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Positive Living: Visual Activism and Art in HIV/AIDS Rights Campaigns.

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‘Story-telling is a historical imperative. We cannot successfully navigate uncharted waters without some script to guide us. This is particularly so for women, especially black women...in post-apartheid South Africa where so much forgetfulness is willed upon people.’

Mamphela Ramphele, *A Life*, 1996, preface.

The HIV/AIDS battle is far from won. South Africa still represents one of the largest case loads of HIV positive individuals, with over six million living with HIV, approximately 1000 new HIV infections daily and over 200 HIV-positive individuals dying daily from tuberculosis. In other countries such as the United Kingdom, non-governmental organisations (NGOs) supporting people living with HIV are similarly struggling to limit escalating numbers, dwindling resources and continuing stigma. The problem of AIDS has clearly not gone away. Old challenges continue such as the fall out from disclosure which might include job losses and ostracism from family and friends or the difficulties of adhering to complex drug regimes. In addition, new issues, unforeseen in the early days of the pandemic, are constantly emerging for those directly affected. Increasingly however, the protagonists’ stories are ‘old news’ and remain invisible in the mainstream media and in the general public’s consciousness.

In South Africa, women and children have frequently borne the brunt of the HIV legacy and are directly affected in quite specific ways: mother to child transmission, economic necessities of sex-work with its increased risks and the economic and emotional responsibilities of family care. Increases in male to female transmission has been attributed to heightened gender discrimination, escalating sexual violence against women and a high incidence of so-called corrective rape perpetrated against black lesbians.<sup>1</sup> This legacy is trans-generational with many grandmothers having

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<sup>1</sup> For an account by an activist and artist from this community whose scholarship and photography provides some of the earliest exposés of this violence see

borne the burden of parenting numbers of children orphaned by the AIDS pandemic.<sup>2</sup>

The conventional family unit split apart under apartheid has once again been transformed under the pressures of HIV/AIDS.

It was in this climate and with a desire to provoke a wider recognition of the continuing complications of living with HIV today in South Africa and elsewhere, that I curated an exhibition, 'Positive Living: Art and AIDS in South Africa' at the Peltz Gallery at Birkbeck, University of London.<sup>3</sup> The South African fight with HIV/AIDS had historically demanded radical and creative tactics in order to garner international support and to provoke national awareness during the struggle for government provision of anti-retrovirals. It has often been recommended as a model for HIV/AIDS campaigns beyond South Africa, with Treatment Action Campaign (TAC) being hailed in the *New York Times* in 2006 as 'The world's most effective AIDS group.'<sup>4</sup> An integral and highly effective dimension of the broader campaign was the visual campaign launched by fine artists, photographers and community artists in collaboration with NGOs. Women from different constituencies in South Africa have often been at the forefront of these initiatives, many of which have an attachment to narrative and the power of story-telling at their core.

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Zanele Muholi, 'Thinking Through Lesbian Rape', *Agenda*, 61 (2004), pp. 116-125. Critically, Muholi is also concerned to reframe and bring greater visibility to her own community's diversity of experiences not just as victims of prejudice. For more detail on her extensive portfolio and visual activist projects see [zanelimuholi.com](http://zanelimuholi.com)

<sup>2</sup> For an interesting experiment in photo voice research incorporating written narratives of their experience by Grandmothers Against Poverty and AIDS (GAPA) in Khayelitsha, Cape Town see E. Miller, J. Smetherham and J. Fish, 'The 'Nevergiveups' of Grandmothers Against Poverty and AIDS: Scholar-Journalism-Activism as Social Democracy', *Kronos*, 38 (November 2012), pp. 219 – 248.

<sup>3</sup> 'Positive Living: Art and AIDS in South Africa' ran from 13 November 2015 to the 22 January 2016 at the Peltz Gallery, Birkbeck, University of London. The exhibition was part-funded by an award from the Wellcome Trust/ Birkbeck Institutional Strategic Support Fund.

