



# SUPPORTING SCHOOL-AGE CHILDREN LIVING WITH HIV AND DISABILITY IN ZIMBABWE

EVALUATION OF THE HIV AND  
DISABILITY IMPACT MITIGATION  
PROJECT OF AFRICAID

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## Introduction

Antiretroviral treatment (ART) for children living with HIV initially lagged far behind that of treatment in adults, although the situation has improved significantly in recent years.<sup>i</sup> The prevalence of disability in children and young people living with HIV was also insufficiently recognised with, consequently, inadequate provision of medical, rehabilitative, educational and psychosocial support for those in need.<sup>ii</sup> <sup>iii</sup> The heightened risk for impairments in children with HIV arises from opportunistic infections such as frequent eye and ear infections affecting sight and hearing, infections impairing neurodevelopment, motor and breathing difficulties, stunting and other concerns. Some impairments arise from side effects of treatment, as well as from causes independent of HIV status, and further investigation is needed. That HIV positive children have significantly higher rates of impairment than HIV positive counterparts has, however, been clearly demonstrated.<sup>iv</sup> <sup>v</sup>

Early HIV diagnosis, and early detection, treatment and rehabilitation for impairments are essential to reduce the risk of infections and impairments becoming life-long disabilities<sup>1</sup> in a cohort already experiencing multiple other challenges from their HIV positive status<sup>vi</sup>. A multi-sectoral approach, with early detection and referral of children with impairments, can make an enormous difference to their self-esteem, agency, educational opportunities, and to their long-term quality of life.

The Zvandiri programme of Africaid, Zimbabwe, is an evidence-based, multi-component differentiated service delivery model for children, adolescents and young people living with HIV (CAYPLHIV) in Zimbabwe, that integrates peer-led, community interventions within national differentiated service delivery. Since 2004, Zvandiri has evolved from one support group in Harare into a comprehensive model, combining community- and clinic-based health services and psychosocial support for CAYPLHIV. Figure 1 shows the theory of change for the Zvandiri programme into which the HIV and disability project was integrated as an essential component.



1 Impairments are defined as developmental, motor, physical, sensory or mental problems that alter someone's ability to function in some way, risking the loss of social, educational, work and other roles and life chances, defined as handicaps. In this paper, the terms disability and impairment are used interchangeably.

Figure 1: vii

# ZVANDIRI Theory of Change

## Context

Poverty  
Orphaning  
Stigma  
ART gap  
Food insecurity  
Disability  
Economic environment  
National / Global Policy

### Medium term (*Indirect Influence*)

- Multi Sectoral awareness of needs of CAYPLHIV, including disability
- ALHIV involvement in policy development
- Integration of CAYLHIV in national training curricula
- Integration of Zvandiri approaches within the national health, rehab and social services system

### Short term (*direct influence*)

- Child:** improved engagement in the continuum of care; reduction in rates of virological failure and psychological distress, improved management of impairments
- Family:** Supportive home improvements
- Community:** Supportive environments, (reduced stigma, linkage to services)
- Services:** Enhanced DSD and multi-sectoral service delivery

### Programme Sphere of control

Early diagnosis, early disclosure, early ART initiation, improved linkage and retention with treatment and care programs, improved adherence, early identification of impairments and referral, enhanced positive health, dignity and preventions, improved service delivery

## Long term (Lasting)

Children adolescents and Young people living with HIV with full physical, social and mental well being

### Possible indirect benefits

More child/ adolescent friendly policies  
Patients treated with more dignity and respect

### Direct benefits

- Improved morbidity and mortality, sexual and reproductive health, psychological well-being (inc resilience, confidence, self esteem, self efficacy)
- Improved children's agency
- Improved children's agency
- Improved functioning
- Improved health care systems
- Improved socio-economic status
- Improved family communications/ parenting

### Outputs

Support groups, CATS Teams, Disability CATS, Outreach Team, Zvandiri Centres, IEC materials, IGP, Advocacy Teams, expert Trainers

### Stakeholders Engagement

Children / adolescents with HIV and their families  
Peer Advisory Board  
Multi sectoral (health, rehab, social services, education)

### Assumptions

Stakeholders acceptance of Zvandiri  
Functioning health system,, incl ART  
Functioning education and social services  
Resources and funding

