

# Stepping into Power



*Forward to  
a Carer's  
Charter*

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a Carer's  
Charter*

*Supporting  
Caring  
Communities*

**Annual  
Report  
2010/2011**

*Supporting  
Caring  
Communities*

*Forward to  
a Carer's  
Charter*



# We Are **Creating** More

## VISION

A caring, compassionate and stigma free society that acts in solidarity to ensure that the wellness of all infected and affected by HIV and AIDS is valued and promoted

## MISSION

We support organisations and networks (including faith based), in targeted provinces, to respond positively, in a gender sensitive and sustainable manner to stigma and other challenges of the HIV and AIDS pandemic, through:

- promoting and advocating a better working environment for caregivers;
- capacity building and skills development for leaders and caregivers;
- psycho-social support services (including the development of staff wellness programmes); and
- HIV and AIDS and wellness education

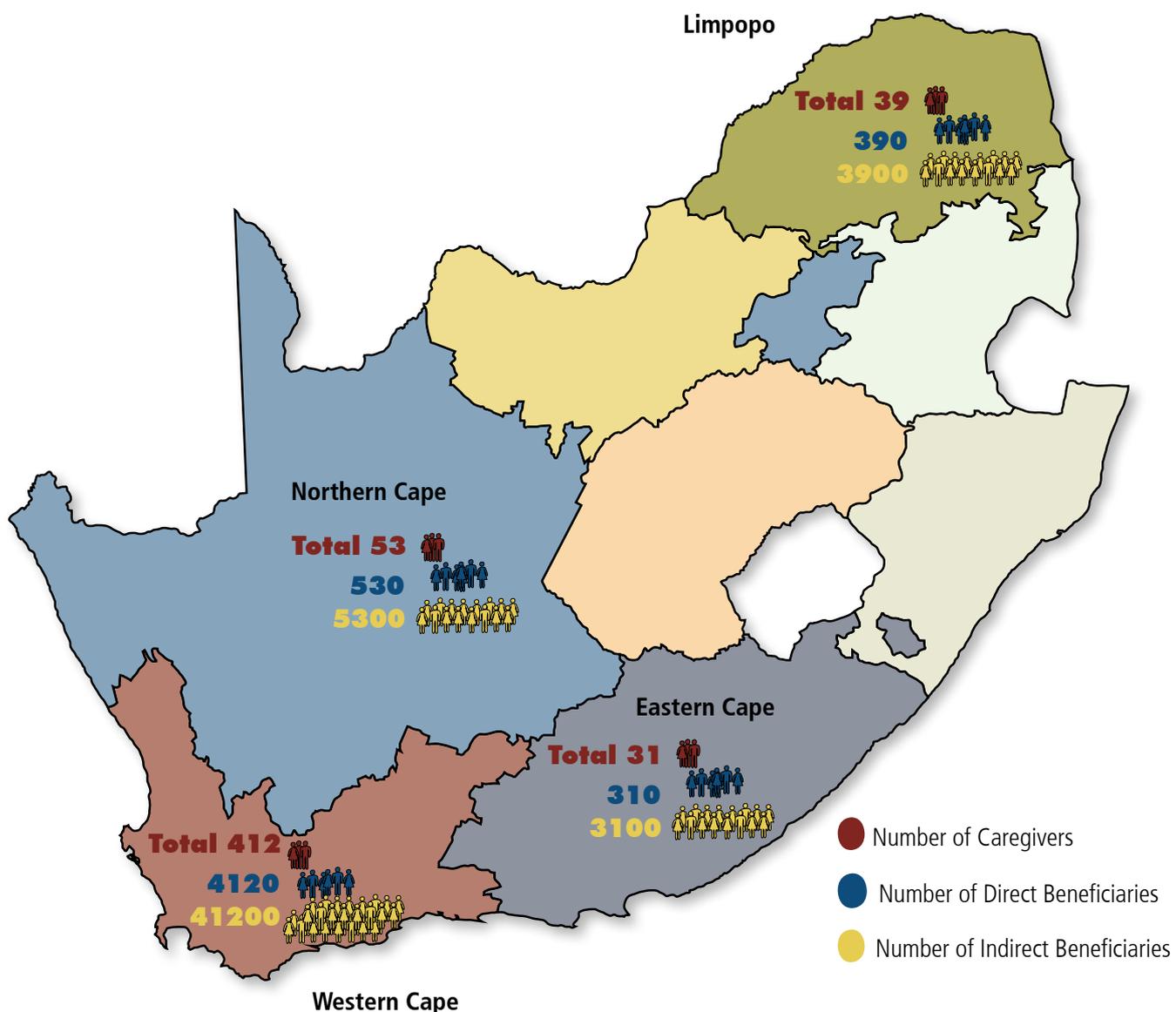
## Linking Learning and Lobbying - the year in numbers

Intervention	Number of events	Total number of people	Number of women	Number of men	Number of organisations
Information "shareshops"	7	148	142	6	38
Community Care Worker Assembly	1	109	96	13	25
Interim CCW Steering Committee meetings	4	8	6	2	8
Consultation meetings	3	68	56	12	20
<b>Total</b>	<b>15</b>	<b>333</b>	<b>300</b>	<b>33</b>	<b>91</b>



# Caring Communities

## Care for the Carer - the year in numbers



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## Chairperson's Report

**A Greek philosopher once said: Change is the Only Constant (Heraclitus of Ephesus, c.535 BC - 475 BC). Certainly we at AIDS Response have noticed the changing landscape around us and, as a Management Board and Trust, this is of critical importance in determining future strategy.**

This past financial year has seen the organisation, now matured from infancy, playing in the big leagues. Our services are in demand. We are contributing services as part of the Global Fund investment into the country, we are also still engaging in other provinces and on a national platform. The Director's report provides more detail in this regard. Despite the broad scope of work, our staff complement has stayed small and lean. This might be seen as positive but it is currently being experienced as a challenge. During this financial year the organisation revised its organogram to allow for the creation of additional posts, but those could not be filled due to funding constraints. Other creative ways of bringing in much needed staff capacity were employed and currently we are programmatically and administratively sound as yet another successful audit testifies.

