

EXECUTIVE SUMMARY

KHULULEKA GRIEF SUPPORT

**REPORT ON AN EVALUATION OF THE
WORK OF KHULULEKA GRIEF SUPPORT**

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A. INTRODUCTION

Khululeka Grief Support (hereafter referred to as Khululeka) was established in 2005 in Cape Town by a group of concerned women psychosocial practitioners to address the loss and grief of children orphaned by AIDS. The primary objective of Khululeka is to build the resilience of vulnerable children and their caregivers by equipping them with tools to process their personal experiences of loss and death.

In its current form, the Khululeka programme responds to grief in three ways: 1) offering training programmes for people in recognising and supporting bereaved children, 2) mentoring those trained to use skills with the children who access their organisations, and 3) support groups for children who have experienced loss.

B. EVALUATION TERMS OF REFERENCE

In May 2013 Inkanyezi Social Evaluation Practice was commissioned to undertake an external programme evaluation of the outcome and impact of activities undertaken by Khululeka Grief Support from the 26 August 2011 to 6 March 2013.

C. LITERATURE SCAN

The need remains for psychosocial programmes for children and adolescents. Amongst children who have experienced the loss of one or both parents,

negative mental health outcomes amongst AIDS-orphaned children are maintained and worsen over a 4-year period. It is important that psychosocial support programmes are sustained, and focus on youth as well as young children (Cluver et al. 2012).

There are five peer-support programmes that train community volunteer facilitators to explicitly support children and adolescents suffering loss and grief in South Africa; Khululeka Grief Support, Dlananathi, Wits Reproductive Health and HIV Research Institute, African Solutions to African Problems (ASAP), and the Philippi Trust. Khululeka offers the only accredited loss and grief training programme in South Africa and is the only programme that has run specifically loss and grief peer-support groups based at schools.

According to expert opinion:

- Peer support programmes are effective in reducing the psychological distress of grieving children (Project Loss Evaluation, 2002; Kumakech et al., 2009; Seasons Evaluation, 2010).

- The Department of Social Development (DSD) policy framework: Psychosocial for Orphans and Other Children Made Vulnerable by HIV and AIDS: A Conceptual Framework regards resilience as the ultimate outcome of psychosocial support for children (DSD n.d.:12).
- Any intervention for AIDS-orphaned children must be scalable, affordable and able to be conducted by lay people (Cluver et al. 2012).

D. METHODOLOGY

The ethical protocol was approved on the 16 August 2013 by the Research Ethics Committee of the Health Sciences Faculty of the University of Stellenbosch, (N13/07/095).

A qualitative methodology was used. Data collection regarding activities, process and outputs focused on the period 2011–2012, whilst 2013 was included in order to consider the programme outcomes and impact.

Five focus groups were conducted, three with a total of 27 children who had attended 75% of Khululeka Peer Support Group sessions, one with six children who had attended peer support group run by an NPO that had received ten-week mentoring accompaniment, and one with NPO facilitators who had received Khululeka training and mentoring. Individual interviews were conducted with 17 facilitators who had received only training from Khululeka, with four supervisors who had only attended Khululeka mentoring sessions with one educator. Visits were conducted to three NPOs which had participated in a ten-week on-site mentoring accompaniment pilot programme undertaken by Khululeka. During these visits, additional interviews were conducted with five of the participating facilitators as well as their supervisors and directors/coordinators.

As part of the evaluation, the evaluators piloted a pre and post-test questionnaire for children in two support groups.

E. DESCRIPTION OF PROGRAMME OUTPUTS 2011–2012

- Number of children who attended at least 60 % of the Khululeka Peer Support Group sessions: 29/41 (71%)
- Number of community caregivers who received only training: 39
- Number of community caregivers mentored: 52 across 15 DSD-funded organisations

- Number of community caregivers trained and mentored: 30 people, across 13 DSD-funded organisations
- Total: 121 community caregivers trained as peer support group facilitators in NPOs in the Cape Metro, Overberg and West Coast areas of the Western Cape

In addition, 24 educators were trained as peer group support facilitators in the Free State.

F. KEY FINDINGS

- ***Children able to process their grief and loss***

Children in the Khululeka run peer support groups all found the group valuable and meaningful.

- ***Caregivers, child and youth care workers develop the skills to identify and support the needs of children experiencing grief and loss***

If 'caregivers' is defined broadly as adults who come into regular contact with children and are responsible for their well-being for a period of time, then this objective is being achieved.

All of the 36 respondents in the above categories reported that they could identify and support the needs of children experiencing grief and loss, and were able to provide examples to substantiate this. These 36 respondents ran peer support groups for 2 780 children in 2011–2012. This is a significant reach in the context of 40 000 double orphans in the Western Cape.

