

AIDS Response

Research estimates that 90% of AIDS care in South Africa takes place in the home, provided by about 90 000 unpaid community carers.

AIDS Response, based in Cape Town, South Africa works to improve service delivery in the HIV and AIDS Sector by providing wellness support and capacity building programmes to health workers, caregivers and their organizations, primarily through (1) a self-care and wellness programme and (2) a learning, linking and lobbying agenda. Neighbourhoods, groups of people and organizations are supported to become nurturing communities through practicing the values of diversity, spirituality, respect, compassion, empathy and self-knowledge.

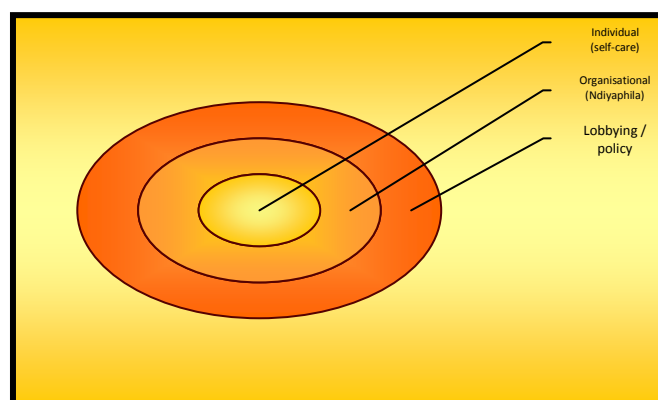
Aims and Objectives

AIDS Response has a vision for “a caring, compassionate and stigma-free society that acts in solidarity to ensure that the wellness of all people infected and affected by HIV and AIDS is valued and promoted.” Working towards this vision, the organization focuses on the following aims:

- To assist community HIV/AIDS caregivers to work in more sustainable ways, central to which is raising awareness of the need for self-care.
- To assist care-based organizations to initiate, develop and strengthen psychosocial support programmes, particularly for staff and volunteers.
- To improve carers’ working conditions through advocacy, mobilization, research and policy development.
- To ensure that the voices of carers are heard, amplified and have direct impact on agendas affecting them

Activities

Operating independently since 2008, AIDS Response works to achieve these aims through a comprehensive set of core activities, fitting largely into either (1) Care for Carers or (2) Linking, Learning and Lobbying.



- 1. Self-Care Workshops:** The Care-for Caregivers (CFC) workshops promote self-care techniques and education for caregivers in HIV and AIDS-related organizations, offering a residential “time-out” experience for groups of men and women. Through a four-phase programme over two years, caregivers are offered a space to reflect and share experience, and find healthy, sustainable ways of coping with trauma and stress. CFC workshops typically run between 2-5 days each, depending on content. AIDS Response offers at least 24 CFC workshops annually to an average of 22 participants per workshop. These participants are drawn from a pool of care-providing service organizations.
- 2. Support groups:** AIDS Response operates a number of support groups specifically for groups of carers who need space and support to reflect, debrief and be refreshed. More recently, AIDS Response has responded to requests for capacity building support to other organizations who want to set up similar support groups for carers.
- 3. Ndiyaphila Project:** *Ndiyaphila* (“I’m well; I’m alive”) is an Organisational Leadership Development stream, building capacity in those organizations whose carers attend CFC workshops to mainstream self-care and wellness principles in the organization itself. This includes regular site visits by AIDS Response to participating organizations for accompaniment and support, along with individual coaching and mentoring.
- 4. Counseling:** Naturally, with its strong focus on psychosocial support and wellness, counseling is a core component of the AIDS Response process. Requests are increasingly received for 1-on-1 counselling, linked to supervision and referral. At the same time, AIDS Response applies an internal wellness programme for its staff, making a small budget provision for different opportunities to promote staff wellbeing (eg. yoga, nutrition education). Counselling at all levels is aimed to influence integral living and sustainable care, careful to always use language that is enabling

and empowering while still challenging individuals to take bold steps to do foundational, formative work within themselves.

5. **Research:** Alongside the CFC process, the Linking, Learning and Lobbying (LLL) process focuses on capturing experience and generating evidence that could strengthen a platform for lobby and advocacy around carer recognition and human rights, mobilize caring communities to express themselves and participate in policy reform, and engage in policy development at every level.
6. **Consultations with Care Workers** (linked to LLL)
7. **Resource Mobilisation:** This pertains to donor relations and the procurement of funds, as well as to the effective development of human resources in staff and beneficiaries.
8. **Governance:** Good governance is essential for the integrity, operation and sustainability of an organization. AIDS Response has its origins in The Grail, delinking and becoming a separate legal entity in 2008. Its Trustees include carers and others who are representative of experience from the field, reflecting the values placed on inclusion, participation and legitimate 'voice' of the care community within the organization.