In the past year, we have ourselves needed tending of mind body and spirit, as all in the caring or helping professions know to be true. I am exceedingly thankful for a phenomenal organisation such as AIDS Response for allowing the space and opportunity for individual staff, Board and Trust members to take the time to heal. We are all grateful to be back, whole and focused. My thanks go to the Director and staff of AIDS Response as well as the Management Board and Trust for their ongoing support to the sector and to each other.

The changes in our environment have been challenging this past year. During past years I have alluded to the need for sustainability plans for the organisation. Plans have been further crystallised from idea to draft. The challenge is illustrated in this peculiarity called the social

enterprise. AIDS Response will be investigating with partners, what this term 'social enterprise' might mean in relation to our core business. The urgency for the investigation is due to the apparent shrinking funding pool available to civil society organisations. As we all know the recent financial crisis impacted on the availability of funding as many funding agencies lost wealth during this time. Those who didn't, changed their funding practices to allow for the greater need within the sector. International funders also withdrew from the country, as our 10+ years of democracy in South Africa allowed them to refocus on more 'urgent' needs elsewhere.

The need for civil society organisations to review how they raise funding within the current economic climate has intensified. Coupled with that is the change within the AIDS sector. With much needed anti-retrovirals being made available, our HIV+ clients and caregivers have entered a new phase in their relationship. The HIV+ person may now potentially live a longer, more productive life and accordingly the urgency and need to fund care and support programmes has shifted.

These changing circumstances beg two questions: Is HIV & AIDS still the optimum sector for the AIDS Response to be operating in? And, are our services still relevant within the current environment? The net result of these changes in our environment mean that organisations like AIDS Response need to revisit their reason for being and way of operating, as well as potentially focus on other creative strategies to secure financial sustainability.

Thus AIDS Response is entering this new financial year posing these questions and facilitating this debate internally. Your support, encouragement and critical contributions will be greatly valued and appreciated.

Yours in wellness

**Mariette Williams, Chairperson**



## Director's Report

### Stepping Into Power

**This is an evocative image. At the heart of this expression is the sense of talking responsibility, of claiming space to do so, of taking risks and stretching boundaries in the process. These three simple words in a nutshell describe the work undertaken by the AIDS Response team during the period under review.**

Contextually, we had a lot on our plate. The external environment provided many challenges and opportunities, often interlinked - as is the nature of things. The ongoing global financial rollercoaster created a sense of uncertainty and being at the mercy of factors way beyond our control or imaginings. We needed constantly to realign as donors and government departments shifted and re-prioritised. Stepping out of victimhood into power meant looking at our own services and products with new eyes... how we rise to the challenge of evolving a model of work that creates a win-win for those who need and can afford and those who need but do not have the resources to make use of our services.

The 'Think Well' to establish and setup a Wellness Centre represented the first concrete step in realising the vision of not just becoming financially more sustainable but also to find a 'home' for AIDS Response where community care workers can find a range of care and support services in acknowledgement of the valuable service they provide to communities. The overwhelmingly positive feedback that we have received from care workers for a 'wellness home' of their own will spur us on in the coming cycle to put in place the building blocks for this ambitious project.

### Community Health Workers Recognised

The national policy debate around the revitalisation of the Primary Health Care (PHC) system and the National Health Insurance (NHI) scheme debate continued to shape our responses as a civil society organisation in the health and wellness sector. In this rapidly evolving landscape the discourse finally shifted to the formal inclusion of community care workers (as a new cadre named the community health worker) in the primary health care system. This shift represents a major victory for those who tirelessly worked for the recognition of community care workers and acknowledgement of their contribution to the health and wellbeing of all poor South Africans. AIDS Response has championed this cause since its inception 10 years ago. Stepping up our advocacy agenda in the previous three years has facilitated the direct contribution of grassroots care workers in discussions to shape this rapidly changing landscape. This is detailed elsewhere in this report as part of the Linking, Learning and Lobbying programme.

### A return to humanity

Globally, there is a rallying call for a more humane and caring society. People from all walks of life are questioning the 'quick fix' mentality that finds expression in substance-abuse, amongst others. This is the same mentality that puts profit, weapons and war before dialogue and community. The need is clearly there for spaces, resources and attitudes that promote more caring for self and others' wellbeing in the world.



AIDS Response has been providing just such an enabling space for the full spectrum of care workers across various provinces and will continue to do so for some time to come. Connecting individual wellbeing with that of the group continues to be at the heart of our interventions to ensure that responses to HIV & AIDS are supported and strengthened. Working in sustainable ways that acknowledge the care and support needs of care givers is an important contribution to creating a more caring community that can step into its own power.

## **Ndiyaphila Wellness Project**

The successes of the AIDS Response Care for the Carer programme, in particular that of the Ndiyaphila Project, show that we are on the right track in linking our work with the community of care workers to a broader community of care. Ndiyaphila means "I am well". The Ndiyaphila Project builds the capacity of care-based organisations in the HIV & AIDS sector to care for their carers. During the period under review, we celebrated the graduation of the 2009/10 intake and also the commencement of the 2010/11 group.

## **Walking the Talk**

The search for authenticity is rather like trying to find the Holy Grail. There are all these obstacles within and without that detract and distract. As an organisation that values self-care and wellbeing we, too, would like to be the change we wish to see in the world. This means that looking after the people who do the work is an important aspect of getting the work done. AIDS Response staff, associates, board members and trustees are invaluable in delivering our vision of more caring communities. Against the backdrop of reduced funding, increased pressures on volunteers to be elsewhere, conflicting life-work demands and just the maddening pace of modern day life, the team pulled through magnificently.

