

"... and one dare to hope and dare to remember".

Memory Work: Coping Strategies in the Face of AIDS

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Enhancing psychosocial support of children affected by
HIV/AIDS:
A special focus on memory work

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Abstract: This paper looks at the need for psycho-social support (PSS) among East and Southern African children and how a relatively new organisation REPSSI, has positioned itself as an advocate and facilitator around the provision of PSS, through a diverse range of strategic partnerships, and by supporting and encouraging innovative, culturally appropriate methods. While this presentation has a special focus on memory work, the work of REPSSI extends far beyond this form of PSS. In this paper, memory work is used as an illustrative example to demonstrate how different forms of PSS need to be integrated with other care and support programmes. Beginning with a historic memory work meeting in South Africa in October 2003, REPSSI's powerfully encouraging and mobilising role for PSS becomes clearer. The memory work case scenario shows that at the micro level, working with individual consultants and various partners, REPSSI's direct support and encouragement has resulted in considerable gains, both in terms of the development of new knowledge, and its transfer to significant numbers of others. At the macro level, their role as networker, strategic thinker and catalyst, has mobilised a large number of separate local nodes of strong but under realized memory work practitioners, to both develop internally as well as to join forces in ways that avoids duplication and that have resulted in a great leap with regard to scaling up comprehensive responses to the orphans and vulnerable children (OVC) challenge in Africa.

Introduction:

Nearly 15 million children are estimated to be orphaned in the 13 African countries in which the REPSSI (Regional Psychosocial Support Initiative) is operational. As the problem of orphans and other children made vulnerable by HIV and AIDS continue to swell, responses generally remain of a physical and material nature. Extended family, community, and faith-based organisations provide the majority of care and support for orphans and vulnerable children (OVC) with a focus on food, clothing, education, health services, and child protection. Such responses are largely influenced by donor demands for tangible statistical results.

REPSSI realises that beyond physical and material support, orphans and other vulnerable children also require PSS and that this form of support can yield

significant sustainable results for children and youth who are subjected to chronic trauma resulting for example from them caring for, and witnessing the illness and death of their parents and sometimes their siblings. Discrimination and social stigma associated with their parents' illness and death further compounds the children's emotional stress. The impact of parental death on children is so complex and can profoundly affect the development of healthy emotional intelligence, adequate life skills, and strong self-esteem. While children have great resilience and varied coping strategies, the heavy deterioration of community and family safety nets in east and southern Africa is causing OVC enormous challenges in meeting their need for love, protection, personal identity, and social connectedness.

While many programs are being implemented to address the 'physical needs' of orphans and vulnerable children (OVC), little attention is being given to the psychosocial needs of these children. Thus, REPSSI believes that omitting PSS in the OVC responses is a serious obstacle to comprehensive responses needed to promote total child development and well being.

Organizational Vision:

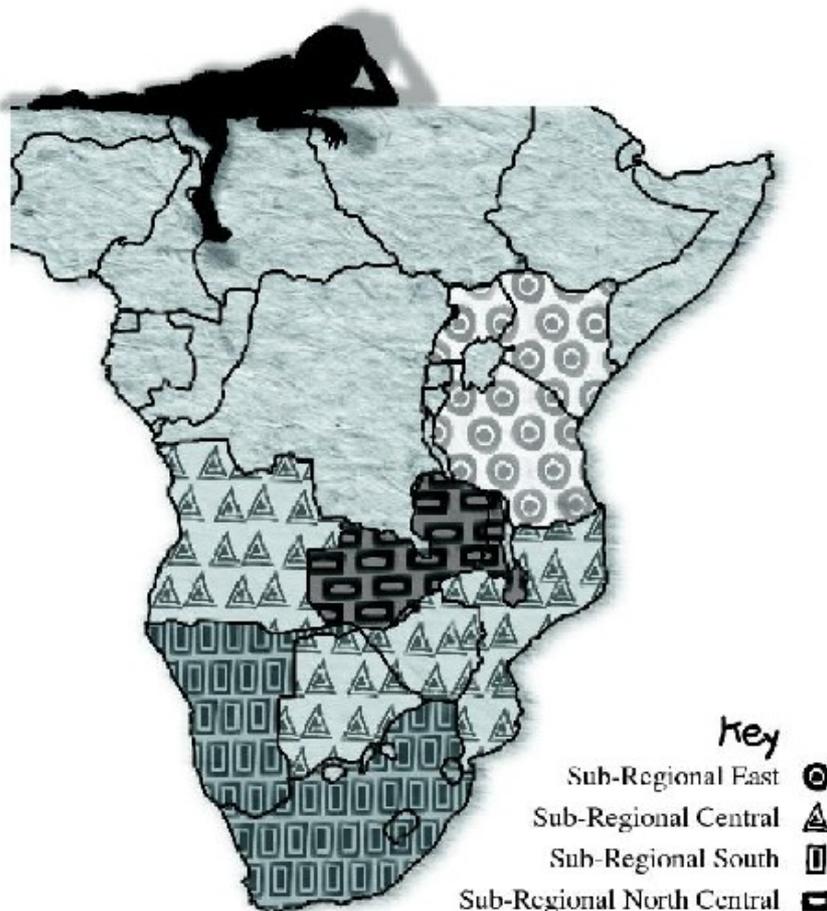
REPSSI which began only 3 years ago in May 2002 strives to be and many would say is, a leading, recognized authority in advocating for and providing quality technical assistance and knowledge in psychosocial care and support to children, youth, families, and communities in east and southern Africa.

It manages to operate in so many countries through the development and nurturing of careful and strategic partnerships with a wide range of individuals and organisations all of whom work with innovative and culturally appropriate methods of PSS.

Mission:

In a nutshell, REPSSI exists to enhance psychosocial support for children, families, and communities affected by HIV and AIDS, poverty and violence through capacity and resilience building in collaboration with partners.

Where are we based?



The 13 countries in which REPSSI operates represent some of the hardest hit countries by HIV/AIDS at a global level: South Africa, Lesotho, Swaziland, and Namibia; Zimbabwe, Botswana, Mozambique and Angola; Zambia and Malawi; Kenya, Uganda and Tanzania.

Why PSS?

“My grandchildren are often sad. I can see they are sad. But I don’t know what to say about their parents dying. I worry that they think that I don’t love them, but I love them with all of my heart.”

These are words of a grandmother who lives in the far north of South Africa in an area called Blouberg in Limpopo Province. She was looking after five grandchildren aged 3 to 17. Her two daughters had died from AIDS, one a year ago and the other only three months ago. She could see that her grandchildren

were sad but she did not know what to do to help them with this sadness. Many people find themselves in this situation when looking after children who have lost parents.

What can we do to help?

Children affected by HIV/AIDS endure the loss of caregivers, livelihoods, and health. Many suffer deprivation, overwhelming loss and grief, upheaval, discrimination, and social exclusion. Support for children’s psychosocial well-being is a key investment in human capital because it underpins all other processes for the long-term development and stability of societies. Psychosocial well-being is essential for children’s survival and development, especially in enduring difficult circumstances.

What is PSS?

The definition of psychosocial support is a long-discussed issue and there is not only one valid answer for it. The definition below reflects REPSSI’s understanding of psychosocial care and support.

Psychosocial care and support are interventions and methods that enhance children’s, families’, and communities’ ability to cope, in their own context, and to achieve personal and social well-being; enabling children to experience love, protection, and support that allow them to have a sense of self-worth and belonging. Such interventions and methods are essential in order for children to learn, develop life skills, participate fully, and have faith for the future.

Domain	Description	Possible Programmatic Application
Psycho Belonging, faith for the future	When an organization or community group provides/organizes / stimulates, etc, and therefore creates a platform that makes it possible for an individual child to disclose feelings, realities, etc., and provides some form of counselling.	<ul style="list-style-type: none"> • Group processes / group counselling • Debriefing in experiential learning, plays • Home visits with quality time spent with children • Drop in centres
Social Belonging, participate, life skills	When an organization or community group actively influences the social environment in the direction of reintegration of affected children into “normality” and creates comprehensive understanding of the specific situation of children (i.e. create somewhat durable social structures)	<ul style="list-style-type: none"> • Training of caregivers and guardians • Community sensitization • Orphan organizations • Kids clubs • Child participation in community committees
Support Self-worth	When an organization or community group explores and systematically builds up the internal / own resources of children in order to enhance their resilience	<ul style="list-style-type: none"> • Life skills training • Positive feedback to children about their performance • Solution-focused approaches / participatory methods / creative self-expression