However, it is not possible to say whether this objective has or has not been reached with parents, extended family members with whom the children may be living – or with educators. It is not possible to determine this because Khululeka has not specifically recruited parents, extended family members or educators into its training workshops in the Western Cape.

- ***Supervisors, mentors and organisations are equipped to support caregivers and child and youth care workers appropriately to provide this care***

Organisations reported that they feel equipped when all staff have had training from Khululeka, they have a full complement of facilitators and they have funding certainty from the Department of Social Development. Organisational well-being is beyond the ambit of Khululeka's work, but to the extent that Khululeka provides training, some mentoring resource materials, organisations do feel equipped to facilitate the grief and loss support groups.

- ***Relevant materials are made available to enhance support for children in need so that child and youth care workers can build their own resource base***

The Khu Kit is used extensively by facilitators to plan their sessions, to refresh their memories and to get ideas for exercises for the sessions.

- ***Issues that the children face daily, which make the issues the Khululeka facilitators, NPO facilitators and school teachers deal with very challenging***

- There are challenges in the conditions of the physical contexts in which facilitators work.*

- There is a lack of services and referral sources.*

- Many educators and facilitators in these contexts also experience much personal grief and loss, making it challenging to have the internal capacity to hold the children, and meaning that often their own grief needs processing.*

- ***Facilitators are able to process their own experiences of grief and loss and they now feel confident to run peer grief and loss support groups.***
- ***All facilitators who have remained in their organisations after their training are running loss and grief support groups with children.***
- ***Regular, consistent In-house supervision enables correct application of the model, correct referrals, and expansion of problem-solving strategies for troubled children and welcome support for the facilitator.***
- ***Educators in the schools from which the children are recruited either for the Khululeka or NPO-run peer support groups are being supported in their attempts to cope with the challenging behaviour of children experiencing loss and grief.***
- ***Vulnerable children are coming to the attention of the DSD through their participation in the peer support groups.***
- ***The Khululeka support group programme for bereaved children has been mainstreamed by the Families and Children component of the Western Cape DSD.***
- ***The accredited Khululeka curriculum encourages training in loss and grief work with children.***
- ***There is a committed group of child bereavement peer group support training practitioners and facilitators present in the Cape Metro.***
- ***The programme is achieving reach beyond the trained participants, through NPOs innovating to reach more grieving children in various ways as well as adults, based on their input from Khululeka. This organic growth of the programme im-***

pact reveals that the impulse for responding to loss and grief in children is now living beyond the confines of Khululeka– and there is therefore great potential for the sustainability of the programme benefits.

- **Enablers to the successful implementation of the programme in NPOs are:**
 - Regular, frequent rhythm of group supervision
 - Access to one-on-one supervision, whether in house or contracted out
 - Referrals from schools – children who require it, get the service
 - Educators feel something is being done for the child and there is a place to get feedback on how the child is doing, and they therefore support the child's attendance in the programme.
 - Having a social worker within the organisation to whom a child can be referred for more in depth counselling or family intervention
 - Having a good relationship with DSD social worker for effective referrals
 - Low turnover of staff
 - Availability of the Khu Kit
 - Being timeously informed by DSD that the funding contract with the NPO's facilitating peer support groups will be renewed.
- **Factors inhibiting the NPOs' ability to sustain the Khululeka model are:**
 - Trained facilitators leaving to find work elsewhere due to the uncertainty of DSD contract renewal
 - Mismatch between Khululeka training course times and hiring NPO staff
 - Lack of community support for the NPO peer support programme
 - Persistence of stigma
 - Closure of NPOs.

It seems that it is factors largely outside of the control of Khululeka that could undermine the sustainability of the programme within NPOs.

- **Some organisations are not implementing the model to the standard taught by Khululeka.**
- **Once a child has participated in a loss and grief support group, there is no uniform process of follow up in operation either by Khululeka or NPOs across the NPOs.**
- **There is limited contact with home caregivers of children participating in peer support groups run by Khululeka and trained NPOs.**
- **In terms of accessing pre and post-test information, the test was not sensitive. There was little difference between pre and post-test answers.**

Although all children said they would recommend the group to other children, and there was evidence of children becoming more comfortable with speaking about their loss to others, the most useful responses had to do with feedback from the facilitators about how to run the group the next time, rather than providing a clear picture of the precise changes that had occurred for the children through their participation in the group.

The sensitivity of the current pilot pre-post data collection tool was also influenced by the 'test wariness' of the facilitators who rightly did not wish to introduce a 'test' element into the group process.