## **Staff changes**

We welcomed Andiswa Madinda as the new Programmes Administrator, replacing Mandisa

Mbaligosi who moved into the Trainee Trainer position. Regan Jacobs joined us towards the end of the year, replacing Amanda Williamson as Finance Officer. We also said goodbye to Ingrid Meintjes, who left at the end of her contract to concentrate on her studies. Kailas Kassan, part-time trainer and psychologist, left us to explore other interests and gifts. Karen Pratt joined us on a part-time basis to strengthen our partnership with NACOSA to integrate care and support to carers as part of the Global Fund programme. Lorna Houston stepped into the newly created position of AIDS Response Operations Manager with effect 1 April 2011 and we have no doubt she will continue to bring passion and focus to our work.

## **Highlights**

There have been a number of achievements during this time:

- Partnerships with various organisations led to the strengthening of care and support to community care workers. Our partnership with NACOSA resulted in a Train the Trainer workshop series and a publication that will be widely distributed amongst care-based organisations nationally. This colourful product is supported by a CD to enable reproduction of the material. The resource has also been linked to the AIDS Response website for accessibility. AIDS Response provided valuable technical assistance to the production of a series of resources used in the training of home-based carers developed by the Thogomelo Project, an organisation working with vulnerable children and their caregivers.
- The development of organisational capacity to develop, plan, implement and assess in-house wellness programmes through the Ndiyaphila Project. In 2010-2011 the programme assumed a more formal shape with the introduction of a new element of seed funding for implementation. Although we are still not able to realize the full intake of participants, the calibre of the 2010/11 group more than makes up for this. This organisational development support process has been four years in the making and we can now finally see the impact

as reflected by a recent external assessment. The findings of this assessment clearly show the need for this intervention and the recommendations thereof will inform our future implementation.

- The Community Care Workers' (CCW) Assembly presented care workers with an opportunity to interact, swap experiences and identify areas of common concern. This platform was the first of its kind nationally as it focused on bringing grassroots care workers from various organisations together to address amongst others the working conditions of care workers and the need for a representative body to take forward the concerns of this sector.
- The annual AIDS Response Wellness Day took place for the 4th time since its inception. The event provided an opportunity for care workers to engage the then MEC of Social Development, Ms Patricia de Lille, on key questions. In addition, participants were treated to various stress release workshops and well-stocked goody-bags sponsored by various corporate donors.
- AIDS Response hosted the media launch of the Nelson Mandela Foundation's 2010 Mandela Day campaign. This resulted in a highly successful partnership with SACL A, a community-based care organisation in Khayelitsha. The purpose was to highlight the poor working conditions of community care workers as part of launching the 67 minutes of care campaign. We received wide media exposure on the day and valuable corporate social responsibility connections were made. As a result, the SACL A building got a much-needed revamp and community care workers enjoyed recognition for the essential service they provide. AIDS Response also delivered four similar CBO/corporate events to celebrate Mandela day with the kind support of various donors (please see acknowledgements at the end of this report).

## Networking

Building relationships is an important aspect of our work as we continue to explore ways of working collaboratively and co-operatively to advance care and support to care workers. We have entered

into agreements with Thogomelo Project, NACOSA and 11 care-based organisations as part of the Ndiyapila Project, aimed at strengthening leadership development around Care for the Caregiver. We have built on existing strategic relationships with the Social Change Assistance Trust and Ikhala Trust in the Northern and Eastern Cape respectively, ensuring that our interventions in these provinces are supported and strengthened.

## Acknowledgements

We remain deeply thankful to all our donors for their continued support and strengthening our work. We are particularly grateful to CORDAID, which has devotedly supported the AIDS Response agenda since its inception 10 years ago. Even though they are exiting from the funding relationship due to regional reprioritisation, we will continue to work with both CORDAID and its partner organisations within and beyond South Africa to advance the position of care work and care workers.

We are delighted to welcome on board three new donors to the AIDS Response family, namely the Joint Gender Fund (JGF), the Africa Group of Sweden (AGS) and the DG Murray Trust. We look forward to further ground-breaking work around mobilising and organising community-care workers with their support.

The ongoing support and leadership we receive from the Management Board and Trustees kept us on a steady course through a difficult year. As the funding climate became even more challenging, this team met even more regularly to motivate and provide guidance.

Building internal capacity remains critical to ensuring that we continue to deliver a quality service to careworkers and their organisations. A list of capacity-building interventions undertaken by the AIDS Response staff during the period under review follows:

- Weekly yoga sessions at the local community centre with Leigh-Ann Voici.
- A staff development foundation week with Michel Friedman to integrate new staff and build team cohesion. We also used the opportunity



to revise the 2009-2011 strategy to inform the 2012-2015 strategy period.

- Khanyisa Balfour's 'Time to Think' aimed at strengthening peer support mechanisms through active listening in the organisation
- 'Working smarter' – Ways of managing stress by Katherine Train to help with maintaining work-life balance
- Mandisa Mbalingotsi successfully completed 'Call the Rain' – an accredited programme to run an HIV prevention programme; and 'Heart and Art of the Trainer' – an exploration of adult education principles and Transactional Analysis 101 facilitated by Diane Salter.
- AIDS Response self-care workshops – all new members of staff are required to complete all four phases of the AR self-care workshops. Both Andiswa Madinda and Mandisa Mbalingotsi have done so.

