Disclosure

Supporting children, adolescents and young people to know, understand and accept their HIV status

Disclosure is the process of informing someone of his / her HIV status and is a key component of paediatric and adolescent HIV testing, treatment and care services. Although younger children may not yet be ready to be informed of their HIV status, it is now widely accepted that early disclosure for older children and adolescents which is conducted in a supportive, planned manner helps to promote HIV and ART literacy, adherence and psychological well-being among children, adolescents and young people living with HIV (CAYPLHIV). National guidelines indicate that the timing and process of disclosure should be guided by the caregiver’s wishes, but that the best interests of the child should be considered at all times. These guidelines are based on the UN Convention of the Child and national Children’s Act which state that every child has the right to information about his/her own health and access to services which keep them safe from harm. However, late disclosure of HIV status remains common; CAYPLHIV with the capacity to understand what is happening to them are being left with limited information about their own HIV status and treatment, resulting in poor mental health and limited ability to understand the importance of ART, adherence and retention.

Zvandiri supports the Government of Zimbabwe to promote child and adolescent focused, quality disclosure services for CAYPLHIV and their caregivers to improve both their mental health and HIV outcomes.

Strengthening the Evidence

- Virological non-suppression is independently associated with not knowing one’s HIV status among ALHIV
- Caregivers of CAYPLHIV receiving Zvandiri services were more likely to inform their children of the child’s HIV status as compared with those not engaged in Zvandiri
- CATS’ role modelling, information and counselling for caregivers, as well as the training and support groups for caregivers, resulted in the transformative effect of a more supportive household for ALHIV and improved caregiver capacity to talk about HIV with their children

Advocacy

- Development of mixed media advocacy campaigns to promote awareness among caregivers, health and social protection cadres, families, communities and policy makers of the rights of CAYPLHIV to timely, child and adolescent focused approaches to disclosure
  - disseminated through radio, social media, TV, newspapers

Guidelines, Curricula and Tool Development

- Technical assistance to the MoHCC in the development of HTS policy and guidelines for children and adolescents, including disclosure
- Technical assistance to the MoHCC in the development of the national HTS for children and adolescents training curriculum including disclosure, 2008 and 2015
- Technical assistance to the Department of Social Welfare in the development of the HIV sensitive case management training curriculum for social welfare cadres, including disclosure
- Development of child and adolescent focused HIV literacy and disclosure counselling tools for children, adolescents and their caregivers, including:
  - Our Story Book, 2008 and 2020 (English, Shona, Ndebele; also translated into braille)
  - Our Story card game; Mfas’ card game;
  - Masas’ film series – Tonde and Tanaka talk about the immune system, HIV and ART – (audio and subtitled)
  - Siyanakekela – a book for caregivers of children and adolescents living with HIV (English, Shona, Ndebele)
- Development of caregivers training manual and support group curriculum, including modules focused on disclosure
- Development of the CATS Service Delivery Manual to guide CATS in supporting children and adolescents to know and understand their HIV status (English, Shona, Ndebele, Portuguese, Swahili)
- Development of Zvandiri Mentor Standard Operating Procedures to guide Zvandiri disclosure services
Supporting Children, Adolescents and Young People to Know, Understand and Accept their HIV Status

Child and adolescent-sensitive disclosure guidance, counselling tools and capacity strengthening for health care workers, CATS, families and CAYPLHIV

Strengthening the Workforce

- Training and mentorship of health care workers to provide child and adolescent sensitive disclosure services and to provide disclosure counselling for caregivers
- Training, mentorship and supervision for CATS to:
  - identify and refer CAYPLHIV in need of disclosure services
  - provide disclosure counselling for caregivers
  - provide post disclosure counselling support for CAYPLHIV
- Training and mentorship of social welfare officers and community case care workers to identify and respond to children and adolescents facing challenges in accessing information about their HIV status

Service Delivery

- Pre-disclosure services including:
  - counselling for caregivers
- Post-disclosure services including:
  - post-disclosure counselling for children and adolescents and their caregivers
  - post-disclosure linkage to support groups
  - check-ins, monitoring and support through WhatsApp, home visits and clinic visits
  - mental health screening and monitoring
- Case conferencing with families, health care workers and social welfare officers for children and adolescents facing barriers to disclosure

Results

Research and programme data confirms that Zvandiri has a transformative effect on children’s and adolescents’ understanding of their HIV status and subsequent adherence and mental health. A combination of approaches has resulted in:

- A child and adolescent focused policy environment to support early, age and developmentally appropriate disclosure to CAYPLHIV
- Improved awareness and understanding among service providers, families and communities of children’s right to full, accurate knowledge of their HIV status in a way that they can understand
- Evidence of the correlation between non-disclosure and virological failure, emphasizing the critical role of disclosure in the HIV cascade for CAYPLHIV
- A multi sectoral approach to supporting CAYPLHIV facing barriers to disclosure, through the HIV sensitive case management system
- Improved capacity of health care workers to provide quality, child and adolescent focused disclosure services
- Improved HIV literacy, confidence and readiness of caregivers to disclose HIV status to their children and to talk about HIV and ART
- Improved knowledge and understanding of their HIV status among CAYPLHIV, improved mental health and capacity to cope with their HIV status and adhere to ART
I was so afraid to tell my child. But when I met Sibo [CATS] I could see my child was not going to die. Sibo showed me that children can grow up with HIV. She helped me to tell my child.

