

## **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 worked 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 tools 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>



# WHY I TAKE MY MEDICINE



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April 29, 2015

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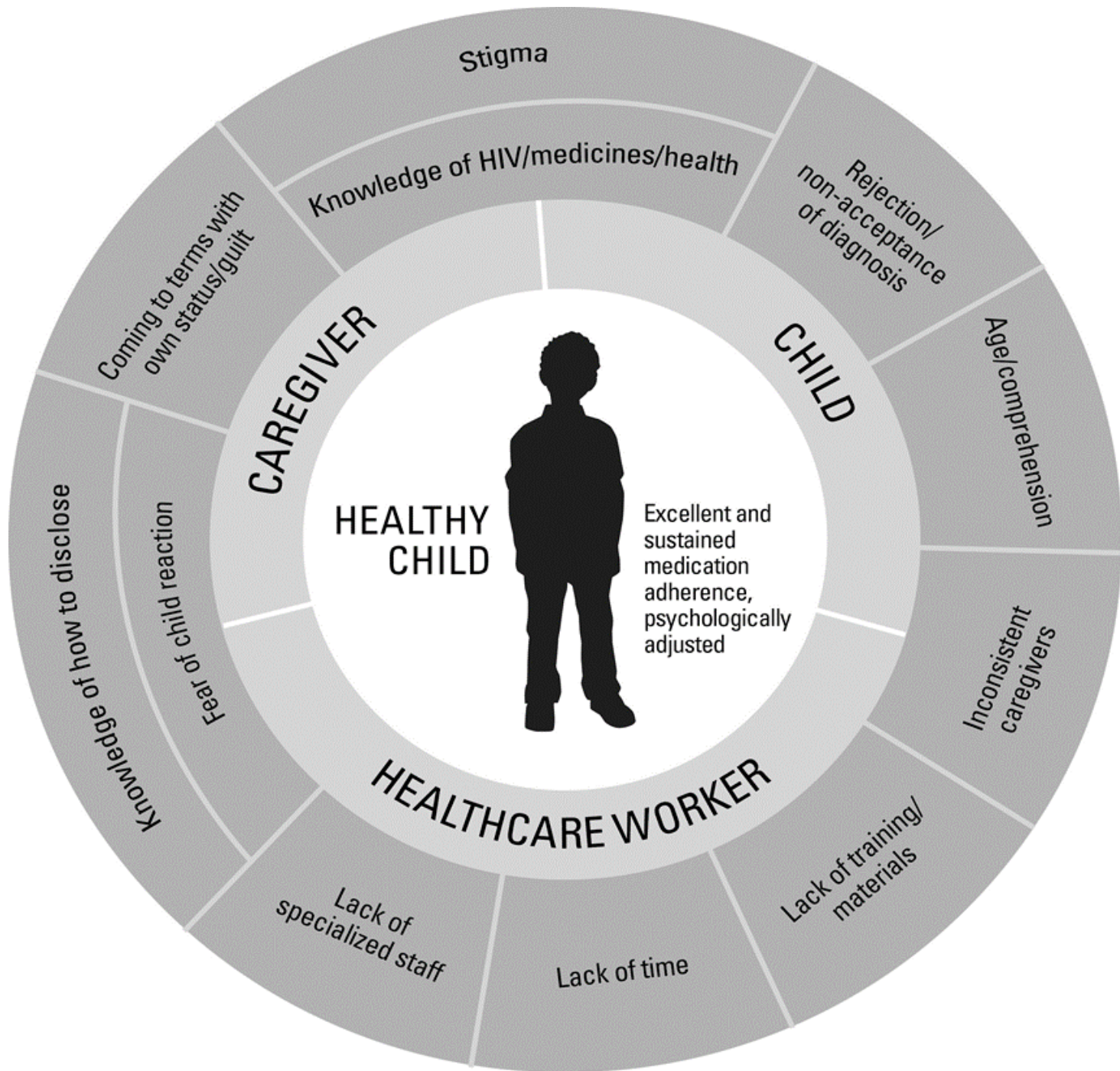
# Overview



- Background
- The intervention itself
- Evaluation of the intervention

# Barriers to disclosing HIV status

- Health care workers don't know how
- Caregiver reluctance
- Impacts health care worker capacity to counsel their pediatric patients
- Needed support materials feasible for use in busy clinic settings



# Solution



- Disclosure program developed and integrated into routine paediatric HIV care
- Rolled-out to all health facilities managing children on ART
  - ▣ Doctors, nurses and counselors trained as teams





# Readiness Assessment

## Assessment of Family and Child Readiness for full HIV disclosure

*The information on this form should be collected over several visits. Issues should be addressed as needed before full HIV disclosure takes place.*

**Name of Child**..... **Name of Primary Caregiver**.....

Can be asked in the presence of the child:

- 1. Who else is in the household?.....  
.....
- 2. Who gives medications to the child?.....  
.....
- 3. Who takes the child to appointments?.....  
.....

Should not be asked in the presence of the child:

- 4. Who knows the child's HIV status?.....  
.....
- 5. Do any other household members also have HIV and if so, are they taking ARVs? .....  
.....