## Moving forward

As we finalise our strategy for 2012-2015, the following emergent issues are in our vision:

- As we speak, the South African government is engineering the large-scale employment of a new cadre of health care provider, viz. community health workers. These health workers will form an integral part of community health teams as part of the effort to revitalise the primary health care system. In the long term this will not only create much-needed jobs, but also bring much-needed acknowledgement and affirmation to care work. In the meantime, while the realities of expectations versus a limited budget are negotiated and various agendas are contested, community carers stand to be left out in the cold. This situation creates further uncertainty and stressors which makes ongoing, easy-to-replicate care and support to these carers essential.
- The fledgling carer movement has the potential to become strong and vibrant, appreciative of and valuing their contribution to the stability and wellbeing of communities. Supporting the mobilisation and organisation of care workers will continue to be high on our list of priorities.

- The quadruple burden of disease (HIV, AIDS & TB; violence and resultant injuries; high child and maternal mortality; emerging chronic diseases) will increase the burden of care on care workers, and women in particular. AIDS Response will work with various stakeholders to find innovative ways of getting more men involved in care work as a way of supporting the emergence of more caring communities.
- Across sectors the need for more sustainable ways of working is emerging. The wellness needs of those working in the civil society are not very different from those in the corporate sector or government. At the heart of the challenge lies the work-life balance. AR will explore and build on opportunities to provide wellness services to paying clients as a means of subsidising our traditional client base.
- We are focusing on the need to bring all our work together under one roof that will also double up as a 'home-space' for community care workers. For years now, carers have asked for 'a room of their own', caught as they are between the intimate space of households that they visit and the community health institutions that make use of their services.

### **In the words of that great community care worker, Mother Teresa:**

*"Life is an opportunity, benefit from it.  
Life is a beauty, admire it.  
Life is a dream, realise it.  
Life is a challenge, meet it.  
Life is a duty, complete it.  
Life is a game, play it.  
Life is a promise, fulfil it.  
Life is a sorrow, overcome it.  
Life is a song, sing it.  
Life is a struggle, accept it.  
Life is a tragedy, confront it.  
Life is an adventure, dare it.  
Life is luck, make it.  
Life is life, fight for it!"*

**Bernice Roeland, Director**

# Care for Caregiver Programme

**This programme provides a basket of services to community care workers and their organisations to promote self-care, stress management and wellbeing.**

## Emerging Trends

AIDS Response's work in the Western Cape Province has largely been focused on the Cape Metro and surrounding peri-urban areas. This past year saw a significant strengthening of the urban-rural connection in the province, with the Breede River Hospice in Robertson and the West Coast HIV&AIDS Initiative being active participants in the Ndiyaphila Project, and also a strengthening of ties with the Engedi Haven for Rural Youth in Ladismith, Kannaland who attended two 5-day workshops.

Being able to include carers from as far afield as Ladismith and Oudtshoorn in our Western Cape CFC programme has extended its reach and impact. These organisations were also able to participate in our Carers' Assembly and Wellness Day, where they reflected on the transformative nature of their experience of AR's work and stressed the need for care and support in their communities. It was a great learning for them as it allowed interaction with carers from other organisations in the city and the sharing of experience and knowledge. The Engedi co-ordinator, Aunty Rachel Niewenhuys, says "if the carers are taken care of, the poor communities are going to be better looked after." We are especially pleased that the group from Ladismith have embraced the self-care tools and are sharing it with a wider community - children, women in prisons and other non-profit organisations - and refer to it as stress relief.

These organisations, together with the others from the Cape Metropole, Boland and West Coast regions of the Western Cape Province, welcomed participation in the AR Carers Assembly where carers came together to talk about the need for CCWs to be acknowledged and recognised. Carers shared their problems and identified strategies to respond to them collectively and developed tools - notably a Draft Carers Charter and a comic strip - for use as advocacy tools.

## Strengthening capacity

AIDS Response is a values-driven organisation that works very hard to walk its talk. AR's core values of self-knowledge, respect, compassion, empathy, spirituality and diversity are complemented by the Paolo Freire's principles of popular education and application of Transactional Analysis and Capacitar. These values and methodologies provide a solid foundation that informs both AR's organisational management and programming content.

**Recruitment** – It is important to find the people who not only have the appropriate skills but will fit into the team's energies. Matching the values of the organisation with personal values can only be gauged through conversation during interviews and intuitive wisdom. We work as a team and we all have specific roles or contributions. Everyone is encouraged to see the organisation as a whole and themselves as a part of that whole.

**Performance** – staff is expected to take responsibility to set their individual performance targets and evaluate themselves and account for what got done and what not. The staff is encouraged to ask for support and the manager to ask "what support do you need?" Each person identifies problems and then we problem-solve together. Alternatively we may check if there is a skills/knowledge gap and identify where learning is needed. Peer feedback is respectfully given and thoughtfully received.



Sometimes it is not even necessary to look for a solution as the advance of technology solves the problem (if it was a technological problem in the first place - which is why the job was not getting done efficiently). Operational challenges may arise, e.g. funding arrives late and needs to be spent faster which places undue demands and stress on staff. In this case it is helpful to examine what needs to take place and how the work can be done without exhausting the team. Then we think how we can work and respond differently to create a win-win situation. Experience has shown when these elements are absent inevitably there is friction.

## Team building

Building a team that takes this ethos forward can be challenging, as we found when searching for a full time trainer with the right mix of values and skills. To this end we appointed a talented young beautician as our programmes administrator with a strong development component to her work. Mandisa was given opportunities for training and growth towards becoming a CFC trainer which she assimilated really quickly and she is now our trainee trainer.

Her reflection: "It felt wonderful to join the facilitator team and move on from being the programmes administrator, where I learnt a lot about the logistics of the programmes. Being in the trainee trainer position is very challenging and it feels like a steep learning curve. It is still early days so I am sure that it will improve in time and my confidence will grow as I do more workshops. I am very excited about being in this position."