Key elements of Psychosocial Support for Children Affected by HIV and AIDS (CABA) include:

- Bereavement and Grief
- Spiritual Support
- Reduction of Risks & Vulnerability to HIV/AIDS
- Stress management, Trauma rehabilitation
- Coping & Resilience
- Life Skills Education
- Identity, Goal Setting
- Self-esteem, confidence
- Stigma management
- Learning through play.
- Peer Care as youth prevention strategy.

Integration of PSS (Mainstreaming PSS) into existing programmes

REPSSI has adopted the following strategies in fulfilling its mandate:

Strategy 1: Use advocacy to promote the mainstreaming of psychosocial care and support in all aspects of child development.

- Strengthen **national OVC networks** to mainstream PSS into their member organizations' policies and practices, for example REPSSI participated in the Namibian National OVC conference in 2005 during which their National OVC Strategy was inaugurated. REPSSI's role focussed around ensuring that there was child / youth participation in this process.
- Sensitize, encourage and support partners to mainstream activities and/or forms of organizations where **children and youth** assume responsibilities **as social actors**. The VSI programme in HUMULIZA - a kids savings club from Tanzania is an amazing example.
- Develop mainstreaming guidelines for enhancing the capacity of **multi-country organizations** to integrate PSS into policies, practice, and care. REPSSI is currently working with Save the Children UK in scaling up community sensitization to PSS through the 'Journey of Life' tool
- Support **policy development and enforcement** at both regional and national levels.

Strategy 2: Develop, share, and disseminate knowledge, skills, and expertise in the application of psychosocial care and support with partners at all levels.

- Use **reflective and interactive processes** for capturing, developing, and sharing knowledge with community groups and organizations. An example here is memory work itself, which is both a therapeutic tool as well as a powerful participatory reflective and qualitative research instrument. By engaging with their own stories and sharing them with others, this kind of work spills into another domain which is very useful in communicating and understanding a wide range of complex issues not easily captured by empirically structured quantitative research methods.
- Through collaborative processes, **harness the knowledge and experience** of recognized partner organizations to efficiently and effectively develop, share, and disseminate knowledge, skills, and

expertise. Via its website and the regular production of resource materials containing REPSSI latest research findings as well as useful resources developed by partner organisations, knowledge and skills are widely disseminated.

- Create a **healthy psychosocial support environment** for all children by working with and supporting **teachers and other organisations providing services to children**.

Strategy 3: Work in partnership with existing organizations that interface with children and youth to enhance and promote the provision of psychosocial care and support.

- Develop internal skills and capacity that enable REPSSI to **communicate with partners** to extract, enhance, and share psychosocial care and support knowledge and skills.
- Provide widespread technical support throughout the region via a **mobile psychosocial support task team**.
- **Share PSS knowledge** with partner organizations through productive and collaborative dialogue.

Strategy 4: Ensure quality psychosocial care and support service delivery while meeting the very urgent psychosocial support demands of the region.

- Consolidate and harness internal skills and capacity to provide **quality assurance** both internally and externally.

REPSSI's goal therefore, is to facilitate and increase the overlap between knowledge development, transfer, and scale-up. Primary elements to the REPSSI scale up strategy include:

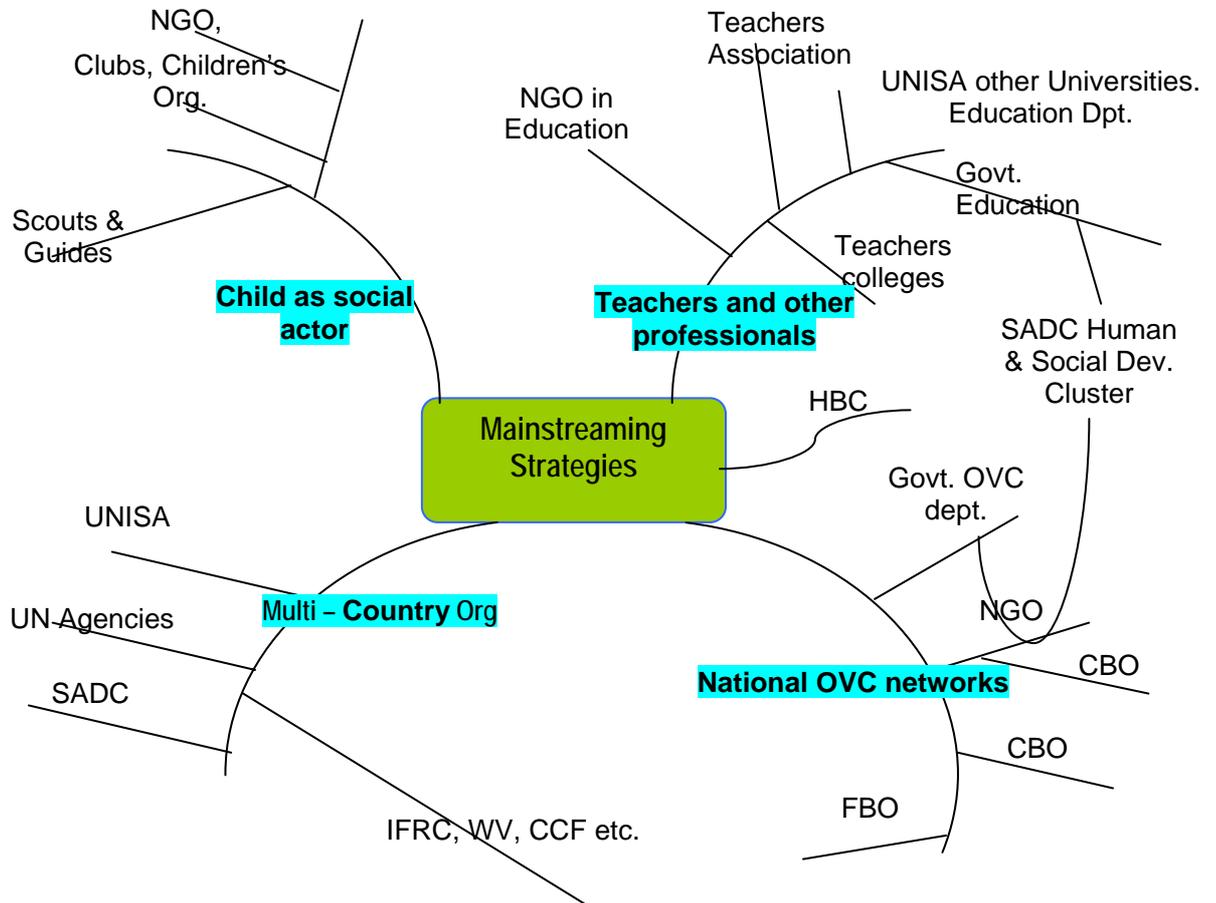
- PSS model development and testing, working with organisations that have PSS expertise.
- The creation of partnerships, alliances, and networks – to facilitate PSS model transfer and scale up.
- Training and mentorship - Regional Pool of Facilitators, the Youth Development Diploma and the New OVC degree being developed in partnership with UNISA & UNICEF.
- Information creation and dissemination - Knowledge Net Centres (KNCs);
- Advocacy, Community mobilisation for better care and support of children -Journey of Life - a community mobilisation tool; and
- Material and technical support for mainstreaming PSS

Other PSS approaches besides memory work that REPSSI is implementing to enhance PSS for CABA include:

- Group intervention therapy
- Participation
- Solution Focused approaches
- Narrative therapy
- Play therapy
- Experiential learning

Mainstreaming and Scaling Up – Taking memory work as an example

REPSSI's role around memory work and the 10MMP is a really good example that highlights the provocative – inspirational – mainstreaming – scaling function that is key to the REPSSI approach. The flow chart below illustrates how this approach is evident in many other areas as well.