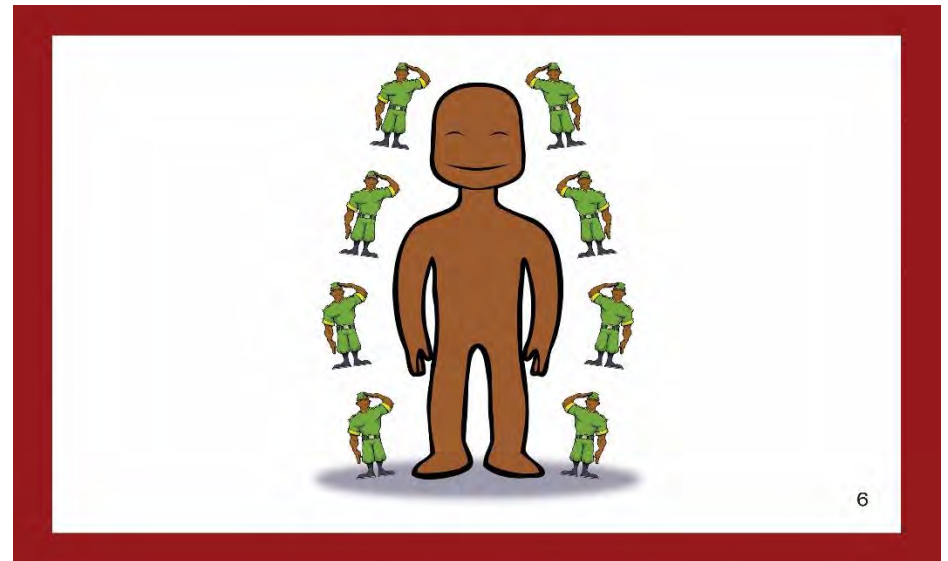
# The Disclosure Book

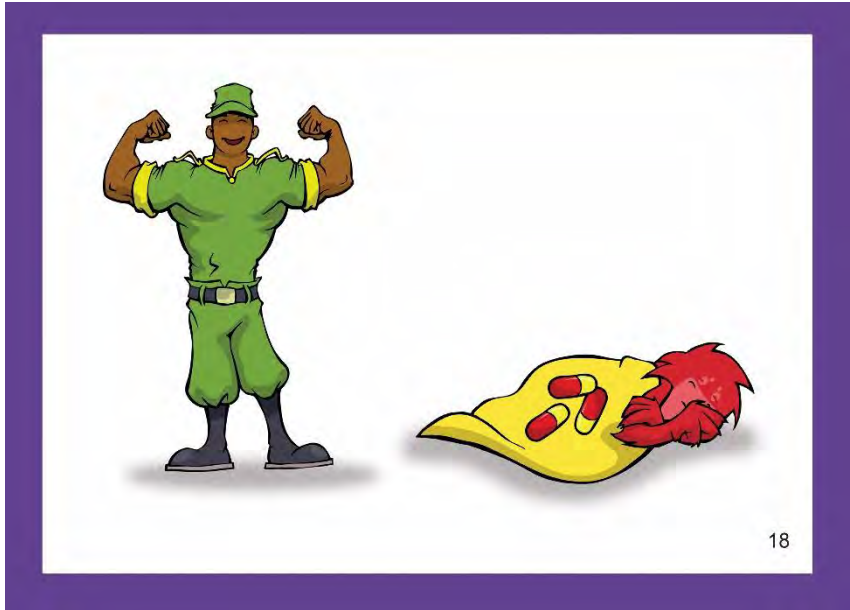
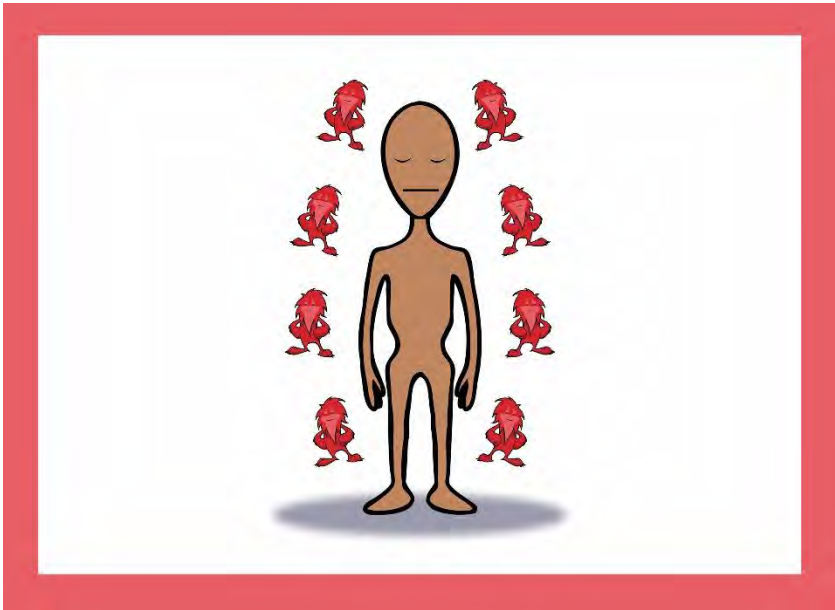
Health Care Worker:

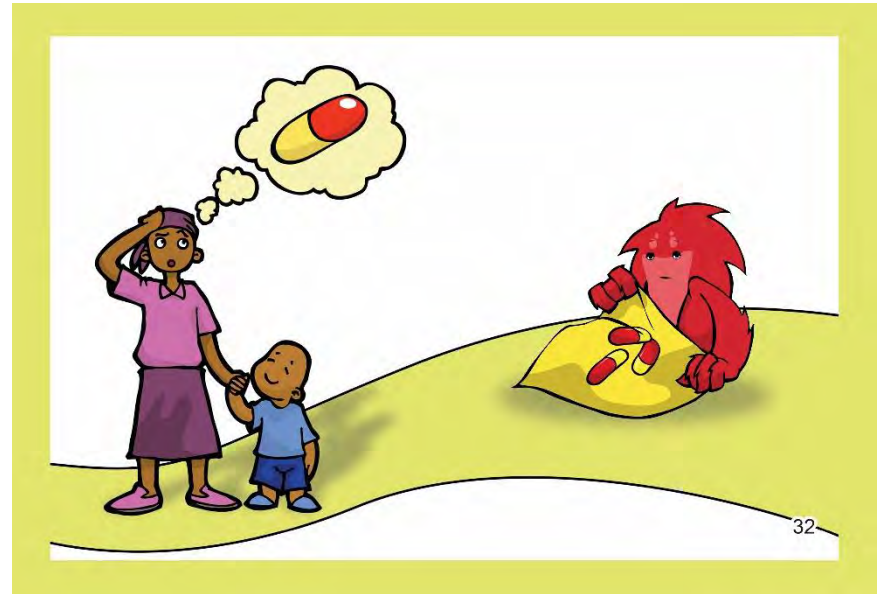
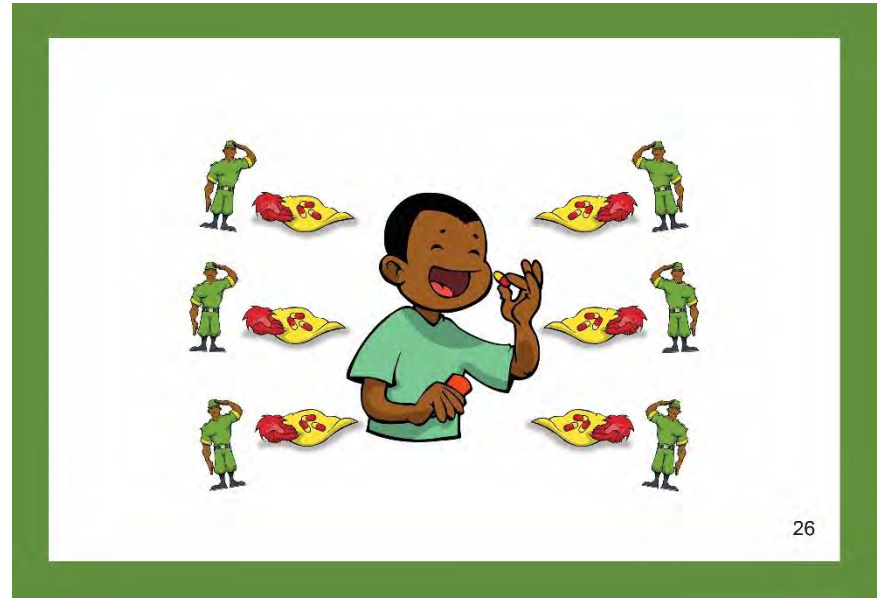
- First read this page to the child and while reading, point to the soldiers around the body.
- After reading ask, "Does the child look healthy?" The child should say, "Yes."
- Then ask, "Are you feeling healthy today? What do you think your body soldiers are doing?"
- If the child feels healthy he/she should explain that the soldiers are protecting him/her from getting sick.