Our Approach

Ways of Working

Illustration/Story

Tools/Resources

Work from strengths, from what is already there; help others to recognize their strengths and build on them.

This way of working is drawn from Popular Education Theory, and adult-learning approaches, to validate lived experience within people.

- a) Illiterate workshop participant who asked a fellow participant to write her story on her behalf (her inability to read and write did not stop her from “owning” her voice and her experience).
- b) creating symbols to express learning – pestle and mortar, grinding of corn

Ice-breakers that affirm diversity

Meditation to help with anxiety

Contracting with participants at the start of a workshop

Option of mother-tongue expression and communication.

Emphasis on body work + creative exercises, e.g. collage-making, hand-art so that not everything is conceptual/intellectual/academic.

Using visual aids to support explanations

Dynamic integration of 6 key AIDS Response values: spirituality, self-knowledge, compassion, respect, empathy, valuing diversity

- a) Creating enabling spaces - where participants have freedom to choose, and can confidently say and safely say NO! - by embodying the values as facilitators and staff.
- b) Religious vs Spiritual: some participants are initially uncomfortable with the methodology if it draws on techniques from other spiritual traditions (eg. NC workshop)

Contracting

Window of the world

Training events or learning experiences are not presented activities-sake alone; instead each activity is a conscious exercise for Transformation of the individual, of the group, of the global community.

Like the ripple effect of a pebble dropped in a well, so AIDS Response holds the vision of influencing and expanding a healing community.

- a) Damaris’ story
- b) Nicky Booysen

Consultation

Think-well share-shops are experiential and respectful sharing and learning processes where everyone is regarded as the expert of their own experience.

Nobantu’s input and experiences as shared at the Thinkwell

Documentation of Thinkwell process

Audio recordings of all inputs

‘way forward’ + strategy developed together by different stakeholders

What we're most proud of

1	<p>The Foundational philosophies:</p> <p>Applying the 6 AIDS Response values in every area of life and work creates an environment of mutual respect, where genuine accountability is possible, and true mentoring can take place. People feel free to practice respect for self and others. This opens possibilities for all participants in the process – staff and beneficiaries – to grow from a sense of insignificance to a very real sense of significance and capacity. It builds confidence that ‘if others believe in me, I can believe in myself.’</p>
2	<p>Pushing boundaries:</p> <ol style="list-style-type: none"> The AIDS Response process for promoting self-care challenges personal conventions and traditions – the environment is safe, but the process is not always comfortable – and participants need to stretch into the unfamiliar in order to progress and grow. Contrary to many interventions, the process is as important – if not more so – than the destination. The CFC-process is less concerned with the external programme activities and interventions offered by community care workers. Instead, it has a niche focus on cultivating the “internal landscape” of carers. Advocacy is addressed from a different angle to other organizations. AIDS Response does not see itself as a voice for the “voiceless”, believing that no one is without a voice. Instead, the CFC and LLL programmes aim to build confidence, particularly in carers, to speak for themselves. AIDS Response practices informed risk-taking; not every next step is immediately clear, but based in conviction about what is important, the organization moves forward in faith and resolve.
3	<p>Care for others means caring for yourself:</p> <p>The quality of care provided by people, especially community carers, is directly linked to the wellness of the carers themselves. CFC offers participants opportunities for ongoing transformation and personal growth, to develop the capacity to grow and change, to flourish and thrive, to be better able to “hold life”, not simply react to it.</p>
4	<p>Attitude of mindfulness:</p> <p>AIDS Response demonstrates (in its staff) and cultivates (amongst its participants) an attitude of awareness in life. People can be conscious and present in each moment, not shut off from themselves by the weight of issues and responsibilities, even when coping with intense struggle. This is evident in the transformed faces of carers who arrive at CFC workshops tense and strained and burdened, and leave having discovered their own power and internal vision and personal agency.</p>
5	<p>Honouring our values:</p> <p>Values matter to AIDS Response. Staff members are not just “doing jobs” or “performing duties”. They are modeling ways to live. As an organization, AIDS Response places high priority on integrity – staying true to core values – in professional life, in office culture, in the interactions with people, in decision-making. Values determine that AIDS Response always works from conviction, and with others where there is a sense of resonance around common values.</p>
6	<p>Listening to carers:</p> <p>The AIDS Response process provides a safe space for carers to express themselves, and to oppose the silence and suppression that is often around them, both from themselves and from others. The platform is, at the same time, safe and challenging, stimulating carers to take responsibility for themselves, for their leadership in their own lives (agency) and contribute to collective action together (advocacy).</p>