## CFC Programme Challenges

In 2010 many organisations lost programme funding from various donors and government departments. This impacted on the number of carers attending CFC workshops as some organisations closed down completely and others retrenched staff. Carers were often unable to attend the workshops offered due to various challenges such as stipend cuts, retrenchment and EPWP training. Carers also spoke of having no food at home and the inability to leave their families whilst they attend workshops where they are well fed.

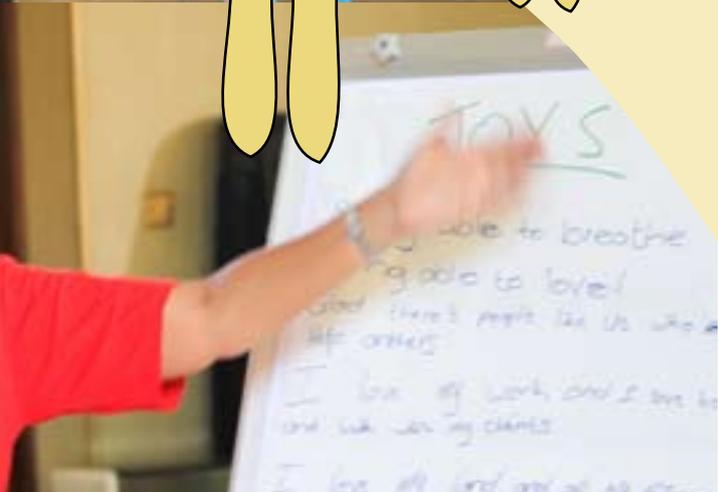
## Lessons Learnt

This situation necessitated a review of the CFC Programme to be more responsive to organisations' and carers' needs. Accordingly AR redesigned the CFC Phases and included HIV and Wellness Education workshops in the sub-districts of the Cape Metropole. The latter will commence in the new financial year. Workshops will change from three days to two days and five days to four days and one-day workshops are also to be introduced - we trust this will assist carers in being able to access much-needed care and support. One day HIV and Wellness Education workshops within the sub-districts where carers can come for the day, minimises the stress related to being away from home or work.

The Ndiyaphila Project (NP) offers dedicated time for co-ordinators to focus on strengthening care for caregivers in their organisations. This is particularly pertinent because many have a heavy workload and little or no experience of conducting care for caregiver sessions. This year we learnt that we need to reduce the number of self care tools in favour of deeper insight and integration of a few tools. The more focussed the content of our capacity-building training the more effective it is likely to be and the greater CCWs ability to transfer the information and tools.

We also realise that we need to consider and investigate other more accessible ways to provide care and support to carers and continue to provide the much needed respite for carers through our Self Care Retreats at The Grail, Goedgedacht and Schoenstatt.





# Linking, Learning & Lobbying Programme

The Linking Lobbying & Learning (LLL) Programme has been able to achieve several key objectives in all three of its focal areas. As with all journeys, there were linear and circular dimensions to the path. Part of it was well mapped and the rest uncharted territory. The latter, in particular, lent itself well to asking for help and support from fellow travellers. At times, we had all we needed to travel well and often not. There were a couple of false starts and turn-offs that ended up being cul-de-sacs. Mostly, however, it was joyful if hard work. The following report aims to give a sense of this amazing journey.

**LINKING** - one of the rings or separate pieces of which a chain is composed; anything serving to connect one part or thing with another; a bond or tie...

An objective for this area of work was the creation of enabling platforms for carers to build solidarity as a sector - locally, nationally, regionally and internationally. We also aimed to facilitate networks of mutual benefit within the sector and, where appropriate, between sectors. Specific deliverables included amongst others:

- Organising and hosting the inaugural Community Care Worker Assembly. This event brought together in solidarity over **100** community care workers from various health districts in the Cape Metropole and beyond, with representatives from the Northern Cape and Eastern Cape rubbing shoulders with care workers from more rural communities in the Western Cape. This three-day event was the culmination of eight years' work by AR to recognise and acknowledge the contribution of care workers.

A highlight of this event was the keynote address by Ms Winrose Nyaguthi, a grassroots care worker from Kenya, where she is part of a care worker movement that is organised on district level. Her story greatly motivated the carers present by emphasising the importance of solidarity at both a local and global level to effect change in the working conditions of care workers. A significant number of participants spoke in the evaluation about 'a boost to their self-esteem' and feeling more empowered to raise their issues with managers and colleagues. The gathering was an important step in building consensus, strengthening solidarity and making a point around their right to employment and a fair wage. The development of the draft CCW charter that reflects certain demands linked to their economic empowerment is encouraging and will form the foundation of the LLL programme's 2011/2012 agenda.

- Development of a sector mandate through consultation with community care workers. 10 'share shops' were held, attended by **185** care workers. This work resulted in a formal submission to government that reflects the input and suggestions gathered. It is important to note that these voices belong to grassroots community care workers and, in the absence of a representative body championing their issues, their efforts are even more significant.
- We participated in a civil society convened Community Care Worker (CCW) symposium aimed at strengthening existing relationships and establishing new ones. As a result an alternative policy and model for integrating CCWs into the public health system was developed. AR's LLL co-ordinator was instrumental in drafting the final 'consensus model' document, working in collaboration with various new and existing partners.
- We attended the School of Public Health, University of the Western Cape multi-stakeholder consultation on 'Community Care Givers: roles, practices, and emerging models in Khayelitsha'.
- We participated in a CCW symposium to develop training, accreditation and career-pathing strategies convened by the Community Health Media Trust .



## Learning - acquiring new or modifying existing knowledge, behaviours, skills, values, or preferences; may involve synthesizing different types of information...