Adapted from **Montague, 2007**

Africaid phased expansion of the Zvandiri programme across Zimbabwe into 51 of 63 districts, reaching 43,856 CAYPHIV by October 2017.<sup>viii</sup> Research studies confirm improved uptake of HIV testing services, retention, viral suppression and psychosocial well-being among adolescents receiving Zvandiri services compared with adolescents receiving standard of care alone.<sup>ix x xi</sup> Taking the model to scale required a positive political environment, government leadership and coordination, standardisation of the model and making strategic choices. Particularly important were nesting the programme within existing services, and capacity strengthening of national, regional and local service providers working jointly with trained, mentored CAYPLHIV called community adolescent treatment supporters, or CATS. The CATS recorded that many CAYPLHIV had repeated infections and impairments, leading Africaid to establish the three-year Zimbabwe HIV and Disability Impact Mitigation Project in Harare in September 2015.<sup>2</sup> Seventeen CATS were recruited and trained, plus two staff members to implement the project. Project evaluation took place from 7th June to 10th July 2018.

### The Zvandiri HIV and Disability Impact Mitigation Project

The project aimed to address the unmet health, rehabilitation, educational and psychosocial needs of HIV positive school age children (6-16 years) with impairments due to HIV or to other causes. The project also sought to address related family needs. Africaid operationalised the project jointly with the three government ministries (health, education and social welfare) and with various disabled peoples' organisations and civil society organisations (CSOs). The catchment area was 23 areas of Harare where the Zvandiri programme was fully operational.

The project had three intended outcomes:<sup>xiii</sup>

**Outcome 1:** Improved access to health and rehabilitation for HIV positive children due to improved knowledge and skills of caregivers and health professionals and networking between HIV and disability services, leading to better physical and psychosocial well-being.

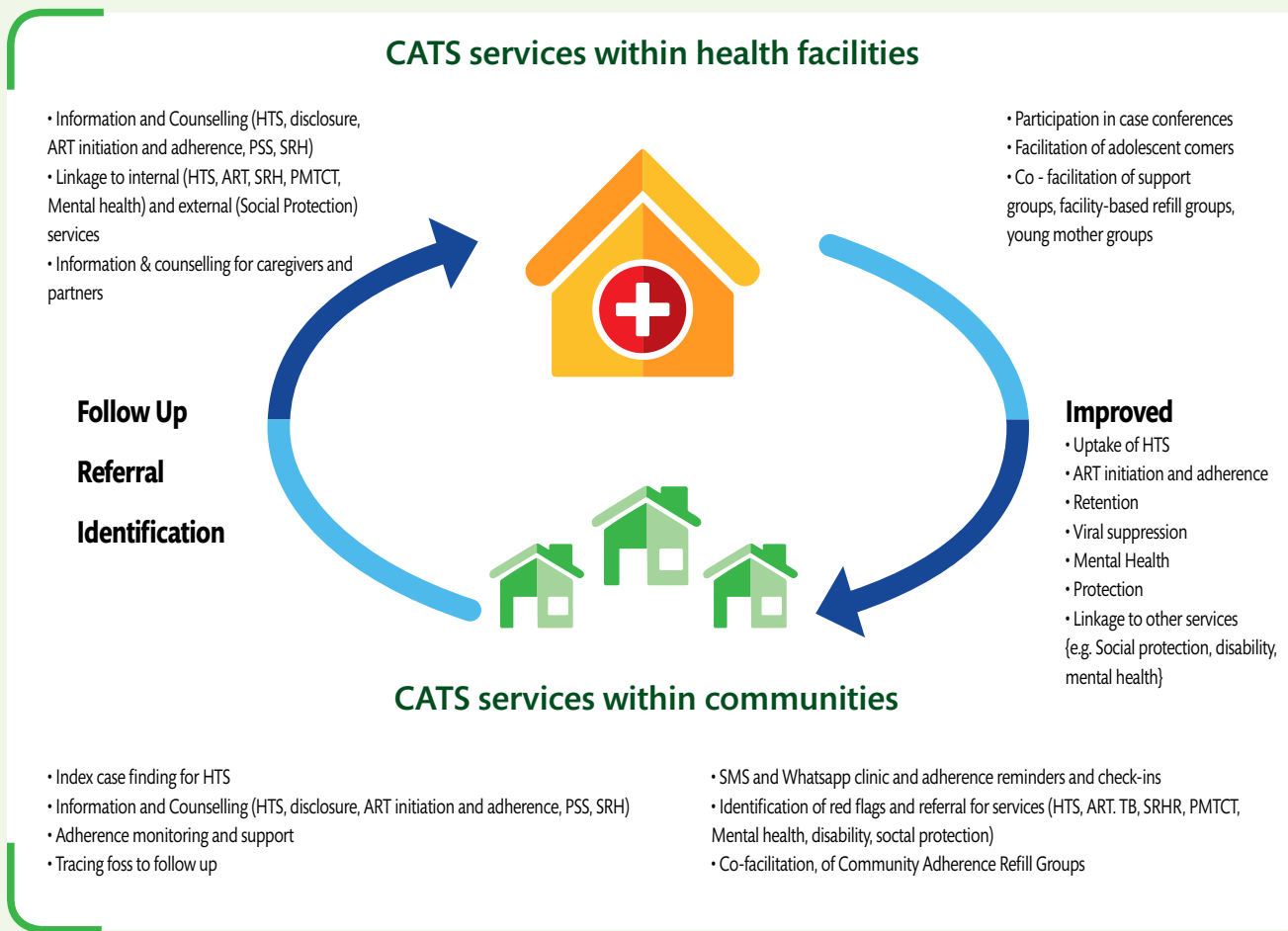
**Outcome 2:** Improved access and quality of education for children living with HIV as a result of improved knowledge and skills of educational and psychological professionals and caregivers about the learning needs of HIV positive children.