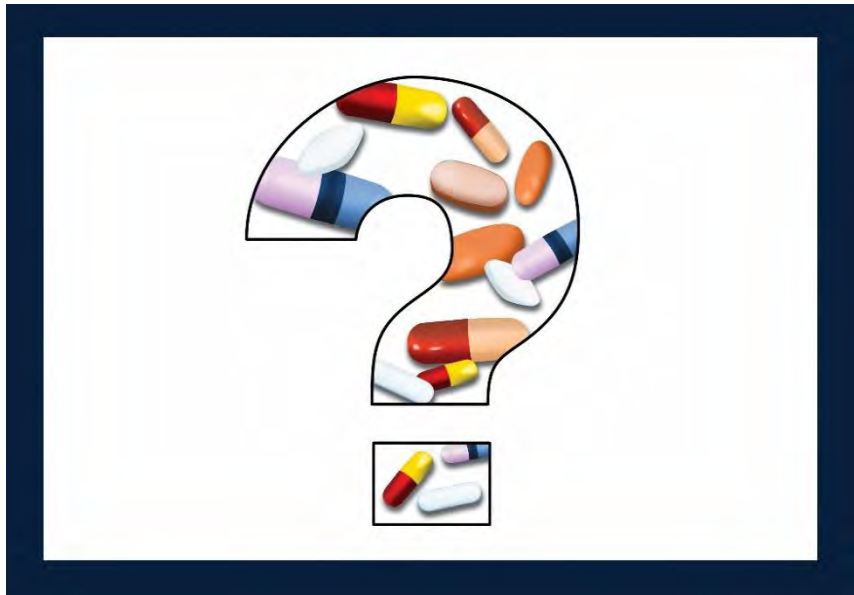
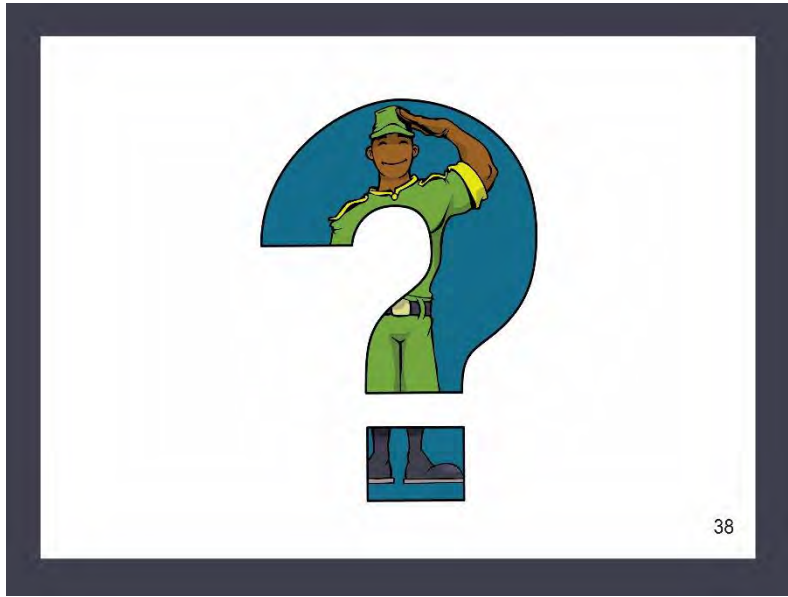
When you are healthy there are many strong body soldiers inside of you protecting you from getting sick.

5









# Evaluation Questions



- Does the disclosure program help caregivers and health care workers engage in the disclosure process with children?
- Does the disclosure program help children adhere to their medication?
- Does the disclosure intervention succeed in bringing children to full disclosure?

# Methods: 4 study sites



- 35 HCW interviews
- 64 CG interviews
- Reviewed over 1018 patient charts
  
- All qualitative data dual coded, managed with Atlis.TI

# Findings



- 31 of the 35 HCWs reported regularly using some component of the intervention with children and/or caregivers
- Disclosure book most highly valued in addressing barriers to disclosure

# Accessible shared language



*“The book simplifies the disclosure process because... it is arranged stage-wise.. you are building a story and you reach full disclosure, it’s not haphazard. And if maybe we were to do it from our own heads, we can jumble things and mix things and actually create problems with the kids that we are disclosing to. It builds the story as you go for the kids to understand.” (HCW)*

# Accessible shared language

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- *[E]ven when you ask them why they are taking the medication, that child will tell you that ‘there are some bad guys in my body and I want my anti bodies to be strong and destroy these bad guys.’ (HCW)*

# Caregivers learn



*“They [CG] generally like the book. It also makes the caregiver understand the virus, you would assume that they already know, but once you use that book you will see the interest of the parent go higher. They will say that I did not understand this myself, so it also works both ways.” (HCW)*

# Reduces CG reluctance



*“When you ask those [resistant caregivers], ‘Does your child know why she or he is taking medication, do you want us to tell the child?’ they used to say ‘no’, but now when you bring in that book, you tell them at first we are not going to talk about HIV, everyone says ‘I like that kind of book.’” (HCW)*

# Reduces CG reluctance



*“I like it because it’s nice. There is nothing that can scare the child, where the child might think that if I continue to take the medication I might die like my uncle. The book encourages the kids that if they continue to take their medication and go to school they can become whatever I want to be.” (mother of an 11 year old boy)*

# Reported behavior change

*“[The book is] very helpful...kids... easily forget why they are taking medications ... and decide not to, but if you bring in the book, you will see that it will come back to them that yes, I have to drink my medication and like that book you will see there is a picture of when you grow up, what do you want to do? You know they get so excited, so they say I have to go to school, I have to play with my friends, I want to be a teacher, whatever, that is when they will decide, ok, I will drink my medication from now onwards.” (HCW)*

# Reported behavior change



*“The child always talks about bad guys. Sometimes, when he almost forgets his medication he says, “no, I am going to take my medication because these bad guys are trying to fight me.” (mother of 7 year old boy)*

# Quantitative data – analysis in process



- Very large increases in children's awareness of why they are taking their medicine
- Preliminary analysis shows reduction in VL pre/post intervention