The objectives for this focal area included strengthening peer learning and support mechanisms for carers, which included learning by doing, learning by sharing and learning by grappling with the theoretical framework of care. In the process we strove to strengthen our understanding of the critical issues affecting caregivers, through documenting and evaluating field experiences (our own and those of other organisations) and through continuous reflection and review. Key deliverables included:

- The CCW Assembly presented a critical platform for learning and sharing. The emphasis was on political education in relation to the gendered nature of care work, the development of a Carer's Charter and various tools for disseminating information about policy issues that affect care workers. Inputs by FEMAL, Participation Junction and Comic Art were invaluable and resulted in a draft Community Care Workers' Charter, the beginnings of an educational cartoon series and greater clarity about the value and process of advocacy by caregivers themselves.
- The production and distribution of a poster that calls for the formalisation of care work in preparation for the CCW Assembly and to support feedback to their respective groups after the Assembly. The production of a series of messages (emblazoned on the Assembly t-shirts) is part of creating an alternative narrative about care work and the value it adds to society. These messages are:
  - Making caring count
  - Caring is working
  - Supporting caring communities
  - Forward to a carers' charter
  - Carers unite
- A broader stakeholder consultation meeting to inform the LLL programme's strategic focus for 2011/12 in relation to government's plan for community health care provision and its potential impact on care workers. This two-day process drew together a host of presenters around policy-related concerns and issues of community care workers as identified through shreshops and the CCW Assembly in the preceding months. As a result, AR identified the following plan of action:
  - Support the call for the establishment of a community care worker sector (broad definition) on SANAC to ensure that the interests and voices of this marginalised group is represented adequately at this level;
  - Prioritise the mobilising and organising of CCWs in two priority health districts in the Cape Town Metropole as a pilot project, working with a number of organisations that presented at the stakeholder meeting;
  - Pilot a Foundation Capacity Building Course for CCW advocates. Also called 'changemakers', these advocates will be drawn from the interim volunteer group and beyond to strengthen and support CCWs to speak with confidence and skill from an informed position around the linkages between care work and the various socio-economic factors that impact on carers and the work that they do;
  - Continue to seek partnerships with organisations and individuals with a similar agenda at local, national, regional and global levels. We will embark on a joint action plan with the Home-Based Carers' Alliance (HBC) Alliance and the Care Action Network to support some of the above and to advance the cause of care workers at all levels.

## **LOBBYING** - a group of supporters and representatives of particular interests who try to influence political policy on a particular issue...

The lobbying work area had as objectives to raise awareness among carers and decision-makers about issues affecting the working conditions and wellbeing of carers and to develop an advocacy agenda with carers. Some significant outcomes are:

- The formation of an interim steering group to take forward some of the decisions of the CCW Assembly. The group, consisting of eight care workers who volunteered their time and energy, met 4 times during the period under review. Amongst others they developed a partnership agreement with AIDS Response, developed a response to proposed amendments to the Labour Relations Act to call for the inclusion of community care workers in the definition of 'vulnerable workers', participated in local and national civil society working groups about the proposed revitalisation of the primary health care system and actively participated in developing the AIDS Response advocacy focus.
- We are also active in the CORDAID Partners' Home-Based Care virtual community.
- We produced short audio-visual advocacy tools to stimulate discussion around issues affecting the working conditions of care workers.
- We joined the Care Action Network (CAN), a 400-organisation strong global network of home-based care organisations. CAN was formed at the 2010 International AIDS Conference in Vienna to advocate more broadly for improved working conditions for CCWs. The LLL programme contributed a presentation on CCWs to the Caregivers Action Network (Community and Home-Based Care Networking Zone) at last-mentioned.

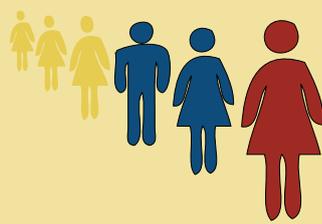
## **Collectively Stepping into Power**

The year under review saw progress in the mobilising and organising of community care workers to make formal input into the policy formulation process that directly impacts on their working conditions. Local, national, regional and global solidarity was boosted by conversations among care workers in the Cape Metropole, across the urban/rural divide, amongst those from different provinces and even with those having different perspectives from Kenya and globally through the CAN platform. The foundations have been laid for dialogue to explore common interests and actions. Partnerships with supportive organisations have been identified and relationships strengthened. Caregivers everywhere are stepping into their power as a collective. The next part of the journey will look at formalising the mobilisation and organising process, deepening the political aspects of our work and to continue supporting and strengthening actions for recognition and acknowledgement of the value of care work, care workers and caring communities.

## **Challenges**

During the year we experienced significant constraints. The part-time programme co-ordinator, Ingrid Meintjes, completed her contract in December 2010. The co-ordination of the programme was then taken on by Bernice Roeland pending the outcome of various funding proposals. Despite not having been able to secure enough funds for the rest of the financial year, implementation continued at a brisk pace as noted elsewhere. The mobilising and organising of community care workers is hampered by fears - of being victimised by their management, the vulnerability of little or scant protection under the labour laws, lack of resources to get to meetings and uneven levels of awareness about key processes (such as the re-engineering of the primary health care system) happening at a local and national level that affect their lives. However, despite these challenges, we can celebrate a year of significant growth and development.





# Stories from the Field

## Strong women becoming stronger...

We, the carers working in South Africa, want all of our country and world to know that:

- Strong women do this work, yet the work done in the home as part of social reproduction – usually thought of as ‘women’s work’ – is invisible, undervalued and underpaid.
- The majority of care work for chronic and other diseases takes place in the home, is thought of as part of women’s domestic duties and is unpaid
- Our government depends on unpaid community and home-based care to sustain the public health service.
- We are the backbone of the health system, which will collapse without us.
- The gendered nature of care work negatively affects the capabilities, development opportunities and quality of life of men and women who perform it.
- We experience and assess the social problems encountered by the community at large.