**Outcome 3:** Increased awareness of the rights of HIV positive children with disabilities in the target area, with new and strengthened policies and guidelines specific to HIV and disability in children.

The Ministry of Health and Child Care (MoHCC) health services provided medical and rehabilitative care, educational professionals within the Ministry of Primary and Secondary Education (MoPSE) were sensitised and trained on the learning needs of HIV positive children with disabilities, and social workers were sensitised and trained within the Department of Social Welfare (DSW) of the Ministry of Public Service, Labour and Social Welfare (MoPSLSW). CSOs focusing on disability provided technical guidance and other inputs such as subsidised assistive devices and were sensitised on the links between HIV and disability. Caregivers and other community members were also sensitised through self-help groups and other activities, with caregivers informed about rehabilitation and other services available in the community and in health including rehabilitation facilities. The CATS identified CAYPLHIV with recurrent infections and impairments in their catchment areas utilising a screening tool developed jointly with the MoHCC and other project partners. They made referrals for CAYPLHIV in need of services to the respective institutions, accompanied children to services, and provided support and guidance to children and their families, including holding support groups in the community and providing HIV and ART information, counselling and support.

<sup>2</sup> In partnership with Christian Blind Mission, main funding from the Big Lottery Fund, UK, and supplementary funding from UNICEF and Maruva Trust, Zimbabwe

**Figure 2: Zvandiri Service Delivery**



## Methods

The evaluation involved both qualitative and quantitative data collection. This was achieved through semi-structured interviews with key stakeholders in two of the three ministries, CSO partners, lead rehabilitation unit staff, project and other Africaid staff; and focus group interviews (FGIs) with CATS and primary and secondary beneficiaries (children with HIV and impairments and caregivers). Site visits were made to rehabilitation departments at two hospitals, to one clinic, and to one home, and there was extensive document review. Key documents, in addition to published literature, included the project proposal and mid-term review, extensive in-house narrative and financial reports, the project's statistical data base, success stories, and review of a political analysis report.

Data from the various sources were triangulated and analysed to address the key questions of the evaluation and, from the findings, to draw conclusions, identify lessons learned, and to make recommendations. Limitations to the data are noted.

## Results

The findings were highly positive with regards all main criteria of the evaluation. Screening of existing beneficiaries found that 56% had one or more impairments, a far higher proportion than anticipated. <sup>xiii</sup> Figure 3 indicates the relative frequency of different impairments in the cohort identified by CATS during the project.

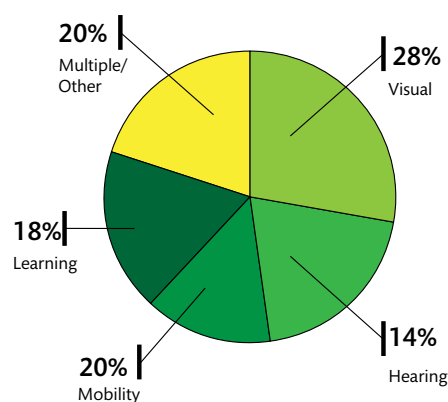
The project exceeded all targets with respect to the number of children assessed, referred and assisted, particularly with respect to early identification of impairments and medical rehabilitation. It achieved the outcomes of: improving the health and rehabilitation of HIV positive children with impairments; improving their educational experience and achievements; and achieving greater awareness of their needs and rights and of the extent of the problem of HIV-related impairments. The latter should contribute to policy changes with particular reference to the Zimbabwe National AIDS Strategic Plan, ZNASP III, and the National AIDS Plan for Orphaned and Vulnerable Children, NAP-OVC II. Prior to the project, baseline information on the extent of impairments in children with HIV within Zvandiri was not available, although CATS had reported children with noticeable disabilities and these had been documented.