Child as social actor: children not immune to HIV/AIDS related stigma and discrimination. We need to realize that children as part of the solution.

Teachers and other professionals:

Schools need to be recognised and acknowledged as centres of care and supported OVC, with teachers being the primary support base.

Multi country organizations:

The International Federation of Red Cross and Red Crescent Societies.

Memory work might be defined as the *creation of a safe space in which to contain the sharing of a life story*. This space might just be a room or the shade under a tree, but is likely goes beyond this to include, for example, the drawing of a map, or the creation of a memory box, basket or book. The scope of memory work is not only restricted to the past. Its purpose is often to deal with difficulties in the present, and its main orientation often tends towards planning and the future.

It was stated earlier that REPSSI modus operandi centers on the development and support of innovative and culturally appropriate methods of PSS.

Let us take a moment to appraise or critically evaluate memory work in this light.

In favour of this approach, the following can be said: Memory work

- offers the opportunity to assist children with the preparation for loss, bereavement, and for the future.
- opens opportunities for communication with the family, breaking the culture of silence relating to death and dying.
- is seen as a holistic approach that facilitates the child and the family to plan jointly to address their needs.
- enables work on prevention of further HIV transmission, and adherence to anti-retroviral treatment.
- has been instrumental in shifting the hopelessness surrounding HIV and AIDS to a range of possibilities including living positively within a context of adversity.
- strengthens the capacity of families to protect, support and care for children affected by HIV/AIDS.

But in what ways is it innovative and culturally appropriate?

It was once said at the SAHARA HSRC HIV and Aids conference by a delegate with the name of Mr Maseko that a truly African therapy or form of healing needs to have the following components (and that their absence might explain the poor take up rate and success of Western rooted therapeutic models):

According to Mr Maseko, an effective African healing practice, should:

- 1) includes a spiritual dimension
- 2) in some way invokes the ancestors
- 3) dedicates a special place, container or shrine in the homestead for communion or communication with these ancestors

This could almost be a definition of memory work. Memory boxes, books, body maps resonate both with similar modern forms like family photo albums, as well as with culturally diverse and ancient forms like totem poles, cave paintings and oral traditions which reference creation stories, ancestor stories, and clan genealogy.

Is Memory work innovative?

REPSSI has for the last several years supported various memory workers via medium to long term consultancies, and partnerships with front line organisations involved in memory work. We have supported and encouraged these individuals and organisations to concentrate their efforts towards developing and evolving memory tools to go beyond the bereavement model and to take in for instance PSS that can be offered in ARV contexts. Over a relatively short space of time, we have witnessed the evolution of a wide range of memory

tools well suited to serve a diverse client need. The tools certainly seem innovative (hero books, body maps, tracing books, lockable memory tins called telephones, etc) and the diversity of clients they are designed to serve range from orphaned children, to children and adults living with HIV, to grandparents looking after children where the middle generation are missing, and a whole range of children facing a variety of difficult circumstances not necessarily directly associated with HIV and AIDS.

The bottom line is that Memory **work is for everyone**, and if you have not explored your own memories, hopes and dreams using some of these tools, it is about time you did.

It is thus clear why REPSSI chose to promote and support Memory Work as one of the key psychosocial interventions: because **memory work presents a great opportunity to develop a sense of self-worth and belonging**.

It was stated earlier that REPSSI is neither a front line organisation nor a funder. By setting itself up in its mission statement and organisational vision as “a leading, recognized authority in advocating for and providing quality technical assistance and knowledge in psychosocial care and support ...” REPSSI carries a regional responsibility to keep an eye on the big picture and to ensure that the scale of the problem / challenge is met.

An early reading of the PSS needs of children in the region and some preliminary understandings around memory work convinced REPSSI that this was a replicable, sustainable and affordable form of PSS, but also that local initiatives were inadequate in terms of coverage and scale. Memory work, like other PSS approaches, is not a new program line for NGO’s working with children affected by HIV and AIDS but as outlined before, REPSSI recognised in this approach, an almost minimum / bottom line, kind of PSS intervention that gives additional value to existing programs.

