them to see that there is life and there is hope. I am an example…. (Being a CATS) helps me cope with my own status and makes me realize that I have something greater in me that I can share with my peers. I still have hope and dreams that need to be fulfilled. Being a CATS is a platform for me to understand myself better. It has empowered me a lot… I have gained a lot of confidence and I know there is more to life. I can speak about my status to anyone.’</td>
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<tr>
<td><strong>Direct benefits</strong></td>
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<td><strong>2.3 Improved health care systems</strong></td>
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<td><strong>2.4 Reduced stigma</strong></td>
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<td>Direct benefits</td>
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<td><strong>2.5 Improved socio-economic status</strong></td>
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<td><strong>2.6 Improved family communications / parenting</strong></td>
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*Note: FGD and KI refer to focus group discussions and key informant interviews respectively, mostly conducted in February to March 2014*
Annex 3: References and materials

References


xviii Willis N (2013) Adolescents with HIV speak out against stigma and discrimination. Research Watch, UNICEF.

Publications citing Zvandiri


Zvandiri products and publications

Zvandiri Toolkit (a pack including training modules, guides and tools)

Resources available for download at www.africaid-zvandiri.org

- The Zvandiri guide to relationships and families for young people living with HIV
- Our Story book
- Red Ribbons and Roses book
- How to Dance
- The Audacity of Hope film
- Disclosure, film by Modesta
- Stigma, film by Loyce
- The Zvandiri online support group
- Bury Stigma, Resurrect Love poster