Table 1 summarises the findings against the main areas of the evaluation. These were relevance and appropriateness; coverage and effectiveness; efficiency; stakeholder inclusion, networking and partnerships; sustainability of results and contribution to policy change. Gender dynamics and human rights were also taken into account, and the potential for scale up. The evaluation found that almost all targets had been exceeded and that, where they remained behind, rapid catch up activities were in place that would continue after the end of the project. This particularly related to education and the involvement of the MoPSE.

**Table 1: Focal areas of evaluation and main findings and results**

FOCAL AREA	MAIN FINDINGS AND PROJECT RESULTS
<b>Relevance/ appropriateness</b>	<b>Highly relevant and appropriate</b>
	Addressed extensive unmet need: 56% of HIV positive children assessed were found to have impairments.
<b>Coverage</b>	<b>Most coverage targets exceeded</b>
	Children screened for impairment: 1752 against target of 1000 Children referred for rehabilitation plan: 1287 against target of 500. 758 received further management (medical treatment, rehabilitation services, therapy, and/or assistive devices) Health and rehabilitation professionals, peer counselors and caregivers trained on HIV and disability in children: 977 against target of 500 Educational professionals trained in HIV-related needs and disabilities: 332 against target of 350 Primary school-age children assessed for learning barriers: 396 against target of 500 Primary school-age children supported by the project showing improved educational outcomes: 364 against target of 350 # of schools better able to support children with diverse needs: 135 against target of 20 79% of primary school-age children with HIV identified with impairments were supported against target of 70% # of children participating in advocacy activities: 67 against target of 25 # of participants attending stakeholder meetings: 100 against target of 50 # of awareness-raising events: 42 against target of 5
<b>Effectiveness</b>	<b>Highly effective regarding health and functional outcomes and in reported improved school performance and quality of life</b>
	86% of children on a rehabilitation plan reported improved functioning 85% of health and rehabilitation professionals, peer counsellors and caregivers demonstrated increased knowledge and skill in HIV and disability services for children 95% of trained educational professionals demonstrated increased knowledge and skills in supporting children with HIV and disability 84% of primary school-age children supported by the project had improved educational outcomes

**Impairments identified**



**Figure 3: Proportion of different impairments identified in children and adolescents living with HIV**



<b>FOCAL AREA</b>	<b>MAIN FINDINGS AND PROJECT RESULTS</b>
<b>Efficiency</b>	<b>After initial delays, catch up was efficiently achieved in planned activities</b>
	Delays occurred in the timing of interventions, particularly in the first year through funding delays. It also took time to develop effective partner relationships, focal points, and coordinating structures. Subsequently, in all respects (institutional structures, use of funds, project management and supervision, monitoring and evaluation) the project was found to be efficient, with strong coordination and active partner engagement and full expenditure of funds.
<b>Stakeholder inclusion</b>	<b>Highly inclusive of key stakeholders including primary and secondary beneficiaries, ministries and relevant CSOs after the design phase</b>
	Open discussion of issues and involvement in sensitisation and training workshops as needed. CATS and beneficiaries led many advocacy activities, and CATS were central to all training and sensitisation workshops for health care workers and non-health providers in the community.
<b>Networks and partnerships</b>	<b>Effective and appropriate partnerships and coordination networks were developed</b>
	Strategic partnerships were developed with the three key Government ministries, (health and child care, primary and secondary education, labour and social services), and also with civil society organisations involved in HIV and disability work.
<b>Sustainability of results</b>	<b>Many factors leading to likely sustainability of results and of project activities</b>
	<p>Heightened awareness and close involvement of and ownership by the three ministries, with MoHCC in the lead, and focal points and coordination structures in place</p> <p>Heightened awareness of the links between HIV and impairment among health, welfare and education staff, and communities and families, through training workshops and sensitisation and communication activities, advocacy, and support groups</p> <p>Empowerment of all CATS to identify children with impairments throughout Zimbabwe and to make appropriate early referrals and supportive follow up</p> <p>Lasting benefits for the children with HIV and impairments, and their families, directly assisted by the project</p> <p>Disability-orientated CSOs sensitised to consider HIV in their community assessments and support</p> <p>Development and sharing of simple impairment screening tools and of guidelines for future sensitisation workshops, of braille guidance materials and other products</p> <p>15 of 17 project CATS were to be absorbed into Zvandiri after the project ended, one as an intern</p>
<b>Contribution to legal and policy change</b>	<b>Review of relevant legislation, policy, plans and programme implementation</b>
	The review found that, although many acts and policies are in place that can benefit HIV positive children and adolescents, they are uncoordinated and sometimes discrepant, and need revision. The project thus drew attention to the need for legal and policy change to benefit the under-served cohort of HIV positive children with impairments and raised awareness among policy makers and programmers at national, district and community level. However, it did not achieve the aim of mainstreaming disability within national HIV plans within the three-year project duration.
<b>Gender and human rights</b>	<b>Not specifically gendered, but realisation of human rights was integral</b>
	More girls were reached than boys (977 to 775), with the widest discrepancy in the age range 10-14 years (405 girls to 260 boys), perhaps a chance finding. Service provision was proportionately similar between the sexes. CATS included 12 girls to 5 boys as more girls applied. Male and female CATS screened both sexes within their catchment areas and community support groups were not differentiated by sex.