For this reason, in October 2003, REPSSI funded and organised a meeting of key African memory work practitioners and allowed them the opportunity to share their approaches, and to engage in dialogue and peer review. Some of the main players present at this meeting were NACWOLA, the International Federation of Red Cross and Red Crescent Societies (IFRC), HealthLink Worldwide, as well as various South African and Kenyan memory work practitioners. There was a great amount of excitement, intrigue, and mutual admiration going on.

However, the need to scale memory work to all East and Southern African children facing difficult circumstances was as heightened given the future projections of the OVC numbers (12.3 million children in Africa who have lost one or both parents to an AIDS-related illness, with that number expected to almost double by 2010, (Children on the Brink, 2004).

Thus from REPSSI’s point of view, several things were noteworthy

- 1) In spite of the excellent and hard work being done by all these organisations, who were and are widely acknowledged experts, their impact in terms of numbers was almost inconsequential (between them, they were struggling to reach the fifty thousand mark)

2) Because of a lack of coordination, there was some duplication and even some risk of competition amongst them.

3) There was a need for REPSSI to invest time and resources into helping this group consolidate their efforts into a united front that might result in scale up

4) While they were all excellently positioned to make a real contribution to PSS in the African context, they were all chronically under-funded and were all trapped into short term funding cycles with uncertain futures as organisations

During the last session of the meeting, those organisations present, were challenged by REPSSI to think "out the box", to identify the number of children they were presently reaching, and to plan and think very boldly indeed along the following lines,

"If there were no funding or budgetary constraints, around how many children you would want to include in your work, and how many African children could you as a collective group reach by the year 2010?"

After some gasps of "Imagine that! As much money as we need!" and some number crunching, the Ten Million Memory Project was born.

Today the 10MMP while still in its early stages, is fast maturing into its dream or vision, i.e., a Pan African and Global social movement around this rich and engaging form of PSS. From its humble but inspired beginnings - a single memory book made by a displaced Ugandan refugee and her child, both of whom were living in London - memory work is now a household word, amongst all those working in the field of PSS. And it is poised to become even more mainstreamed and scaled.

With regard to this meeting, through REPSSI's advocacy, memory work has been made an issue within Aidsfocus and these efforts have led up to the conference itself as well as the production of memory work film - Strength from Remembering, directed by Rene and Eva Schraner. Through Aidsfocus picking up memory work as a main focus, the memory work component has been included in programs of Aidsfocus member organizations in Uganda (via co-operate), Togo (via Swiss Red Cross), in different countries in Asia and SADC region (via World Vision) and in Switzerland (via AIDS & CHILD foundation and REPSSI's advocacy coordinator).

REPSSI acknowledges that any expertise around memory work that we lay claim to, was developed and resides with our memory work partner organisations. While we are certainly not a funder, or a front line organisation, we are a PSS technical capacity building organisation.

Conclusion:

The opportunity to present this paper at this conference has provided REPSSI with a chance to review some of its practices and achievements to date - review whether we are living up to our name as leader and authority around psychosocial care and support to children in Africa. This process has also given us the opportunity to acknowledge some of the special relationships we have with our partners, who are collectively too many to have detailed or even to have mentioned in this presentation. By tracking the story or history of the ten million memory project (10mmp), from a single memory book to the emerging pan African social movement it is today, beginning with the historic memory work meeting in SA in October 2003, REPSSI's powerfully encouraging role, not as front line service provider but as facilitator, mobiliser and catalyst has become clearer. Through this exercise in remembering or reflection provided by Aidsfocus, we ourselves are encouraged to keep working within and further exploring our present model.

I might also mention how important our relationships with the North are to us. One of our pioneering members of staff, Irene Bush, who is also our advocacy coordinator, lives in Switzerland and she helps to keep us globally connected. Stefan Germann and Kurt Madoerin, REPSSI advisors, also come from Europe. All our funders are based in Europe but it is not only a funding recipient relationship we want with the North. We are certain that we have a lot to learn from European providers of PSS and we have been looking forward to rich exchanges at this meeting.

In conclusion I can just say, we need to work together in order to effectively influence the children's comprehensive development which includes psychosocial well being. Let us create space for memory work in the responses that we are already implementing.

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