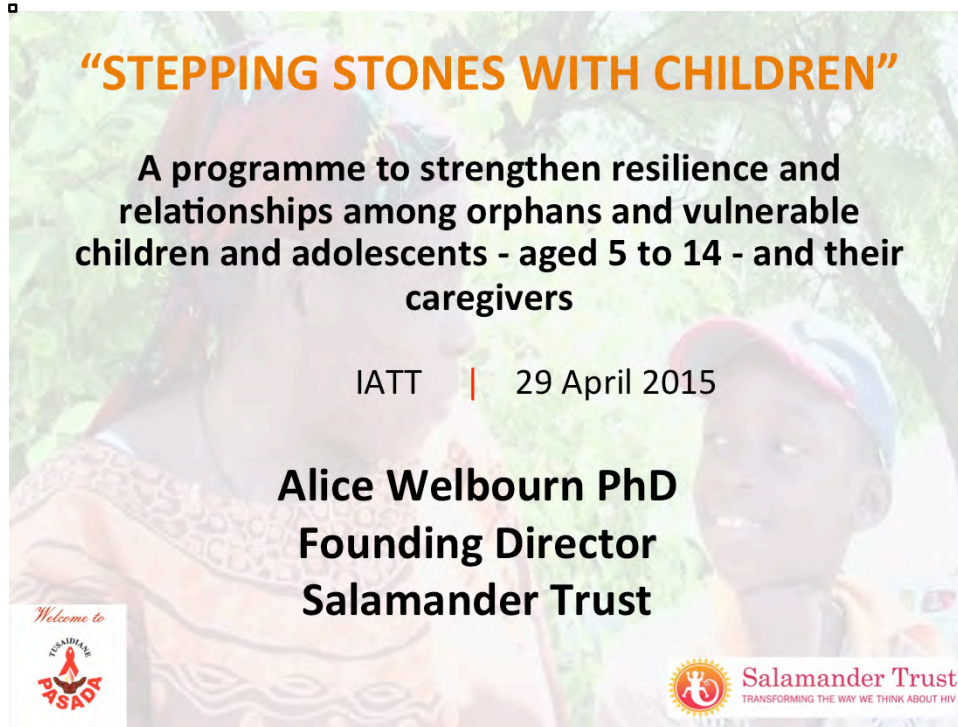
# Important steps for success



- Systematic adaptation of materials
- Pilot testing and revision
- Training
- Monitoring and Evaluation during roll out

# Acknowledgements:

- We would like to thank the caregivers and HCWs who participated in the evaluation. We would also like to thank UCCB for their assistance in conducting and translating interviews and the Namibia Ministry of Health and Social Services Study Group for providing ongoing consultation to ensure the programmatic relevance of this evaluation.
- *Sponsorship:* This evaluation was supported by National Institutes of Health (NIH) research grant 1R21HD074071-01.




**“STEPPING STONES WITH CHILDREN”**

**A programme to strengthen resilience and relationships among orphans and vulnerable children and adolescents - aged 5 to 14 - and their caregivers**

IATT | 29 April 2015

**Alice Welbourn PhD**  
**Founding Director**  
**Salamander Trust**

Welcome to  
TUSADANE  
TASADA

 **Salamander Trust**  
TRANSFORMING THE WAY WE THINK ABOUT HIV

Welcome to “Stepping Stones with children”: a programme to strengthen resilience & relationships among orphans & vulnerable children & adolescents aged 5-14 and their caregivers. This is *not* a disclosure programme per se but disclosure forms a part of it. We will explain this later.

## Intimate Partner Violence & HIV

- **Globally, 1/3 of women experience IPV**  
(WHO 2013)
- **IPV -> increase in acquiring HIV by 1.5**  
(WHO 2013)
- **Salamander report for WHO consultation 2015: 89% of women with HIV reported experiencing GBV**

Welcome to





**Salamander Trust**  
TRANSFORMING THE WAY WE THINK ABOUT HIV

For the Salamander report, see: [http://salamandertrust.net/index.php/Projects/SRH&HR\\_Survey\\_for\\_women\\_with\\_HIV/](http://salamandertrust.net/index.php/Projects/SRH&HR_Survey_for_women_with_HIV/)

#### LINK TO IMPACT OF VIOLENCE ON CHILDREN - RELATIONSHIPS WITH CAREGIVERS AND VULNERABILITY TO HIV

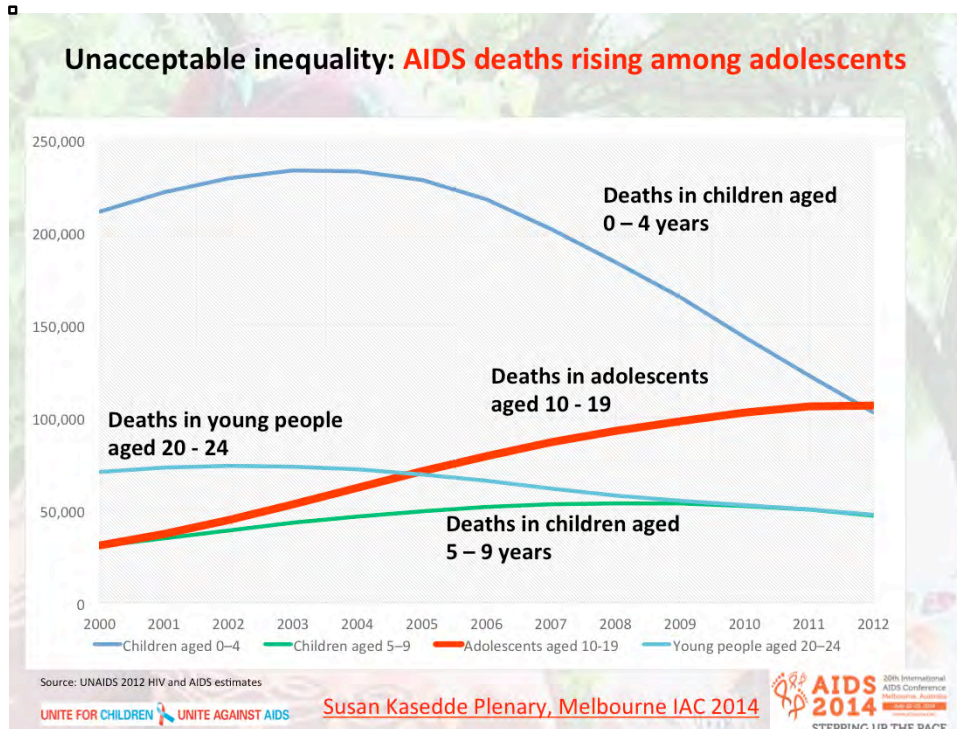
If women with HIV are experiencing GBV, this makes it that much harder for them to thrive and survive – and inevitably has a knock-on effect on how they can care for their children.

Similarly, children are witnessing this violence and will undoubtedly suffer as a result. We know that children who have witnessed GBV can often grow up to become perpetrators or enter abusive relationships with perpetrators.

Meanwhile, caregivers of orphans (often grandmothers) are often angry that their children have died), grief-stricken at their loss, desperate, over-whelmed by numbers of children in their care and don't know how to cope. They often shout and beat the children in reaction.

Orphaned children are bewildered, bereft and feel they are to blame for their parents' death. They "act up" and "misbehave" in response. How their caregivers treat them can have an effect on their vulnerability to HIV as they grow older.

Of course we are not blaming caregivers or children for their feelings or actions. We need to understand and support both caregivers and children alike in order to enable them to build resilience and move forward together in more positive ways – and to overcome violence in their relationships.



This and the following slide are taken from UNICEF’s Dr Susan Kasedde’s Plenary from Melbourne. They spell out the enormity of the challenge facing 10-19 year olds with HIV. This is why we are working with 5-14 year olds, to help them through their teens.

“I’d like to start by talking about this picture. The only group in whom AIDS deaths are increasing is adolescents. Every day 300 adolescents are dying due to AIDS.