<sup>4</sup> For an important account of the HIV/AIDS campaigns from a personal and scholarly perspective, see E. Cameron, *Witness to AIDS*, (London, I.B. Tauris, 2005). And for a detailed history of Treatment Action Campaign and its impact from a global health perspective see, M. Mbali, *South African AIDS Activism and Global Health Politics* (Basingstoke, Palgrave Macmillan, 2013).

Using 'Positive Living' as a starting point, this article offers itself (in line with the original intentions of the exhibition) as a [very] short history of some key visual strategies developed to raise political consciousness in South Africa and internationally over one of the darkest periods in South Africa's history since the first democratic elections in 1994. It outlines the conceptual, political and intellectual rationale underpinning the curatorial choices made, together with some of the lessons learnt from public debates and private discussions conducted during the course of the exhibition. <sup>5</sup>I am well aware that others have dedicated their research to exploring how specific media (photography, fine art or craft) have been mobilised as tools to combat deep levels of prejudice and ignorance around HIV /AIDS. <sup>6</sup> My own objective is not to provide a comprehensive analysis of existing art and visual projects engaging with HIV and I am well aware of gaps in this 'history' of strategies. There is no mention of the creative use of television and TV soap operas or of the ongoing oral and visual community project launched in July 2016 at the KwaMuhle local history museum in Durban, 'South African Voices – Towards a Museum of HIV Memory and Learning', nor of a number of smaller but nonetheless highly effective local

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<sup>5</sup> I ran an extensive public engagement programme over the course of the exhibition in order to revive an understanding of the longer history of struggles over the ways in which HIV and those who are HIV-positive have been represented. It was also important to me to establish connections between the lessons learnt from the South African campaigns and those historically run in Europe and the US and to promote awareness of issues currently facing a variety of HIV-positive constituencies in the UK. Events included: On World AIDS Day 2015, presentations and a panel discussion with three visual activists crucially important during the 1990's AIDS campaigns in the UK ( Dr. Simon Watney, Sunil Gupta and Parminder Sekhon); a Wellcome Trust-funded conference 'Women and HIV/AIDS in South Africa: Medicine, Art, Activism' co-convened with Dr. Hilary Sapire with the participation of Justice Edwin Cameron , Vuyiseka Dubula and Cathy Campbell and others whose lectures are published in this volume; artists' talks in the Peltz Gallery with the participation of Nontobeko Peyi from the Keiskamma Art Project, Nondumiso Hlwele and Gideon Mendel.

<sup>6</sup> A. Weinand, 'Portraits, Publics and Politics: Gisèle Wulfsohn's Photographs of HIV/AIDS, 1897-2007', *Kronos*, 38, 1, (January 2012), pp. 177 – 203; A. Wienand, 'David Goldblatt : In times of AIDS', *De Arte*, 87 (2013), pp. 7-21; K. Thomas, *Impossible Mourning: HIV/AIDS and Visuality After Apartheid*, (Lewisburg, Bucknell University Press, 2014); B. Schmahmann (ed), *Material Matters* (Johannesburg, Witwatersrand University Press, 2000) ; G. Barz and J.M. Cohen (eds), *The Culture of AIDS in Africa: Hope and Healing Through Music and the Arts*, (New York, Oxford University Press, 2011).

initiatives all over South Africa.<sup>7</sup> Rather, the aim of ‘Positive Living’ and of this article, is to suggest to the reader that there is a dialogue between different kinds of visual activism usually perceived as separate spheres though they each make distinctive contributions and often engage different audiences. In other words, we need to understand better the cumulative contribution of work often assigned as ‘craft’ produced as both local and often rural community responses to HIV and conversely, the role of ‘documentary’ photography together with fine artists’ conceptually and emotionally challenging responses to the pandemic. Unlike most writing on visual strategies which focuses on one particular medium, through the curatorial strategies adopted in the exhibition and through this written account, I am interested in looking comparatively at different visual strategies as part of a wider understanding of the ways in which visual and material culture (notwithstanding any limitations) can produce powerful tools for social change.