CATS involved in implementing the project commented favourably on how they themselves had grown from being involved.



*'I learned counselling skills and how to empower children to support others regardless of HIV or disability'*

*'I learned that being disabled, people can do things in life, and (the project) changed my attitude to people with disabilities';*



*'I learned the ability to love other children living with HIV and disability, and felt satisfaction from their trust that is even higher than for their parents.'*



They will carry this learning and their positive attitudes into the future and have shared their learning with other Zvandiri CATS.

Despite the significant outcomes of the project, a number of constraints unforeseen in the design phase arose during implementation: the full extent of disability among children living with HIV had not been realised, and the depth of poverty impeding uptake of services; limitations in the coordination between ministries, although this improved, and the importance of bringing all stakeholders on board during project design. Also, it took time to convince health staff less familiar with the work of CATS that they had the capacity to undertake effective screening for infections and impairments that could lead to disability.

Considerable financial constraints face many families and also the various services. High turnover of service staff could threaten the sustainability of results and ongoing training, mentoring and quality assurance are needed. During the project, however, rehabilitation staff commented that they were able to meet the greatly increased demand arising from the project. Insufficiently staffed to undertake outreach activities themselves, they fully appreciated the role of the CATS, particularly in increased referral of adolescents.

Assistive devices were also of serious concern. The Department of Social Welfare is tasked with providing them on client referral from the MoHCC, but lacks the resources to meet the demand. During the project, donors and CSOs stepped in to provide devices at reduced cost or free for impoverished families, and managed to address the immediate needs of almost all project beneficiaries. However, maintaining the devices and providing further affordable devices will remain a challenge.

Numerous other challenges faced the majority of families in meeting basic needs for all their children, including those with HIV and impairments. CATS assisted with practical support in various ways (e.g.

to obtain birth certificates so that the children could attend school, or with transport to services). They also referred those in greatest need to the government Basic Education Assistance Module (BEAM) programme and to other support services, although the extent of assistance was not assessed.

## Discussion

The early treatment of infections and identification and response to impairments to avert disability should be advocated as a rights-focused, cost-effective and feasible way forward, even in resource-constrained environments. As differentiated service delivery models are scaled up to respond to the specific needs of individual CAYPLHIV, now is the time to ensure that services are responsive to those with disability. The utilisation of peers, in the form of trained CATS, has demonstrated an effective model for sustainable scale up and integration of support for HIV positive children with impairments with HIV-related treatment, although various constraints remain. Poverty will continue to be a serious barrier to ongoing service utilisation even when the services are available and, in the impoverished economic environment of Zimbabwe, a risk is that rapidly scaled up screening may incur extensive unmet demand. Advocacy for increased entitlement and exploring different options for the necessary support are essential. Nonetheless, early diagnosis and treatment is a human-rights based as well as a potentially cost-effective strategy long term.

Further review over time will prove the extent to which the gains are sustainable and scalable, but several integral factors suggest the potential for both. Central is that the Zvandiri model, with CATS leading the intervention on the ground, has already demonstrated scalability and sustainability within the overall WHO framework and criteria for scale up<sup>xiv</sup>.