At UNICEF, we’ve analysed the best data available and what we’ve found is that ten years ago, in 2005, 69,000 adolescents died of AIDS. By the end of 2012, that number had increased by 50% yet AIDS deaths had fallen by 30% across all age groups. This trend in AIDS deaths in adolescents can be seen in the red line above.

This is a humbling reminder that we have not done our best for adolescents. We must turn our attention to addressing this gap. We have got to end the AIDS epidemic among adolescents. And to address this inequity, we must act with urgency.

I’d like to share some more information with you on the current epidemic in adolescents.”

## HIV and AIDS Among Adolescents

1. One in five people are aged between 10 and 19
2. 2.1 million adolescents live with HIV, 1.7 million (82%) in Sub-Saharan Africa, girls account for 60%
3. In all other regions: HIV concentrated in key populations
4. Two thirds of all new HIV infections in 2012 were among adolescent girls
5. HIV is now the second leading cause of death among adolescents, 300 deaths every day

UNITE FOR CHILDREN UNITE AGAINST AIDS Susan Kasedde Plenary, Melbourne IAC 2014



This is the second of Dr Kasedde's slides:

1. "One in five people in the world today are aged between 10 and 19 which means that globally there are an estimated 1.2 billion adolescents.
2. Of the 35.3 million people living with HIV in the world today, 2.1 million are adolescents.
3. 82% of all adolescents who are living with HIV (1.7 million in total) come from sub-Saharan Africa: the region that accounts for just 16% of the world's adolescents accounts for 82% of all HIV infections in adolescents. Eastern and southern Africa, home to just 8% of all adolescents in the world, accounts for 63% of all adolescents living with HIV.
4. In all other regions, HIV is concentrated in highly vulnerable adolescents such as adolescent males who have sex with males, adolescents who use drugs, transgender adolescents, adolescents who sell sex.
5. And speaking of inequity and injustice, here's another thing to think about: of the 2.3 million new HIV infections that occurred in 2012, 300,000 - or just over 800 new infections each day - were among adolescents. Two thirds of these were among adolescent girls.
6. Just over a month ago, in a report on the Health of the World's Adolescents, WHO highlighted that HIV was the second leading cause of death among adolescents,

## What is “Stepping Stones”?

- ✧ 1993-1995 – original Stepping Stones developed and published, rural Uganda
- ✧ Includes older & young men & women
- ✧ 1995-present – translated and adapted around the world
- ✧ [2008 Jewkes BMJ RCT: reduced IPV & HSV-2]
- ✧ 2008 Stepping Stones **Plus** (SRH & HR)
- ✧ 2014 Stepping Stones for Peace & Prosperity (for post-conflict settings)
- ✧ **2012 Stepping Stones with Children** work started



So what is “Stepping Stones” exactly? Stepping Stones is a programme based in the **community**. Above we chart the history of the programme over the past 22 years. It began when I was diagnosed with HIV when pregnant in 1992.



The programme has since gone global to over 100 countries. Adapted and translated into at least 30 languages, it reduced intimate partner violence (or IPV) in an RCT conducted by the South African Medical Research Council. The “What Works for Women” website grades it as Gray II evidence level for effectiveness, both in addressing violence against women and transforming gender norms. Women in countries including Malawi, India (where it has also ended child marriage in communities where it’s been used) and the Gambia have *themselves* reported IPV reduction, in response to being asked “what has changed for you?”.

**REDUCTION IN CAREGIVERS BEATING CHILDREN WAS REPORTED BY BOTH ADULT AND CHILD PARTICIPANTS AFTER “STEPPING STONES WITH CHILDREN” PILOT WORKSHOPS IN DAR es Salaam in December 2013 and January 2014.**

Jewkes et al 2008 *Impact of Stepping Stones on incidence of HIV and HSV-2 and sexual behaviour in rural South Africa: cluster randomised controlled trial* BMJ

2008; 337 <http://www.bmj.com/content/337/bmj.a506>

<http://www.whatworksforwomen.org/search?utf8=%E2%9C%93&q=%22Stepping+Stones%22>

<http://pag.aids2014.org/flash.aspx?pid=1806>

(eg COWLHA/Salamander Trust 2013; Bradley et al 2011, Paine et al 2002). You can view a film about COWLHA Malawi’s experience of using Stepping Stones to reduce IPV here: <https://vimeo.com/69251113>

## Stepping Stones with Children: *a potted history.....*

- “What do we tell our children?”
- Experiences with 10 year old girls, Entebbe
- Gap in material for under 14s
- Hejoaka: huge HIV disclosure issues to “children” – and adults’ *fears*
- Van Reeuwijk: widespread sexual activity 10-16s



- a) 16 months after the original Stepping Stones workshop in rural SW Uganda, all participants said they had found the programme very helpful – but women said “what do we tell our children”?
- b) The late Professor Rose Mbowa of Makerere University Dept of Music, Art and Drama, our lead trainer, ran a Stepping Stones workshop in Entebbe. She was approached by 10 year old girls who said they wanted to be part of it also. So they formed a 5<sup>th</sup> peer group. At the end of the workshop they stood up in front of community leaders and requested that they stop being pursued by sugar daddies. So we know even the original programme works with children as young as 10. (see [http://steppingstonesfeedback.org/resources/25/Rose\\_Mbowa\\_Using\\_role\\_play\\_to\\_change\\_attitudes.pdf](http://steppingstonesfeedback.org/resources/25/Rose_Mbowa_Using_role_play_to_change_attitudes.pdf))
- c) We have recognised quite a large gap in available material for under 14s so decided to focus on 5-14s in this programme now.
- d) Dr Fabienne Hejoaka in her doctoral research in Burkina Faso found a huge challenge of “disclosure” to children by adults, even when the “children” were in their early 20s. They were still deemed “children” because they had not gone through formal marriage rituals, owing to poverty. But as “children”, they were not considered old enough to be trusted with such sensitive information.\*
- e) Dr Miranda Van Reeuwijk, in her doctoral research in N Tanzania reported widespread sexual activity among 10-16 year olds. <http://dare.uva.nl/record/305838>

\*Tiendrebeogo, G., Hejoaka, F., Belem, E., Compaoré, P., Wolmarans, L., Soubeiga, A. and Ouangraoua, N. (2013). Parental HIV disclosure in Burkina Faso: Experiences and challenges in the era of HAART. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 10(sup1), pp.S46-S59.

## PASADA, Dar es Salaam, Tanzania



- Long track **record** of HIV-related health services across Dar es Salaam
- Widely **respected** organisation – for *all*
- Stepping Stones successfully used with **older youth** – eg car washers' cooperative
- Wanted to work with **younger** children and adolescents



ALSO: PASADA OFFERS SERVICES FOR CHILDREN WITH HIV.

AND CONDUCTED STEPPING STONES WITH CHILDREN IN SCHOOL.