The longer history of how HIV/AIDS has been represented visually specifically in relation to questions of agency and the ethics of representation (which are also at the heart of the South African campaigns) began in the UK and the US in the 1980s in the dark days of ‘Gay Plague’ that cost the lives of so many of my friends. In these international contexts much has changed since the anxious campaigns and media panic of the 1980s. Visual and material interventions have been central in transforming public opinion. An enduring example initiated in San Francisco, ingeniously mobilises techniques usually associated with the private and the domestic. Turning conventional notions of memorialisation on its head, the gendered craft of sewing and patchwork is deployed to create an extraordinary alternative memorial of monumental proportions – the Names Project AIDS Memorial Quilt. The quilt, which is still growing, was established in 1987 and now commemorates over 48,000 individuals each with a 3 x 6 foot panel, who have died from AIDS or HIV-related illnesses.<sup>8</sup> There are many factors contributing to the effectiveness of the quilt as both a consciousness raiser and memorial, not least the fact that it was first displayed on

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<sup>7</sup> See Rebecca Hodes, *Broadcasting the Pandemic: A History of HIV on South African Television*, (Cape Town, HSRC Press, 2014).

<sup>8</sup> <http://www.aidsquilt.org/about/the-aids-memorial-quilt> sets out the history and ongoing exhibitions of the Names Project AIDS Memorial Quilt.

the 11 October in 1987 in the quintessential site for memorialising US events and individuals of national importance, the National Mall in Washington D.C.

That less ignorance and greater support exists is a tribute to the bravery of those who were on the front-line of these debates and whose own lives were directly affected by the issues. Three key figures in the UK were participants at discussions staged in the 'Positive Living' exhibition. Art historian Simon Watney who was also co-founder of OutRage, began the debate in 1987, with one of the first books to engage the ways in which visual representations in the media were compounding dangerous myths about the disease *Policing Desire: Pornography, AIDS and the Media*.<sup>9</sup> Sunil Gupta, a gay rights activist and internationally renowned photographer, took up the gauntlet thrown by US cultural theorist and gay activist Douglas Crimp and co-curated a landmark exhibition in London in 1990 which set the bar for a thoroughgoing critique of media and other representations of the AIDS pandemic and showcased an early wave of art works designed to resist the onslaught of hysteria and violence directed largely at HIV-positive gay men. An edited collection with the same name as the exhibition 'Ecstatic Antibodies: Resisting the AIDS Mythology' ensured that the debates were widely circulated and it is still a foundational text on these questions today.<sup>10</sup>

Photographer and LGBTQ activist Parminder Sekhon spearheaded various visual campaigns to engage Black, Asian and Minority Ethnic constituencies in Britain, co-founding NAZ the first HIV and sexual health agency for this group in the UK and using alternative posters and other media-savvy campaigns to overcome the triple-headed monster of prejudice, ignorance and fear purveyed in government health campaigns and the official media during the 1990s. One of the critical achievements for me of these early visual and intellectual interventions is that while these historic campaigns had prioritised countering the 80s and 90s view of gay men as the 'perpetrators' of a self-inflicted virus – they had also recognised the need to

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<sup>9</sup> S. Watney, *Policing Desire: Pornography, AIDS and the Media* (London, Comedia, 1987)

<sup>10</sup> T. Boffin and S. Gupta (eds.), *Ecstatic Antibodies: Resisting the AIDS Mythology* (London, Rivers Oram Press, 1990). The introduction to the edited collection explicitly cites Douglas Crimp's statement that "...art *does* (Crimp's emphasis) have the power to save lives, and it is this very power that must be recognised...We don't need a cultural renaissance; we need cultural practices actively participating in the struggle against AIDS ..." (p.2)

understand the ways such prejudices were inflected differentially through the prism of racism.<sup>11</sup> The racialisation of the gay communities meant that HIV was experienced differently in BAME communities in the UK and in African American communities in the US for example. Parminder Sekhon and Sunil Gupta had been crucial in paving the way for this recognition by insisting on nuancing the campaign to take account of these factors.<sup>12</sup>

