

# 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 widowed, poor, with HIV and limited educational opportunities. They may often be living in isolation and fear due to HIV-related stigma and experiencing gender-based violence. In this context few children or guardians feel safe to express grief or anxieties. Children and caregivers alike lack comprehensive sexuality and life-skills education.

Our programme builds upon experiences of the original “Stepping Stones” community programme on gendered and inter-generational relationship skills\*, to support caregivers and their children, to communicate on these sensitive issues and build individual and collective psycho-social resilience.

### Caregivers, gender and AIDS-related deaths

Many caregivers “fall between the cracks” of the ten 2011 UNGASS targets, since they tend to be grandmothers who have buried their own children through AIDS-related deaths & they are not normally of reproductive age. They form the invisible backbone of the community AIDS response worldwide yet they do not normally get recognised as a part of any key population. Caregivers rarely have support to disclose to, or communicate about HIV, sexuality and death, with the orphans in their care, who also have or are affected by HIV. The role of caregivers is chronically under-addressed from a gendered perspective by donors investing in HIV worldwide.

### Challenges Facing Orphans Affected by HIV

Meanwhile, adults often underestimate children’s ability to understand HIV and to take action in their own lives. Since carers 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 problems begin at around seven years; by age 12 many children have realised by themselves. Legally, in Tanzania, disclosure before age 14 must be conducted with the guardian present. This produces another major barrier to disclosure for orphans living with HIV. Children experience unexpressed grief, sorrow and anger about the effect of HIV on their lives. This affects their psychosocial wellbeing as well as their ARV adherence. Moreover, health providers feel they lack the skills and training to disclose 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*



5 – 8 years children do a drawing exercise during a workshop in Dar es Salaam, Tanzania.



Children aged 5 – 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 carers 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 increase their collective resilience to the chronic challenges they face
- ✧ We eventually envisage this programme being adapted 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 24 adults, 12 5-8 year olds and 12 9-14 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 30 sessions, which were 3-4 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 well-being.

**“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 so 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 how 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 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 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*



“Our Forest of Love”, 9-14 year old children in a pilot workshop in Dar es Salaam, Tanzania.

**“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 join other African partners for roll-out in six other African countries. We eventually envisage further roll-out to address this issue globally.

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For more information about the “Stepping Stones” training package visit: [www.steppingstonesfeedback.org](http://www.steppingstonesfeedback.org) or email Nell Osborne at: [nell@steppingstonesfeedback.org](mailto:nell@steppingstonesfeedback.org).