For a poster regarding PASADA's work with young adults in slum areas, see [http://steppingstonesfeedback.org/resources/25/SS\\_PASADA\\_Poster\\_Toronto\\_2006.pdf](http://steppingstonesfeedback.org/resources/25/SS_PASADA_Poster_Toronto_2006.pdf)

PASADA was founded in 1989 just as AIDS was starting, when only counselling and palliative care were available. Its dedicated staff now supports 155,000 clients, most of them extremely poor, 70% of whom live in Dar. Half of those who have tested for HIV in Dar have passed through its doors. Of Dar's 4.5 million population, 75% are without their own water or electricity. Those who need to be on anti-retroviral (ARV) treatment have to come every month because of drug shortages. This costs clients extra time and money in terms of transport, childcare costs and time off any work.

## Our Planned Programme Outcomes

- ✧ To build on past Stepping Stones experiences: **gendered and inter-generational relationship skills** & follow in its global footsteps
- ✧ To create a **safe & supportive training environment** to enhance sharing, communication and support for carers & young children alike
- ✧ To support caregivers and their children to **communicate** on these **sensitive issues**
- ✧ To train caregivers **to respond effectively** to social, physical, sexual and psychological needs of the girls and boys in their care
- ✧ To **build small networks** of shared mutual support in their communities
- ✧ To **reduce isolation** faced by both children & caregivers & to **increase their collective resilience** to the chronic challenges they face



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## Innovative features

- ✓ 5-8s, 9-14s girls & boys & adult caregivers in 3 parallel groups, mainly separate, with some plenaries & encouragement to share learning
- ✓ Holistic, comprehensive programme including psycho-social, physical, sexual and material themes (29 sessions in total)
- ✓ Uses positive language, mindfulness, virtues, visioning, as well as role-plays, games, & drawing
- ✓ Builds positive cross-gender & inter-generational communication



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## Stepping Stones with Children Research & Development Process

- Initial scoping exercise with children and caregivers **2012**
- Relevant materials adapted from sources which are already proven **2012-2013**
- 3 Pilot workshops – close documentation of observed process of individual exercises, sessions & facilitators' and participants' evaluations **2013**
- Review of changes brought about by using materials from pilot workshops, adaptation where needed **2014**
- Further revision on basis of independent reviewer feedback **2014-5**
- Now finalising to use, together with M&E process to capture changes more formally **2015**



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# Can orphans and their caregivers be supported to build shared resilience in the context of AIDS-related deaths?

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### Introduction

**Background**  
Many communities are unsafe places for orphaned children. Their guardians are mainly women, often stressed, poor, with HIV and limited educational opportunities. They may often be living in isolation and have due to HIV-related stigma and deteriorating physical health. In this context few children or guardians feel safe to express grief or anxiety. Children and caregivers alike lack comprehensive security and life skills education. Our programme builds upon experiences of the original "Stepping Stones" community programme on gendered and inter-generational relationship skills. It supports caregivers and their children, to communicate on these sensitive issues without individual and collective psycho-social resistance.

**Caregivers, gender and AIDS-related deaths**  
Many caregivers "fall between the cracks" of the UN 2011 LINDASS target, since they need to be guardians who have raised their own children through AIDS-related deaths & they are not normally of reproductive age. They form the invisible backbone of the community AIDS response but they are not normally recognised as a part of any key population. Caregivers rarely have support to disclose to or communicate about HIV, sexually and death, with their partners in their care, who also have to be affected by HIV. The role of caregivers is chronically under-addressed from a gendered perspective by donors investing in HIV education.

**Challenges Facing Orphans Affected by HIV**  
Mothers, who often underestimate children's ability to understand HIV and to take action in their own lives. Since parents fear to disclose to children with HIV, children often receive false information, which can make them further vulnerable. Sexual matters are taboo and are not talked about. Disclosure programs begin at around seven years. By age 12 many children have reasonably understood the "stigma" in "talking" disclosure before age 14 could be considered with the guardian present. This produces another major barrier to disclosure for orphans living with HIV. Children experience widespread grief, sorrow and anger about the effect of HIV on their lives. This affects their psychosocial wellbeing as well as their AIDS adherence. Moreover, health providers feel they lack the skills and training to discuss HIV status to children.

*"My father died but my mother didn't tell me. She just said that he had gone on a journey. Then I went to an uncle's house and my aunt told me that he had died... I am very angry with my mother that she did not tell me the truth."  
Story told by a 10 year old girl*



Children aged 6-8 years during a workshop

### Programme Outcomes

- To build on experiences of the original "Stepping Stones" community programme on gendered and inter-generational relationship skills.
- To create a safe and supportive training environment to enhance sharing, communication and support for parents and young children alike.
- To support caregivers and their children to communicate on these sensitive issues.
- To provide caregivers with the psycho-social skills to respond effectively to emotional and psychological needs of the girls and boys in their care.
- To build small networks of shared mutual support in their communities.
- To reduce the sense of isolation faced by both children and caregivers and to address their collective resistance to the chronic challenges they face.
- To eventually evaluate this programme being selected for use by organisations worldwide, following in the footsteps of the original "Stepping Stones" programme.

### Methods

**Pilot Implementation**  
3 pilots were conducted in urban and coastal regions of Tanzania. Each pilot workshop included 20 adults, 12-14 year olds and 10-14 year olds. Most of the children involved and many of the adults are living with HIV. The two children's peer groups included male and female participants. The adult groups were largely female. There were five facilitators to lead the three separate peer groups in each site. The workshops consisted of 20 sessions, which were 4 hours each. Workshops were conducted intensively over 15 days. The sessions contained diverse participatory activities, appropriate for informal learning in low-literacy settings. The sessions covered psychological, physical, sexual, material and spiritual dimensions of wellbeing.

*"I realized when I was shouting 'no loudly in that role play just now that this is how I normally treat my young brother when he is being naughty. He must fear and hate me as much when this is how I treat him, even though all I am trying to do is to make him behave. I've just realized now that now I behave towards him is going to affect how he behaves."  
Young adult male caregiver*

### Results

**Lessons Learnt**

- There was 100% voluntary attendance throughout.
- Children reported widespread sexual abuse and physical violence.
- Children expressed strong desires for honesty around HIV disclosure and death, demonstrating deep maturity and clear future visions.
- Caregivers expressed initial terror of disclosure to children, fear of the enormity of their responsibilities and concerns regarding children's HIV adherence, but displayed shared courage and resolve.
- Several caregivers chose to disclose to the children during each pilot workshop and more caregivers have disclosed to the children in their care since.
- Old and young together expressed joy at new learning, relief at sharing and joint determination to build mutual trust and support.