In South Africa the most enduring visual activist projects relating to HIV originated during Thabo Mbeki's presidency in response to his administration's denial of the relationship between HIV and AIDS. Between 1999 to 2006, fine art, photography, printmaking, painting and other creative practices produced effective challenges to the South African government's AIDS denialism. A spate of important art exhibitions

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<sup>11</sup> See also Mehboob Dada, 'Race and the AIDS Agenda' in Boffin and Gupta (eds.), *Ecstatic Antibodies*, pp.85-95.

<sup>12</sup> This work continues today in the UK particularly in relation to the South Asian and African Diaspora. One of the more successful and engaging initiatives has been developed by the Terrence Higgins Trust and was presented at an event in connection with 'Positive Living' by Takudzwa Mukiwa, a health improvement specialist who developed the digital and social media campaign, 'It Starts With Me'. Central to the campaign are a series of YouTube videos which star HIV positive members of the African Diaspora prepared to speak to camera about the specific ways in which the virus has impacted their lives. The videos are helpfully outspoken about situations which are specific to these communities in the UK. So, for example, a female pastor of an Evangelical Christian church discusses her dilemma about admitting to her congregation that she is taking medication for HIV in the context of a belief system where faith alone is supposed to heal the sick. Another shows a young gay male from Nigeria talking about his experience of living with HIV. In Nigeria, both male and female same-sex sexual activity is illegal with death by stoning applied in those Northern states under Shari'a Law and a maximum of 14 years imprisonment in southern and northern states under federal law. Police blackmail and violence is the order of the day for members of the LGBTQ communities. Because of this repression of their rights in Nigeria the Terrence Higgins Trust made the decision not to disclose the young man's sexuality in the video in order to increase the number of Nigerian viewers in the Diaspora. These are some of the complex ethical and practical considerations and circumstances specific to the African Diaspora which make testing and disclosure still so problematic today in the UK and in other Diasporic contexts. See Terrence Higgins Trust, 'Pastor Elizabeth: Living with HIV for 17 Years', YouTube, 3 June 2015. See also Emmanuel Akinwotu, 'Blackmail, Prejudice and persecution: Gay Rights in Nigeria', *The Guardian* (30 March 2018), available at <https://www.theguardian.com/global-development/2018/mar/30/blackmail-prejudice-persecution-gay-rights-nigeria>, retrieved on 14 May 2018.

were staged both within South Africa, (notably at the Durban Art Gallery under the directorship of Carol Brown) and internationally, for example in Los Angeles in collaboration with David Gere's global project 'Make Art/Stop Aids' at the University of California, Los Angeles (UCLA).<sup>13</sup> While theatre's immediacy has made it a dynamic health education tool, I maintain that visual activism combines the double impact of immediacy of message with the power of legacy: preserving knowledge and passing down lessons regarding sexual and mental health. As the founder and director of Make Art/Stop AIDS David Gere's own experience is that, 'Artists are able to shape transformative insights and possibilities that literally redirect how people think and act.'<sup>14</sup> Similarly, Clara Rubincam's research at Aids and Society Research Centre (ASRU) at the University of Cape Town (UCT) suggests that while youth may be sceptical of any biomedical scientific rationale for HIV they will actively engage with experiential explanations. Her research on the work of Treatment Action Campaign (TAC) peer educators confirms the importance of various 'rhetorics of persuasion' including personal testimonies and parables (2014b).<sup>15</sup> I would argue that Rubincam's research also suggests that specifically visual narrative projects might have some continued appeal for adolescents if tailored to appropriate themes and visual languages including digital media. The act of making in and of itself should also not be underestimated as a technique for enabling difficult conversations and disclosures which would otherwise be prohibitive.

