Strengthening the identification, management and support of children, adolescents and young people living with HIV and disability

The prevalence of disability in children, adolescents and young people living with HIV (CAYPLHIV) has been insufficiently recognised with, consequently, inadequate provision of medical, rehabilitative, educational and psychosocial support for those in need¹,². The heightened risk for impairments in children living 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 possible side effects of treatment, as well as from causes independent of HIV status, and further investigation is needed. HIV positive children have significantly higher rates of impairment than HIV negative counterparts has, however, been clearly demonstrated³,⁴. 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 in a cohort already experiencing multiple other challenges from their HIV positive status⁵,⁶.

Zvandiri supports the government to strengthen the identification, referral, management and support for CAYPLHIV with disability and their caregivers.

Strengthening the Evidence

• Operations research in Harare found that 54% of children living with HIV and adolescents living with HIV, 6-16 years, are living with disability, following identification and referral by CATS⁴.
• Evaluation of the CATS-led disability intervention found that the engagement of trained, mentored CATS is an effective strategy to identify, refer, support and motivate children and their caregivers to seek early treatment for infections and to access both HIV and disability-related services⁴.

Advocacy

• CATS-led advocacy for the integration of disability within HIV policy, training and service delivery through print and social media, radio, video and television
• Film project led by young people living with HIV and hearing impairment to promote awareness among CAYPLHIV with disability
• Youth-led advocacy for the inclusion of disability within HIV programming at the IAS Education Fund workshop, Harare, 2019

Guidelines, Curricula and Tool Development

• A policy analysis on HIV and disability for children, adolescents and young people, in partnership with MoHCC
• Development of a disability identification tool for CATS to identify and refer CAYPLHIV at risk of disability
• Development of a training curriculum on HIV and disability in children and adolescents for health workers and non-health workers
• Development of a training curriculum on HIV and disability for CATS
• Development of Zvandiri Mentor Standard Operating Procedures to guide the provision of disability services for CAYPLHIV
• Development of the CATS Service Delivery Manual to guide CATS in the provision of disability services - Chapter 9: Supporting your peers with disability
• Adaptation of Zvandiri IEC materials and counselling tools into braille and audio tools
Strengthening the workforce

- Training and mentorship of health care workers and rehabilitation officers to identify, assess, manage and support CAYPLHIV with disability
- Training and mentorship of CATS to identify and refer CAYPLHIV in need of disability assessments, management and support

Service Delivery

- CATS-led identification of CAYPLHIV with disability
- Referral to disability services for further assessment, diagnosis and management, including rehabilitation services and assistive devices
- CATS-led counselling for CAYPLHIV with disability:
  - Use of disability-sensitive IEC materials (Masas’ card game, sub-titled animations, Our Story book in braille)
  - Adherence monitoring and support
- Information, counselling and support for caregivers of CAYPLHIV with disability
- Integration of CAYPLHIV with disability in support groups for CAYPLHIV and in Community Based Rehabilitation (CBR)
- Referral of CAYPLHIV to other clinical, rehabilitation, education and social protection services as needed
- Engagement of CAYPLHIV with cognitive challenges in psychological learning camps
- Financial support for assistive devices and diagnostic procedures where possible

Lessons Learned

- 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.
- 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.
- 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.
- 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. They assist school participation and learning, reduce stigma and discrimination, and build self-esteem, confidence and agency.
- 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.
Results

My child had a challenge of blood coming out of the ears and it’s something that developed when he was still young. I did not know what to do or where else to find help. Zvandiri took my child to an ear specialist and he has since improved. I am happy he can now play with other kids of his age and he can now go to school because he can hear the teacher.

Caregiver

My granddaughter always had pus coming out of her ears. She was always given antibiotics at the clinic, which never worked. I had lost hope. When my child went to Zvandiri in town with others to get her ears checked, she was referred to Harare Hospital to be seen by a specialist of the ear. She was given medication for the ear infection. The problem is not as big as it was before. I am so happy with Zvandiri

Caregiver

Staff are very conscious of HIV and disability. Staff are now more conscious of the need to look out for more disabilities among children living with HIV. The trainings gave a platform for the staff to know the other needs of the children in our care so they can be appropriately assessed and supported.

Nurse

In Hatcliffe a child had a hearing challenge. This child used not to go to school. Zvandiri made sure she got treatment. She is now going back to school

Nurse

The child had a problem of his eyes always red and would sit in front of the class close to the board. I referred him for help and he now has specs and the performance is now improving... the reports show improvement.

CATS

The project enabled the staff to look holistically at disability - improving our service delivery for children living with HIV and disabilities.

CATS

The clinic asked me to follow up on a child who had defaulted. When I got to the home, I found he couldn’t walk. Life was really difficult for him and his mother. I referred him and he now has a wheelchair and comes to the clinic

CATS
Elizabeth’s Story

Elizabeth is a 7 year old girl born with HIV. Elizabeth’s parents are also living with HIV and are on Antiretroviral therapy (ART). She has a younger brother who is HIV negative. Elizabeth started ART when she was 2 years old. She was tested after the parents noticed that she was growing and developing slowly. When Elizabeth was found to have a high viral load, the clinic nurses referred her to a CATS for adherence support. During a routine home visit, the CATS identified Elizabeth as being at risk of disability, using the CATS disability identification tool. The CATS discussed Elizabeth’s case with her supervisor at the clinic, after which the CATS contacted Elizabeth’s mother inviting her to the clinic for further assessment.

Following the assessment, Eliza was confirmed to have multiple disabilities – hearing impairment, leg length discrepancy, left leg and arm deformity and learning challenges. Elizabeth was referred to rehabilitation services, school psychological services and for an audiology assessment. She continued to receive enhanced support from Zvandiri through home visits and during clinic visits— for management of her high viral load and disability. The CATS provided HIV, ART and adherence counselling using visual aids and sign language for Eliza, as well as for her caregiver. The CATS was sometimes joined by the community sister, social welfare officer and staff from Kapnek Trust, a disability-focused organisation. Eliza was encouraged to join the local support group where she integrated with other CAYPLHIV. The CATS used SMS and WhatsApp to send adherence and clinic reminders to Eliza and her mother.

Eliza is now adhering well and is virally suppressed. She has been placed in school and is doing well. She has a wheelchair which enables her to be more independent and she is connected with other children and young people. Her mother has gained knowledge, skills and confidence in caring for and supporting Eliza.

References