*"I work as a counsellor in a health centre in my neighbourhood but we have never been taught things like this. I am going to take all I have learnt here back to my workplace and share it with my colleagues so that they can all benefit from this programme as we have here."  
A female, adult participant*



Children playing a game of hide-and-seek during a workshop

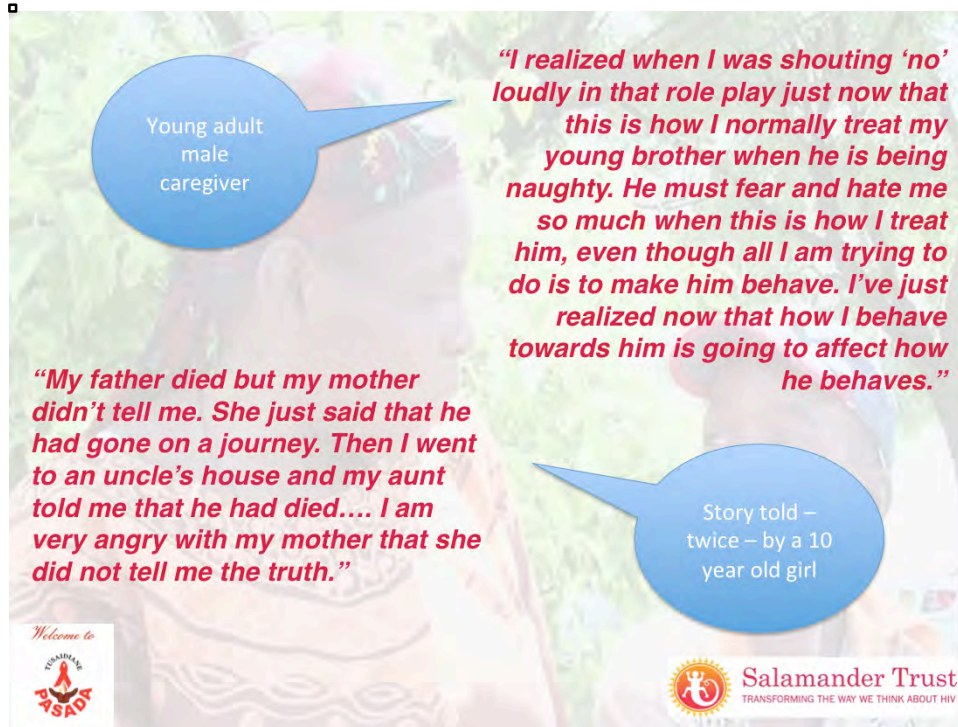
*"In all my life I have never felt somewhere so safe and cared for as I do here."  
An adult workshop participant*

### Conclusions

**Conclusions**  
Preliminary findings are highly positive. After further evaluation and refinement, we will pilot other African partners for roll-out in six other African countries. We intend to evaluate further to address the issue globally.

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This full poster and other recent resources can be viewed at: <http://steppingstonesfeedback.org/index.php/page/Resources/gb?resourceid=25> Do explore the whole site!



Here is an example of two quotes from a child and from an adult caregiver.

In the case of the girl, we supported her and her whole group to understand that our caregivers love us and want the best for us and that people used to think that it was best to hide sad news from children in the hope that they would just forget about the person, or in the belief that children can’t handle bad news. But now research has shown clearly that it is much better for children to be told the truth and that is what this workshop is about – to support parents and caregivers to understand that, so that adults and children can communicate together much better over such hard things. This really seemed to help the children to understand where their caregivers were coming from. And they were glad to hear that the research shows that it is better for them to be told things. They agreed with this research.

In the case of the young adult caregiver, this moment was a real revelation for him. He was actually in tears. We supported him to understand that he had been trying his best to do the right thing, so his intention was good. And that now he had a different view of the effect of his shouting this workshop could now help him to develop a different way of connecting with his brother.

## Lessons Learnt from first 3 pilots: Part 1

- ✧ There was 100% voluntary attendance throughout.
- ✧ Children reported widespread sexual abuse and physical violence.
- ✧ Children expressed strong desires for honesty around HIV “disclosure” and deaths, demonstrating deep maturity and clear future visions.
- ✧ Caregivers expressed initial terror of “disclosure” to children, fear of the enormity of their responsibilities and concerns regarding children’s ARV adherence, but displayed shared courage & resolve.



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## Lessons Learnt from first 3 pilots: Part 2

- ✧ Several caregivers chose to *disclose* to the children during each pilot workshop & more caregivers have disclosed to the children in their care since.
- ✧ Old and young together expressed *joy* at new learning, *relief* at *sharing* and joint determination to build *mutual trust* and *support*.

***“When did I feel happy?  
The day my caregiver told me I have HIV.”***

**Boy, 10 years old, December 2014**



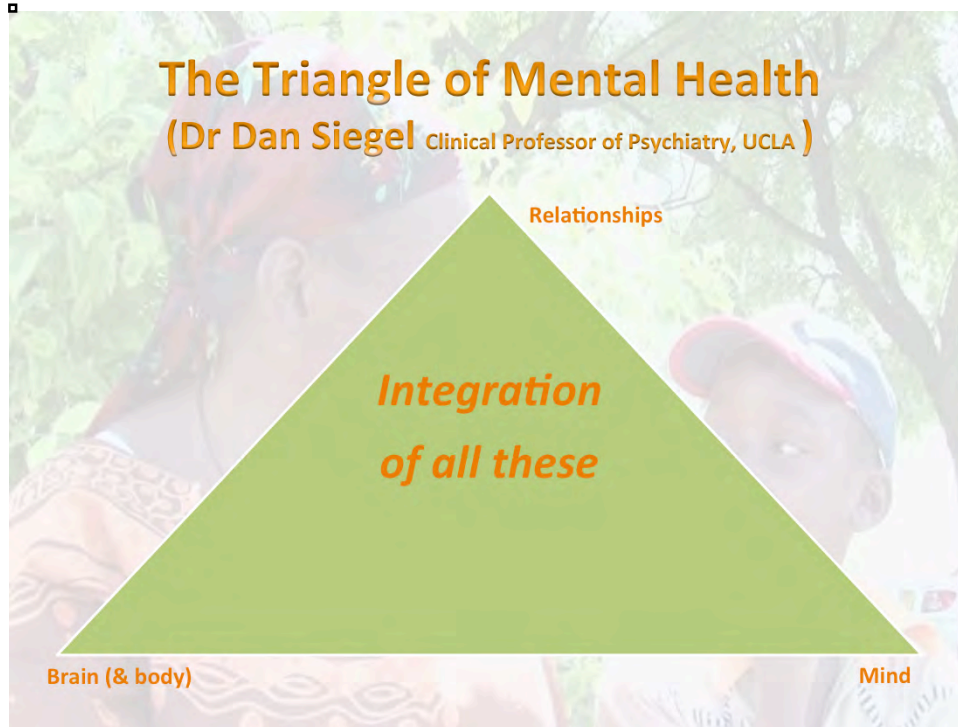
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## Contents of Stepping Stones with Children

A Psycho-social dimensions	B Physical well-being	C Sexual well-being	D Material well-being
Journey of Life	All about HIV	Relationships, love & sex	Learning & contributing
Using our brains	Testing & talking about HIV	Sexual feelings & safety	Child labour
Gender & sex	Living well with HIV	Pornography	Livelihoods
Child and SRH rights	Partners in health care	Delaying, starting and stopping having sex	
The Tree of Life	Friendship	Condoms	
How to be Assertive	Going to school	Children by choice not chance	
All about Virtues	Alcohol & other drugs	Protecting each other from sexual abuse	
The Power of Love	Growing up	Supporting survivors of sexual abuse	
Positive Discipline			
Coping with loss			
Understanding death			
Virtues, positivity, mutual respect, inclusivity, safety woven through			

The programme has four main elements: psycho-social dimensions, physical well-being, sexual well-being and material well-being. Of course many sessions, such as the ones on friendship and going to school, relate to all four of these elements.

