

## **IATT Webinar - Why I take my medicine: Supporting HIV disclosure to children**

The webinar featured presentations from the Ministry of Health and Social Services (MOHSS) of Namibia, I-TECH, Namibia, the University of Washington and Salamander Trust. It was inspired by the following [article](#) that was previously shared via the IATT as well as the Stepping Stones curriculum for children and their caregivers. The webinar featured presentations by Dr. Ndapewa Hamunime, MOHSS, Namibia; Dr. Laura Brandt, I-TECH Medical Director, Namibia; Dr. Gabrielle O'Malley, Implementation Science Director, I-TECH, University of Washington; and Dr. Alice Welbourn, Founding Director, Salamander Trust.

Approximately 40 participants attended the webinar from a wide range of countries, including Angola, Mozambique, DRC, Lesotho, Zimbabwe, among others.

[Disclosure Book](#)

[Disclosure Register](#)

[Disclosure Form](#)

[Readiness Assessment Form](#)

[Why I Take My Medicine presentation](#)

[Stepping Stones presentation](#)

[Webinar recording](#)

### **What do We Know?**

A systematic review of HIV status in children in resource limited settings showed that few children know their HIV status. Influencing factors were related to the child's age and perceived ability to understand the meaning of the diagnosis, characteristics of the primary caregiver, including education level, openness about their own HIV status, fear of stigma as well as concerns for the general emotional and physical health of the child (Vreeman, et al 2013).

HIV status disclosure to children has also been shown to have an impact on retention in care. A study in 3 West African countries with the leDEA project measured the effect of HIV disclosure on children 10 years of age and older demonstrated that disclosure improved retention rates (Arrive et al, 2014). Furthermore, a recent study in Tanzania found that among HIV-exposed infants lost to follow up and subsequently located, 30% did not return to care because their guardians either had not disclosed their own HIV status or were afraid of family/community stigma related to their HIV status or that of the child. Similarly, among children whose HIV status was unknown, 14% cited disclosure/discrimination as the reason for becoming LTFU (Braitstein, et al 2011).

To minimize the emotional distress experiences during disclosure, it is important that the process is gradual and supported. This webinar presented tools that have aided children and their families disclose a child's own HIV status in an age and culturally appropriate way and with the support of healthcare providers and community-based structures.

### **HIV Disclosure Intervention – Namibia**

## Background

In 2003, Namibia initiated the national ART programme and as a result, many children with HIV were started on treatment. However, these children did not know **why** they were taking medication. Caregivers and healthcare workers recognized the importance of disclosure, but did not know **how** to disclose safely while avoiding any negative consequences. Furthermore, the very limited number of specialized staff such as social workers and psychologists meant that the disclosure process had to be supported by available staff – typically nurses and lay counselors.

The study was piloted, amended and subsequently rolled out to all health facilities providing paediatric ART services. Doctors, nurses and counselors were trained as teams to ensure they received the same information. Children aged 6 years were eligible for partial disclosure, while full disclosure was available to children aged 10 years and older. Health workers discussed the importance of disclosure with caregivers and showed them the book – **which doesn't mention HIV-** prior to beginning the process. The disclosure book has been translated into 6 local languages.

- Prior to initiation, a readiness assessment is performed to identify barriers, assess the child's readiness for disclosure and provide an opportunity to discuss the preferred disclosure method (i.e. location (home or clinic) and who discloses to child – caregiver, health worker, or both).
- A disclosure form is completed for each child and for the duration of the disclosure process. The form allows caregivers and healthcare workers to identify and monitor progress and allows multiple health care workers see the content of the most recent interaction with the previous health care worker and the last chapter of the book shared with the child and caregiver. Plans are underway to integrate the disclosure electronic health record system.
- The intervention uses a children's **book** to accompany the disclosure process. The book was adapted from a similar tool used in Botswana and tailored to fit the Namibian context. It includes instructions/prompts for the health workers to assist with explaining the concepts in the book. **The images in the book emphasize adherence to medication and reinforce a positive image of living a "normal" life for the children** (i.e. going to school, working and starting a family). The book is also provided to families in a portable black & white version that excludes health worker prompts.
- Adolescents appreciated the images/animation included in the book even though they are targeted to younger children.

## Key findings

- **A major finding stressed by the presenter was the relief health workers felt by having a standardized tool to assist with disclosure.** Health workers appreciated the stage-wise format and simplified structure. They believed this help to reduce confusion and anger experience by some children upon disclosure.
- The presenters discussed how **the book gave the children a sense of empowerment**, while also creating a learning opportunity for their caregivers.
- Disclosure empowered children and propelled **a behavior change through continual reinforcement of adherence to medication in the book.** Qualitative feedback indicated that

the use of the book increased the caregiver's understanding of HIV and the interest of the parent in discussing these issues more openly.

- Preliminary quantitative analysis (discussed only, not shown) indicates that 91% of children who did not fully understand why they were on medication showed some understanding after participating in the intervention.
  - **Children who had reached full disclosure were more than twice as likely to have lower viral loads (<100 copies/ml).**
  - **Preliminary analysis of the quantitative data shows that viral load decreased significantly by 0.5 log copies, while adherence increased by approximately 7%.**
  - Without disaggregating for age, it takes 2.5 years on average to reach full disclosure.
  - Children averaged one visit every 4-5 months.
  - Younger children were shown to take longer to reach full disclosure compared to older children. Further analysis of differences between younger children and adolescents was suggested.