Caregiver

He had questions on why he was the only one infected in the family. This was difficult for me to explain but with support from the clinic, he later understood and this made life easier for us. The counsellor and CATS played the masas game with our child and with time she understood.

Caregiver

We were facing real challenges with one adolescent. He was 14 years old and was always sick. The clinic said he was failing treatment. The parents refused to tell him why he was taking ART. We had a case conference with the clinic and his CATS and agreed to do a home visit to the family. The CATS really helped explain to his caregivers why disclosure is important. It wasn't easy for them but they told him. He was angry at first that they didn't tell him earlier. But now the CATS visits him at home and he attends support group. He is doing well on treatment.

Social Welfare Officer

We have so many adolescents with high viral loads who haven't been disclosed to. This makes it hard for them to adhere. The CATS counsel their caregivers and refer the children to us. We then talk to them together. It really helps a lot.

Nurse

Lesson learned and Recommendations

- CATS are effective at promoting the identification of children and adolescents in need of further information about their HIV status, to promote adherence and mental health

- While CATS do not lead disclosure processes themselves, they have been found to be an effective, acceptable source of information and counselling for caregivers as they consider and prepare to disclose to their own children

- A multi sectoral response is essential for complex cases where the best interests of the child is not being upheld and requires a planned, integrated, enhanced response

- CATS play a central role in post-disclosure counselling and provision of psychosocial monitoring and support through home visits, support groups, MHealth and at clinic

- Child and adolescent sensitive HIV counselling tools (books, games, videos) are essential in supporting disclosure processes

- Child and adolescent sensitive HIV counselling tools need to be available in formats for CAYPLHIV with disability

- The use of standardized HIV counselling tools by health care workers and CATS promotes understanding and consistency for CAYPLHIV and their caregivers

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**Masas’ - 1:** Tanaka and Tonde talk about the immune system

**Masas’ - 2:** Tanaka and Tonde talk about HIV

**Masas’ 3:** Tanaka and Tonde talk about antiretroviral medicine
Reason’s Story

Reason is a 15 year old boy who describes his childhood struggling to understand why he was sick and taking medicine every day while his older brother was not. He speaks of the confusion, shame and isolation he experienced as a result of not being told he is HIV positive and how this affected his mental health, education and adherence to ARVs. Reason tells the story of the support he received from CATS in helping him to understand his HIV status and his journey towards confidence, self-worth and a hope for the future, as well as adherence and good health.

Ivy’s Story

Ivy is 14 years old. Ivy started ARVs as a small child but at the age of 14, she had not yet been told what the medicines were for. She lived with her Grandmother who told Ivy that the medicines were for a headache, but she did not have a headache. In her film, Ivy describes the anger and confusion she felt and the way she threw all her tablets away when she realized her Grandmother was lying to her. She also stopped attending clinic because her Grandmother couldn’t afford the transport. Ivy narrates how her health continued to deteriorate, she lost trust in everyone and felt that she may as well die. When the clinic asked a CATS to follow up Ivy at home, she began to receive counselling and financial assistance for transport to the clinic. After the death of her mother, Ivy was disclosed to by the health worker who then worked together with the Zvandiri team and CATS to provide post counselling and adherence support. Although she initially feared that she would die like her mother, Ivy tells us that this has now changed as a result of the continued counselling she has received and the support the CATS is giving to her Grandmother.

Thanks’ Story

Thanks is 18 years old. In her film, she narrates her experience of losing her mother, testing HIV positive and being sent far from home to live with relatives, all within the same few months at the age of 15. She tells the story of living with relatives who did not want her there and who refused to allow her to take ARVs, even if that meant she would die. Thanks then explains that this changed when the Zvandiri Mentor began supporting her and counselling her aunt. She was also linked to the Case Case Workers from the Department of Social Services who started visiting Thanks at home, together with the CATS and Zvandiri Mentor. Thanks explains how she started to adhere to her treatment and tells of her joy at finally growing and starting puberty. She still had many questions, particularly around the way she came to be living with HIV and was angry and disappointed when she learned that her mother has passed away before telling her that she was HIV positive. Thanks describes how being linked to a CATS helped her to accept her status, to realise that she is not alone and that HIV does not define her.

References