**Preamble to the Draft Carers’ Charter produced at the 2010 AIDS Response Community Care Worker Assembly**

## Creating a caring space...

For Jacque Pondo at **Sothemba AIDS Action** it meant doing what was necessary to convert an old Wendyhouse standing unused in the back garden into a carer’s space. It took a lot of work, but once completed, the carers now have their own dedicated space and meetings take place there twice a week. It may not seem like a major event for the organisation, to make a space for the carers to meet, but it has had profound effects in the lives of the carers.

Some of the patient advocates at Sothemba AIDS Action give their views about their regular support group:

*“Before this group, I was a woman sitting at home doing nothing. Now, this helps me to be strong.”*

*“It’s important to come here as a group. The most important thing is the bond we have with each other. When I came here I was empty. I didn’t have a lot of ideas. Here I have learnt a lot.”*

One of the Sothemba carers is finishing her social work training and also runs a men’s group. She tells us, *“Now I can go to the support group that I run. When I arrive there I smile. The learning experience I’ve got here is very good. Now I can stand for myself and speak for myself.”*

# Ndiyaphila Project

Ndiyaphila (I'm well; I'm alive) builds capacity in those organisations whose carers attend CFC workshops to mainstream self-care and wellness principles into the organisation itself. 80% of participants in care-based programmes are aware of their own stress levels and how it affects them on personal and professional levels. Through Ndiyaphila, AR aims to equip them with basic self-care techniques to manage these stressors.

On an individual level, the results are visible on a psychological, emotional, physical and spiritual level as people take more responsibility for their well being. Organisations too realise the importance of working in more sustainable ways. Caregivers supervised by co-ordinators who have participated in the programme report favourably on the integration of self-care methodology. Staff members who feel cared for and have the opportunity and tools to do so, are more likely to stay in their jobs, to be happy and productive. On a sectoral level, we see the solidarity among careworkers that, if strengthened, supported and encouraged, may lead to care workers becoming more organised.

Significantly, the Ndiyaphila project has done more than deepen personal growth for participants. Managers, especially, acknowledge the considerable gains in professionalism, initiative, adaptability, and productivity amongst both carers and their co-ordinators. They demonstrate a greater sense of responsibility towards work, and greater attention to the quality of that work.

## Carer responses:

*"I used to put other people's needs first and stand in the background myself. But, because of the AIDS Response courses, I learnt to look after myself and draw the line. Now I can say 'until here and no further'."*

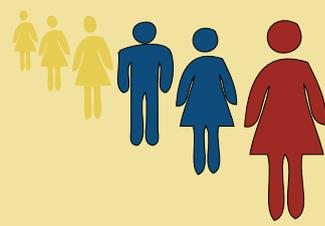
*"Until this year, I didn't care for me. I forgot that I'm also a patient – a person living with HIV. I was taking lots of risks, but wasn't listening to my own body. I decided this year to put me first."*

*"I've always cared for others, and not for myself. People have serious problems and I feel an empathy with them. But now, I realise that I have to start with myself."*

*"Before AIDS Response, I used to put the needs of others before me. I just didn't have any power. I felt powerless. AIDS Response showed me that I can't be empty like that – at one point, I had even forgotten it was my own birthday, I was busy with other people's lives – I need to be full. I had forgotten about myself. Now I make sure to do something for me."*

*"With what I've learned, you have to put yourself first. You can't satisfy every person. Focus on you to give yourself power, then you can be fit to help others."*





## Co-ordinator responses:

*"Learning how to plan my work and my day through developing a schedule, so that I know what to do and can be in control of my time, has been a big benefit for me. Before, I would just come to work and do things, and be overwhelmed and distracted when different things came up during the day and I tried to do everything."*

*"The caregivers themselves are more creative. They are able to adapt what I teach them and apply it to other settings, like their work with vulnerable children. The principles seem to be internalised for many of them and integrated into their work."*

*"When we come here to this CFC-room and have a session, when we check-in and de-stress... these things have been so good for me. AIDS Response really changed me. I manage stress really well now, and it's better for everyone who works with me. I used to throw tantrums if I didn't get my way. But I've learned, instead, to breathe deeply until I'm rational. I've really grown... a lot. I talk to colleagues much more rationally. I still stress, but I don't carry it the same way any more. I'm learning to accept my limitations through Ndiyaphila, and that has been very empowering."*

## A manager reflects...

*"We've seen a shift in two of our staff members who have been participants in the Ndiyaphila programme, in the way in which they engage with their work. Particularly with the participant in the most recent intake, we have noticed how she now comes across as someone who takes personal ownership of the work. In the past, we used to have some difficulties, but now she is engaged and so much more expressive. She operates from a different space altogether – the kind of person you want to engage with. We used to find her to be defensive, not prepared to acknowledge her mistakes, and receiving instruction and criticism poorly. Now, she is more open."*

*"I am certain this is linked to the fact that she's been through Ndiyaphila, and has picked up some kind of inspiration. She's getting something there that is making her clock tick. In part that inspiration has come from the kind of peer interaction and support with other care-work co-ordinators from other organisations. This peer-support has helped her to not feel alone in her challenges, it has helped her to feel safe to make mistakes, and to learn to appreciate herself and others better. Before Ndiyaphila, she was happy to operate as an island, but now she is the initiator of collaborations within the organisation, reaching out to other departments, and not feeling threatened by integration and co-operation."*