The glue which holds all the sessions together is seen in the bottom green line – an emphasis on our virtues and strengths within us that we all have, on positivity, mutual respect, inclusivity and safety. This is woven through the whole programme.



Since Stepping Stones was first created, we have always sought to support participants to work together to view the bigger picture, to understand the issues and challenges facing each separate section of their community, to step out of their own box and to view the world differently through stepping into one *another's* sandals and perspectives. We have always worked from the principle that we all carry the power of good within us, from cradle to grave and that, although we might lose sight of it at times, owing to ways in which we have been treated by others and our defensive responses to these, we can always re-find those **strengths within us** with the care and support of those around us. ....

We have often been asked what our theoretical framework was and have always found that a hard question to answer. However with new evidence on inter-personal neurobiology, we can now answer that clearly. Here we explain briefly Dr Dan Siegel's triangle of mental health\*, which we see connects strongly with our programme.

Dr Siegel's triangle consists of three equal prime points, the MIND process that regulates our information flow in us; the BRAIN (which is connected through our spinal column to the workings and energy of all our essential organs of our body, including our heart, lungs, liver and kidneys), and RELATIONSHIPS – which is how our information and energy is shared between us and individuals and 1, 2 or more other people.

## MIND

Component	Programme Structure & Exercise
<b>Mindsight</b>	Developing insight about our own thoughts and feelings and empathy for other people's thoughts and feelings Gender roles questioned throughout Understanding how our brains work Wheel of awareness Ways to support own and others brain development during childhood and adolescence
<b>Self-compassion</b>	Ability spotting* to learn how to spot our own and other's strengths and build on them Positive language Critical consideration of influence of how we speak about ourselves and others Mind maps to analyse complexity of problems and find realistic solutions
<b>Emotional balance</b>	River of life as tool to explain emotional balance Assertiveness training Breathing & meditation exercises

Firstly, let's look at our minds. The three components that Siegel identifies which are perhaps most connected to our minds (though they are all inter-related remember) are: insight; understanding why we behave as we do and emotional balance, shown in this chart here.

For each of these three components, we have various different exercises throughout the programme which support these qualities to develop in the participants. We show some examples of relevant exercises in the right hand column here.

\*See the next slide for a reference regarding ability spotting, introduced to us by Dr Elspeth McAdam

## BRAIN/BODY

Component	Programme Structure & Exercise
<b>Regulating our bodies</b>	Breathing and meditation exercises Body language exercises Using SIFT to notice our bodily sensations, images, feelings and thoughts
<b>Ability to pause before acting</b>	Using brain in hand model to remind us to connect upper and lower brains Using wheel of awareness to gain perspective from overwhelming feelings Volcano – what lies beneath angry feelings Practising pausing before acting through role plays and peer group support to (re)act differently
<b>Intuition</b>	Dreaming and back-lighting* Ability spotting – as listener* Support from peers

Now let's move on to the next 3 components identified by Dr Siegel. These relate more to our brains, which are connected to all our essential organs in our bodies and are shown in this chart with more related exercises. They are: regulating our bodies; learning and *using* an ability to *pause* before we act; and intuition – bringing the wisdom of the body up into our awareness.

\*Dreaming and back-lighting and ability-spotting are particular techniques drawing on the work of psychiatrist Dr Elspeth McAdam through the Namweza programme and in schools and with young adults: see eg <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-6427.2009.00461.x/full>

## RELATIONSHIPS

Component	Programme Structure & Exercise
<b>Communication</b>	Assertiveness training – eg “I”-statements Role plays about friendships, peer pressure and decision-making including negotiating about sexual relationships Role-plays as members of other peer groups Meeting with other peer groups to share and compare Sharing information from the programme with others
<b>Empathy</b>	Practising questioning and listening skills Using role plays to learn about how others think and feel Playing members of other peer groups in role plays Meeting with other peer groups to share and compare
<b>Morality</b>	Learning how to use our virtues to acknowledge, guide and correct our own behaviour and that of others Practising using our virtues including kindness, courage, justice, cooperation, self-discipline and responsibility Dreaming and back-lighting Moving from I-statements to We-statements (“We-dentity”)

Dr. Siegel’s last 3 components of mental health well-being are shown in this chart here.

They are: **attunement** – to feel *with* another person; **empathy** - ability to make maps in your mind of someone else’s experience; and **morality** - for the greater good of society – a “we” map.

Again please remember that all 9 components relate in some way to **all** the triangle.

## Other key sources:

- Tina Payne Bryson (with Daniel Siegel)
- REPSSI
- Virtues Project
- Gill Gordon & HIV/AIDS Alliance past training manuals
- Jonathan Brakarsh
- Winston's Wish
- Dick Bolles ("What colour is your parachute?")
- Elspeth McAdam
- Kate Harrison
- Paul Gilbert and Choden



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These images show:

- a) Top left – the 5-8 year olds showing their individual trees of life and how together these form a forest of love.
- b) Bottom –right – how the storms which beset us all are less harmful if we stand together as a forest, supporting one another.
- c) Bottom left – rowing down the middle of the river of life, avoiding the whirlpools to one side and the rocks on the other
- d) Explaining how different parts of our brains work and how we can find our emotional balance in the middle.



The main documentary film can be viewed at: <https://vimeo.com/125781314> The password, if needed, is Watoto (case sensitive)

The participatory films will be posted on our vimeo.com site for Salamander Trust soon: <https://vimeo.com/salamandertrust/videos>

The **themes** of all the participatory films were chosen by the participants themselves, who were trained how to design, film, direct and edit their own films.

The film trainings were conducted by Dr Dominique Chadwick of Social Films (<http://socialfilms.org/>) with Salamander Trust Associate Nell Osborne

The main documentary was filmed by Dominique Chadwick with support from Nell Osborne

The introductory film is made by Nell Osborne

## WITH HUGE THANKS TO....

### **Salamander Trust:**

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- Sue Holden (Programme Coordinator)
- Florence Kilonzo, Elspeth McAdam (advisers & co-authors)
- Pfirael Kiwia & Willbrord Manyama (trainers & co-authors)
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- Nell Osborne (Stepping Stones Community of Practice Coordinator)
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- Simon Yohana, Nelson Chiziza, Jovin Tesha & Training and Facilitation Team Members

### **Our Funders:**

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*And all the children & their caregivers in Dar es Salaam.....who have taught us so much*



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We plan to organise training of trainers workshops across Africa next year for interested organisations. If you would like to learn more, please contact us through the Salamander or Stepping Stones websites.



**Kivuko na Watoto | Stepping Stones with Children**

By Gill Gordon with Nelson Chiziza, Sue Holden, Florence Kilonzo, Pfiriael Kiwia, Willbrord Manyama, Elspeth McAdam and Alice Welbourn

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The full programme includes: a two-volume manual with handouts, a counsellors' guide, two short documentary films, five participatory films and a guide to the films.