What we're most proud of

7	<p>The Operational Team for AIDS Response:</p> <p>The success of AIDS Response is not in the programmes. The organization is aware that success lies with people. The AIDS Response operational team consists of high-quality, capable, competent people, with strong character. Every person in the team can be trusted to do the best possible job, and then to do more than just the job.</p> <p>Team-life facilitates personal wellness and growth for every individual. AIDS Response takes job satisfaction seriously: team members routinely offer affirmation and positive feedback to each other, job satisfaction is budgeted for under an internal staff wellness programme, and indicators have been developed within the overall strategic plan for AIDS Response.</p>
8	<p>Making visible the substance of the work of community care workers:</p> <p>The Linking, Learning and Lobbying programme, complemented by the CFC-platform, is able to raise recognition of care work as an essential service through showcasing stories of carers, facilitating that they share their own stories in a range of settings, and conducting research. This generates both evidence and shared conviction to strengthen advocacy around the value of care work, and appropriate support for care workers.</p>
9	<p>Collaborative Ways of Working:</p> <p>No single organization has the complete solution. There is no single way. AIDS Response appreciates that organizations working in the same sector are interconnected, and can work as part of a bigger entity. Choices about collaboration and partnership, however, are important, and are based in a shared value system and common philosophy about ways of working. In this environment, AIDS Response focuses on creating space and opportunity for each partner to focus on being the best they can be in their particular area of expertise.</p>
10	<p>Social Transformation and Healing:</p> <p>The work of AIDS Response towards social transformation, including education, is connected to healing. Methodologies drawn from Transactional Analysis and CAPACITAR reinforce the belief that 'by healing ourselves, we are healing the world.'</p> <p>AIDS Response sees that part of its work is to gently sensitise partners to this intangible quality – the deliberate integration of spirituality into care work, that goes beyond traditional psychosocial support services.</p>
11	<p>Facilitation process:</p> <p>AIDS Response works through a facilitation process, in line with popular education methodology, the capacity for which and quality of which are high. This process allows participants to participate in assessing, analyzing, designing, forming and reflecting on their own life experience, and to act from their own internal resources to move forward in life.</p>

Our results

Result/Outcomes	Indicators	Tools/Resources	Illustration/ Story
The Linking, Learning and Lobbying Programme	LLL Task Team Care worker consultations and Think Wells Increase in strategic partnerships Case studies Policy submission	Case study booklet Base of grounded expertise and information Politics of Care Work	Impact Resource Allocation with SCAT Opportunities <ul style="list-style-type: none"> - network - space Erna
Establishing transferable, sustainable Models of Care that can be applied to individuals, groups or organizations.	CFC self care workshops, and capacity building for support groups. Organisational capacity development for self-care Ndiyaphila awards	CFC Manual Newsletter Brochure Website Images/photos	Karen's story about award receipt
Growth in new personnel, leading to increased opportunities to expand programme scope, to increased capacity for strategy development and to deeper organizational change.	Increased number of staff, including programme and admin. Coordinators and research. Increase in range of skills and knowledge available. More advisors linked to the team, offering a broader range of expertise and improving institutional knowledge, strategy	staff policy work plans process documentation contextual information CCW Conditions Gender/HR for health	Damaris's story
Requests from more organizations around South Africa for access to CFC and support to develop workplace care programmes.	Contracts e.g. SARCS, SCAT, TAC, NACOSA		SARCS
Carers finding their voice			AAA – Budget Day Picket
Organisational Development and Learning through deliberate Action and Reflection			Manual + Ndiyaphila 5 day