# The AIDS Response Trust

Financial Statement for the year ended March 2011

## Detailed Income Statement

Figures in Rand

	2011	2010
<b>REVENUE</b>	<b>2,258,605</b>	<b>2,535,022</b>
Funding - City of Cape Town	211,989	16,280
Funding - Cordaid	582,603	735,757
Funding - Missio	-	173,039
Funding - DG Murray Trust	247,410	2,627
Funding - Trudy Newton	-	58,750
Funding - Joint Gender Fund	693,117	107,260
Funding - National Department of Health	-	1,297,097
Funding - Provincial Department of Health	55,000	29,964
Funding - Global Fund	182,577	-
General donations	26,320	8,329
Discount received	753	3,634
Income generation	203,807	64,733
Interest received	55,029	37,552
<b>EXPENSES</b>	<b>2,545,892</b>	<b>2,109,723</b>
Auditors' remuneration	18,000	2,433
Bad debts	20,969	6,400
Bank charges	13,543	10,134
Cleaning	2,545	2,152
Communication expenses	47,850	25,572
Employee costs	504,448	528,922
Equipment, repairs and maintenance	21,641	38,791
Fundraising expenses	50,861	15,745
Governance	16,760	37,685
Insurance	12,746	-
Organisational and staff development	66,226	31,711
Printing and stationery	17,130	8,339
Programme costs - (CFC / LLL)	1,628,267	1,289,863
Provision for doubtful debts	8,485	-
Rent paid	105,415	85,624
Security	3,664	15,125
Travel costs	-	5,822
Utilities	7,342	5,404
<b>Nett Income</b>	<b>(287,287)</b>	<b>425,299</b>



# The AIDS Response Trust

Balance Sheet for the year ended March 2011

## Balance Sheet

Figures in Rand

	2011	2010
<b>Current Assets</b>	<b>561 693</b>	<b>1 960 412</b>
Property, plant and equipment	4	3
Cash and cash equivalents	541 588	1 897 466
Trade and other receivables	20 101	62 943
<b>TOTAL ASSETS</b>	<b>561 693</b>	<b>1 960 412</b>
<b>Current Liabilities</b>	<b>274 861</b>	<b>1 386 293</b>
Deferred income	221 066	1 312 292
	53 795	74 001
<b>Equity</b>	<b>286 832</b>	<b>574 119</b>
Accumulated surplus	286 832	574 119
<b>TOTAL LIABILITIES &amp; EQUITY</b>	<b>561 693</b>	<b>1 960 412</b>



# Partner Organisations

April 2010 - March 2011

Western Cape	Eastern Cape
Abigail Women's Movement	Bathurst Advice Office
Action Against Aids	Burgersdorp Advice Office
Arisen Women	Hewu
Breede River Hospice	Hofmeyr Advice Centre
Centre Of Hope	Indwe LDA
Child Welfare (Bredasdorp)	Masiphakameni LDA
Child Welfare SA Wellington/Paarl	Matatiele LDA
Childline/Lifeline	Mt Fletcher Advice Centre
Community Bible Society	Nonesi Advice Centre
Community Media Trust	NACOSA
Cotlands	Sterkstroom Advice Centre
Desmond Tutu HIV Foundation	<b>Northern Cape</b>
DOPSTOP	Bakaulengwe
Eagles of Jesus Christ Ministries	Bakgethwa- Wipa HBC
Elgin Learning Foundation	Bosele
Elshadai Christian Ministries	Christanna Care and Support Group
Etafeni Day Care Centre Trust	Gomotsang
FAMSA	ICWIMP
Great Commission Ministers Network	Iteke o direle sechaba
Gugulethu Day Hospital	Joyous
Haven of Hope	Kgatelopele Social Development Forum
Helderberg Hospice	Komaggas Adviesdiens
House of Hope Ministry	Mandulo NGO
iThemba Labantu Care Centre	Mier HIV/AIDS Care and Support
Koinonia Welfare Development Program	Nababeep Advice Office
Luthando Frail Care Centre	Noord-Kaap Vigs Forum
MaAfrika Tikkun	Pelonomi
Masincedane Community Service	Protiro Caregivers
Masisebenze Assessment Centre	Richtersveld Advice Office
Metro District Health	SA Red Cross Society Kimberley Branch
Mothers to Mothers	Spoegrivier Advice Office
MSAT Western Sub District	Thabiso NGO
NACOSA	Wegdraai Care Centre
Nokuthembeka HBC Response	NACOSA
Olive Leaf Foundation	<b>Limpopo</b>
Philippi Trust	Catholic Institute of Education
SA Red Cross Society	Ikhwezi Lokusa Primary
Siyaphambili Orphan Village	Peter Herman's Primary
St Luke's Hospice	Slzo Primary
St Luke's Church	St Bede's Secondary
Stellenbosch Hospice	St Brendan'+B20s Secondary
Tafelsig United AIDS Project	St Martin's de Porres
Tygerberg Hospice	NACOSA
West Coast Community HIV/AIDS Initiative	St Paul's Secondary
Y.M.C.A	St Scholastica Primary
Yizani Sakhe Organisation	Subiaco Primary
Zanempilo Trust	Treatment Action Campaign
Khethimpilo	<b>Gauteng</b>
	Southern African Catholic Bishops Conference



# Acknowledgements

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## Donors

### Grants

City Health  
CORDAID  
Joint Gender Fund  
DG Murray Trust  
NACOSA - The Global Fund  
National Department of Health  
Provincial Department of Health

### Donations in kind

#### Nelson Mandela Day

A J North  
Ciplamed  
Community Chest  
Engen  
Footwear and Safety Gear  
Johnson & Johnson  
Media24  
Merrypak  
Paarl Media Cape  
Peninsula Beverages  
Revlon  
Sh'zen  
Sheraton  
Victoria Garden

#### Wellness Day

Adcock Ingram  
AJ North  
Community Chest  
L'ORÉAL  
MTN  
Nampak  
Red Cross Disaster Relief  
TIFF Gifts Factory Shop  
Vodacom  
Woolworths

#### Other Donations

Trudi Newton

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