Critical also is the enabling environment generated by the relationships built with and between the relevant ministries, CSOs and other partners, and hence national ownership and institutionalisation of the Zvandiri programme with the additional focus on disability.

A number of general recommendations can be drawn. It would be beneficial to identify children with impairments as young as possible and also to raise the age limit of screening, as many young people with HIV will not have been reached with impairment-related services in the past. For long-term results, the link between HIV and disability should be routinely included in training curricula for health and social workers, education professionals, and community workers including community rehabilitation workers. Collaboration and learning between the various ministries and departments, and with disability- and HIV-related organisations and wider community-based services and structures needs to be strengthened and sustained, with strong community and family engagement.

Further efforts are also needed in relation to the education system, to bring gatekeepers such as school heads on board and to allow CATS to provide sensitisation and awareness sessions within pre-school, schools and colleges for staff and students regarding both HIV and disability. Integrating modules on HIV and disability into the MoPSE curricula would also be of benefit.

## Key Lessons Learned

A number of key lessons were learned from the project evaluation that are of relevance to further scale up and adaptation of the project both within Zimbabwe and in other settings implementing the Zvandiri model or similar peer-led programmes.

1. The extent to which HIV is linked with disability in CAYPLHIV is high and has been underestimated. Active identification in the community and referral of CAYPLHIV with recurrent infections and impairments contributes to the prevention of disabilities through increased service access at an early stage.
2. Engaging trained CAYPLHIV, the CATS, is an effective strategy to identify, refer, support and motivate beneficiaries (children and caregivers) to seek early treatment for infections and to access both HIV- and disability-related services, as well as for ART adherence.

3. Nesting the programme in existing and collaborating health, education and welfare services raises the potential for long-term sustainability and the acceptance of trained CAYPLHIV as valuable contributing partners. It also sensitises health providers when providing ART to explore wider needs than ART adherence alone.
4. Differentiated service models for CAYPLHIV that seek to tailor service delivery to the specific needs of sub-populations of people living with HIV should integrate disability.
5. Early detection in the community and intervention are feasible and cost effective to treat infections and reduce impairments that may lead to long-term disabilities and handicaps. They assist school participation and learning, reduce stigma and discrimination, and build self-esteem, confidence and agency.
6. Poverty remains an overwhelming problem even with the support provided, and mechanisms to assist families need strengthening, including acquiring and maintaining assistive devices and continuing long-term therapy where required.

### Limitations

A main limitation to the evaluation was the tight time frame, restricting the number of interviews, focus groups, site and home visits. This limited direct assessment of the quality of outcomes regarding strengthened capacity of all service providers and primary and secondary beneficiaries, and how effective the training had been (Outcome 2). However, review of reports, interviews with other key informants in disability-related organisations and the MoHCC and MoPSSW, and focus group interviews provided information on the reported benefits of training, social welfare and on the involvement of the education ministry. More in depth quality assurance is needed, especially regarding benefits within the education system. This will require quality assurance undertaken by the ministry itself.

It was also too soon to know the extent to which the review of legislation and policy would contribute to Outcome 3. This, as well as the longer-term influence and benefits of training and sensitisation, should be followed up.

### Conclusions

The project has added to the evidence base of the considerable extent to which children with HIV are at risk for impairments and has shown clear benefits from early identification of impairments, referral and intervention that prevents or reduces the extent of long-term disability. Benefits were seen regarding health, rehabilitation, school participation and learning, stigma reduction, and increased well-being. The project has demonstrated that it is feasible, even in a resource constrained setting, to reach high numbers of children with HIV and impairments in the community and to link them effectively with institutional services. The active involvement of disability-trained CATS within an existing model of differentiated service delivery for CAYPLHIV has demonstrated that this cadre is capable of adding the dimension of disability to their wide-ranging leadership roles regarding HIV and treatment adherence, community and family support. The project has also demonstrated that, through proven results and strong stakeholder inclusion of the relevant ministries and disability-related CSOs, it is possible to gain their trust and support for CATS as a valued part of the overall, integrated response. CATS ensure that the perceptions, needs and values of youth themselves remain at the forefront throughout.

Adding the dimension of programming for HIV positive children with impairments is an urgent and important additional benefit that should be implemented much more widely within and beyond Zimbabwe. The model presented might also be usefully linked with community rehabilitation services for children with disability more broadly, beyond the focus on HIV-related disability, and this should be further explored.

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