The questionnaire nature of the pilot tool could also have resulted in the largely one-word answers to most questions. A more interactive, activity based data collection process tool could yield more qualitatively rich data.

G. KHULULEKA ORGANISATIONAL CHALLENGES

Capacity

During the period under review, the Director held operational and implementation roles, thereby restricting time for monitoring and evaluation as well as relationship building with partner NPOs.

Cohesion

There seemed to be some disconnection between different parts of the Khululeka team. Each unit functions well but there is not much team process or cross-fertilisation between different teams concerning the content and outcomes of the work. This is largely an organisational development issue, and related to Khululeka working mainly with contract staff. This means most employees as well as the board have other work. This means it is very difficult to make a regular structural arrangement for the whole team to meet, and it may not even be a reasonable expectation.

Programme resourcing

During the period January 2011 to June 2012, most resources were used to equip NPOs with trained facilitators, reflecting Khululeka's theory that NPO-based facilitators are best placed to offer support to grieving children.

The smallest amount of available resources was spent on directly running or following up the impact of peer support groups for children.

H. PROGRAMME MONITORING AND EVALUATION

Khululeka is currently only recording its activities and outputs. There are no systematic processes or tools for tracking outcomes or impact of the programme.

I. DISCUSSION

The focus of Khululeka's work: Psychosocial support versus bereavement specific work

The support groups provide a very important holding and processing space for the children. Yet, as with all interventions in the developing world we can ask: 'Is it enough?' What does seem to be important is to consider strengthening the support around children. It is recognised that the ongoing support that children will receive is from the family, caregivers and teachers around them, and so strengthening caregivers' responsiveness and ability to support children is important in addition to a therapeutic intervention.

Pathway 1: The Khululeka-run peer support groups

What is the value of Khululeka running high-intensity sessions for a small number of children? As the data has shown, it is valuable for the children who participate. It is also valuable for Khululeka trainers of facilitator workshops who stay connected to children's grief issues by way of reading the reports or attending debriefing sessions of the Khululeka peer support group trainers. However, a much diluted value is 'passed along' to the NPO facilitators actually working with the bulk of the children affected by loss and grief.

For the adult training facilitators to benefit from the expertise of those running sessions with the children, there should be more direct contact between these two types of contracted professionals within the programme.

Pathway 2: Training others to facilitate child loss and grief peer support groups

Since supporting children to process the internal pain of grief requires that the facilitator has been able to process her/his own grief, the quality of the holding relationship is essential for achieving this healing. Therefore, developing standards and making the pathway clear, especially in training the 'soft skills', is important to improve the likelihood that the NPO facilitators will maintain the quality of holding a relationship that is necessary for the success of the Khululeka model.

Care of carers and reflective practice

Khululeka recognises that 'facilitators are very important to our model' and that recognition, supervision and 'holding' of facilitators are important in organisations. South Africa cannot afford professional social work/therapeutic services for everyone. The fact that the Khululeka programme works with community-based lay facilitators is in itself a valuable contribution to the healing of South African society.

However, because the programme affects facilitators personally, a reflective practice amongst the Khululeka community of child grief practitioners and the facilitators they train and mentor is essential.

Contracting with partners

Beyond the complicated and demanding process of arranging the logistics for training and mentoring participation of facilitators, there is a need to involve participating NPOs in the growth of the programme, particularly with those who are already experimenting with innovations to increase their own impact on grieving children.

A continuing relationship with partners, some consistency about which staff deal with partners, and coherence between who is trained and who facilitates peer support groups with children would further enhance the Khululeka programme.

J. KEY RECOMMENDATIONS

- Khululeka peer support group facilitators should continue facilitating groups with children.
- Strengthen and deepen relationships with partners.
- Involve NPOs in monitoring the effects of the programme, for their own learning.
- Consider using a step-by-step (phased) community training model aimed at independence of trainees.
- Strengthen community systems.
- Recognise that Khululeka's 'therapeutic' role strengthens carers and systems around children, and also develop this role by focusing on strengthening relationships around children through networks as well as 'training' others in responsive caring or support skills.
- Develop Khululeka's role as a community of practice around bereavement.
- Create more cohesion within the Khululeka team.

- Develop a monitoring and evaluation framework and systematic process for data collection.
- Expand programme funding sources.
- Consider a funding relationship with DBE to enhance the ability of teachers to support children suffering grief and loss.
- Consider incorporating a session into the curriculum to support HIV status disclosure of children.
- Scale up the piloting of the ten-week mentoring accompaniment activity.

K. CONCLUSION

Khululeka Grief Support is making a meaningful contribution to the healing of adults and children who have suffered loss and grief. With minimal resources the Khululeka team has facilitated reaching a large number of children suffering from loss and grief.