What are we learning? What can we share?		Illustration
1	Even though our focus is on care for the carers, we can't only work with carers themselves. It is important and necessary to work with all workers in an organization so that the whole organization understands the philosophy of self-care. Otherwise, care workers can become even more isolated and frustrated by organizations that don't support them after a CFC workshop.	Coordinator who broke her ankle
2	In a process like that of AIDS Response, which depends so much on facilitation, the qualities of a facilitator – rather than their “hard skills” and the content of the programme – are a priority. <i>(eg. a commitment to lifelong learning, facilitative skills – listening, redirecting, questioning, not focused only on training and teaching)</i>	National Department of Health visit to CFC workshop
3	Sometimes it is necessary to “stray from the script”. Things seldom work out exactly according to our plans. We need to learn to trust our intuition.	Flexibility in working with process
4	The “internal process” for participants at a CFC workshop is what matters most. The disciplines of reflection and sharing, and the practice of various tools and techniques need to be simple enough that participants easily internalize and integrate these elements in order to take them home, and even pass on to others.	Meditation Finger Holds
5	Facilitators are not separate from the participants. They are co-participants. It is important for the integrity of the process that facilitators (eg. staff) practise what they preach.	Disclosure + status testing
6	We are not – as is often taught to us – separate parts, disconnected. Body, mind and soul are powerfully interconnected. A focus on spirituality can help to restore this sense of connection. Not everyone is immediately comfortable with this philosophy, particularly if they come from a strong faith tradition. People can be restless and awkward and resistant at first, and so the process needs to be handled sensitively.	Participants experience restlessness + stigma at first
7	Carers have often stigmatized or compartmentalized themselves in order to cope with the stress of care, and to not fully feel the burden of responsibility. They may have had experiences they are not prepared to think about themselves, or share with others. Body work techniques (dance, craft, yoga, tai chi, painting, etc.) are very helpful tools to activate the body to express and release stress, and help move individuals to a place of deeper acceptance.	
8	Goodwill is increasing (anecdotes from the field and donations from individuals) + champions are emerging and developing to promote the work of self-care.	Trudi Newton; Joanna Beasley Richards; Pregs Govender; Ann Hope Staff + facilitators, trustee and board members; SARCS interviews to the interventions
9	It is the right time now to address carer's rights – it has been a process of evolution, a seed is now germinating, rooted in self-care (Tools available: Membership of SACAC working group; Policies; Foundational work on self-care and assertiveness)	AR recognised by policy makers, e.g. CCWMFP Caregivers articulating their issues more strongly, e.g. Niki Booysen's

What are our challenges and emerging issues?

What would we like to learn from others?

1	Monitoring and Evaluation <ul style="list-style-type: none"> What are the most effective ways to assess the capacity and quality of facilitators in this work? At what point in a process with people and organizations, does a support-organisation “let go”? How do we measure clearly enough the impact of our work in terms of evidence of transfer to others and whether genuine capacity that has been developed? How do we track and link the micro-work with the macro-work [progress and success at the local community level linked with big picture responses, eg. policy and advocacy; collective care work of many local communities] How do we measure, not only the results/impact, but monitor the effects (sometimes negative) of the work we do?
2	Recruiting/Retaining <ul style="list-style-type: none"> How are other organizations working to attract, develop and retain appropriate staff and volunteers? How are other others developing and negotiating genuine partnerships, which are based in resonance around shared values?
3	Grief & Loss <ul style="list-style-type: none"> As organizations, have we adequately moved beyond having workplace policies in place, towards practicing genuine support and care within our organizations, particularly around those who have suffered personal loss? Are we applying care, not just “out there” but “in here.”? In terms of the AIDS Response programme, the Grief and Loss component of the CFC workshops may be too limited, especially when grief and loss form such a high portion of the care work. Are we adequately acknowledging accumulating grief and loss that is not only death and dying, but issues of injustice; displacement, disenfranchisement; loss of optimism and hope?
4	Celebration <ul style="list-style-type: none"> How do we make known exactly what we do in language that people – partners, donors, community members, etc. - understand? How do we shift so that we don’t focus on HIV only, but shift to focus on healthy people; healthy communities; wellness? How do other organisations mark (ritualise) their successes? Are we accurately and adequately naming our victories, and describing how we achieved that victory, for our own inspiration, and in order to learn and share with others?
5	Donor Relations <ul style="list-style-type: none"> What is the impact of retreating/withdrawing donors on responses by NGO’s and grassroots community groups? What possible alternative/innovative ways of working are around? Is there a better way for the sector to move forward together in the absence of international donor aid?
6	Principles for participation and inclusion <ul style="list-style-type: none"> How do we ensure that, in practice, we are really not speaking for/representing people; instead, we are genuinely letting them share their own stories? It is often difficult to “get caregivers” to opportunities to participate (eg. timing of participation in workshops or policy meetings may conflict with care/counselling responsibilities. This may result in loss of income or guilt/torn between two commitments). What is the experience around financial incentives to carers to participate in activities (eg. workshops?). Is this helpful, or is it simply bribery? Does it build a sense of agency and ownership, or does it weaken it?

How are other partners prioritising/making provision for CFC?

- In the workplace/amongst staff
- In programme integration/design
- In policy and advocacy
- In budgets?