### Discussions and recommendations

- For countries attempting to implement a similar intervention, presenters recommended systematically adapting the book to their system by piloting in selected sites, incorporating feedback from the pilot phase, training health workers (since there was a marked difference in application of the tool between trained vs. untrained health workers) and monitoring and evaluating outcomes during roll out.
- If the primary caregiver was unavailable at time of child's first visit, the program was described to the accompanying adult and the healthcare provider requested the caregiver attend during the next visit. If the primary caregiver was unable to attend the consultation due to distance, the health care providers would discuss the book without mentioning HIV or disclosing their status, as the principles of adherence to medication are common across all conditions.
- It is important to adapt the flow and language of the book to the maturity of the child.
- For children who knew their status, interviews with health workers and caregivers indicate that disclosure often resulted in confusion (about how they acquired the virus because they never had sex), crying, anger, and thoughts about dying. However, the children appreciated the program as it presented an opportunity to learn more about HIV and reinforce certain concepts.
- Anecdotal evidence suggests that while the book was not used to encourage caregivers to disclose their status, parents benefitted from the book and increased their own understanding of HIV and clarified some key concepts about their own health.
- M&E was performed using only routine programme indicators and data collected through the existing system (i.e. routine patient charts, electronic health records and disclosure forms). Regular monitoring was key to the success of the intervention, as the components were adjusted based on feedback from the data.

### Stepping Stones for Children Curriculum – Salamander Trust

Conducted in partnership with a community-based organization, Pasada, based in Dar es Salaam, Tanzania, this presentation shared results of the first pilot study of Stepping Stones curriculum focusing on young children and adolescents.

The paediatric curriculum was developed in response to feedback from participants in the original Stepping Stones programme as well as research. Women wanted to know “what to tell their children?” in regards to HIV. Young girls in Uganda requested more support to stop being approached by *sugar daddies*, demonstrating the need to empower young women especially who were at high risk for acquiring the virus and engaging in early sexual activity. Research from Burkina Faso documented caregivers’ coping with the fear of stigma by concealing their child’s HIV status and treatment due to fear of stigma (Hejoaka, 2009). Lastly, Van Reeuwijk et al, documented widespread sexual activity among 10-16 year olds in Northern Tanzania, which underscored the importance of HIV disclosure among peri-natally infected adolescents as well as the need for scaling up prevention efforts.

Characteristics of the curriculum:

- Separate age groups 5-8 year olds; 9-14 year olds and adults that meet separately and jointly
- Holistic taking into account biological, psycho-social, sexual and material aspects of life
- Emphasizes cross-gender and intergenerational communication

Anecdotal preliminary results from December 2013/January 2014 indicate that:

- The program helps children to understand caregiver reasoning and reinforce the feeling they are loved
- There was 100% volunteer attendance
- Widespread sexual abuse and physical violence of children
- Children are requesting HIV disclosure while caregivers are apprehensive about disclosure due to fear of negative reaction from child
- More caregivers disclose status to children following participation in program

### Discussion

- Participants had high personal motivation to adhere to program as location was residential and attendance was not required. In addition, participants were provided with travel stipends.
- A facilitator manual is currently being finalized and a training of trainers program is in the works.
- While there is no graduation process, the long-term goal is that as children progress through the program, they become facilitators and trainers.
- As the program is still in its early stages, there is no national scale up as of yet.

### **ADDITIONAL RESOURCES ON DISCLOSURE**

Arrive´ E, Dicko F, Amghar H, Aka AE, Dior H, et al. (2012) *HIV Status Disclosure and Retention in Care in HIV-Infected Adolescents on Antiretroviral Therapy (ART) in West Africa*. PLoS ONE 7(3): e33690.

doi:10.1371/journal.pone.0033690

<http://www.iedea.org/sites/default/files/media/users/471/22457782.pdf>

Braitstein, P et al. 'Wamepotea' (They have become lost): Outcomes of HIV-positive and HIV-exposed children lost to follow-up from a large HIV treatment program in western Kenya. *J Acquir Immune Defic Syndr.* 2011 Jul 1; 57(3): e40–e46. doi: [10.1097/QAI.0b013e3182167f0d](https://doi.org/10.1097/QAI.0b013e3182167f0d).

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3145828/>

Hejoaka F. *Care and secrecy: being a mother of children living with HIV in Burkina Faso.* *Soc Sci Med.* 2009 Sep;69(6):869-76. doi: [10.1016/j.socscimed.2009.05.041](https://doi.org/10.1016/j.socscimed.2009.05.041). Epub 2009 Jun 18.

<http://www.ncbi.nlm.nih.gov/pubmed/19540644>

M.A.J. van Reeuwijk(2010): Children, sex and HIV/AIDS in Tanzania *MT Bulletin of the Netherlands society for tropical medicine and international health* pp. 4-5

Vreeman RC, Anna Maria Gramelspacher AM, Gisore PO, Scanlon ML and Nyandiko WM. *Disclosure of HIV status to children in resource-limited settings: a systematic review.* *Journal of the International AIDS Society* 2013, **16**:18466 <http://www.jiasociety.org/index.php/jias/article/view/18466> |

<http://dx.doi.org/10.7448/IAS.16.1.18466>