During the # Fees Must Fall campaigns begun in 2015, the University of Johannesburg arts faculty circulated a statement in support of the students' demands

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<sup>13</sup> See the collaboration between Durban Art Gallery and the Fowler Art Gallery at UCLA which produced the exhibition and catalogue, '*Not Alone: An International Project of Make Art/Stop Aids*' which toured South Africa visiting Durban, Johannesburg and Cape Town between 2008 and 2010. See also *AIDS ART/ South Africa*, at Iziko: South African National Gallery, Cape Town, 29 November 2003 to 16 February 2004. This was a collaboration between the South African National Gallery and Wellesley College, MA, USA. *Bodies of Resistance* was an exhibition collaboration between the New York organization Visual AIDS dedicated to increasing public awareness of AIDS through the visual arts; the Natal Society of Arts in Durban and Real Art Ways in Hartford Connecticut. It ran from 1 December 1999 to 20 July 2000.

<sup>14</sup> <http://makeartstopaids.org>

<sup>15</sup> C. Rubincam, 'Peer Educators' Responses to Mistrust and Confusion about HIV and AIDS Science in Khayelitsha, South Africa', ASRU Working Paper, No. 343, (August 2014), pp. 1-43.



and in recognition of the violence with which they had been met by private security firms employed by the University on campus. It is a useful contemporary reminder in the South African context of the continuing appeal of the visual arts as a critical force for social change. ‘As a creative community and a Faculty committed to community engagement and social justice we are deeply concerned that the right to free expression and dignity is compromised on our campuses, and we can no longer stand by and be silent. We believe that the arts and design disciplines present unique opportunities for fostering dialogue...’<sup>16</sup>

### **Narrative and agency: photography**

The critical consciousness-raising work of South Africa’s celebrated fine artists forms part of the historical context for this broader history of visual activism around HIV/AIDS. Photographers initially deployed the black and white documentary genre familiar from the days of the liberation struggle against apartheid. Both Gideon Mendel and Gisèle Wulfsohn have drawn upon this legacy. Gideon Mendel (an award-winning South African photographer, known for tackling human rights issues, and now living in London) initially located his work within this genre in his celebrated series, ‘A Broken Landscape’ many of which photographs were taken in the 1990s.<sup>17</sup> Michael Godby in his thoughtful account of the various manifestations of this series, notes that one of the significant and subtle innovations which Mendel brought to earlier models of documentary photography, ‘...was to go beyond documenting the lives of the families hit by the illness and record the work being done to combat the disease through education and care.’<sup>18</sup> Gisèle Wulfsohn, also intent on her work having a wider remit than galleries or photojournalism, turned her 2000 series ‘Living Openly – 31 HIV Positive South Africans Share Their Stories’ into a pop up educational exhibition and free booklet given away at clinics. Voice and narratives supplied by photographic subjects becomes an increasingly vital component in any of the more successful photographic representations including

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<sup>16</sup> Cited in K. S. Berman, *Finding Voice: A Visual Arts Approach to Engaging Social Change*, (Ann Arbor, University of Michigan Press, 2017), pp. 70 – 71.

<sup>17</sup> Gideon Mendel, *A Broken Landscape: HIV&AIDS in Africa*, (London, Network Photographers in association with ActionAid, 2001).

<sup>18</sup> M. Godby, ‘Aesthetics and Activism: Gideon Mendel and the Politics of Photographing the HIV/AIDS Pandemic in South Africa’, in G.Barz and J.M.Cohen (eds.), *The Culture of AIDS in Africa: Hope and Healing Through Music and the Arts* (New York, Oxford University Press, 2011), pp. 215 – 221.

Wulfsohn's subsequent project completed in 2005 'Conversations – HIV and Families'.<sup>19</sup> In addition, photographers' early choice to limit their prints to black and white (rather than colour prints) with its clear association to the photojournalism of the liberation struggle, lent dignity and monumentality to the documentation of the catastrophic spread of HIV in South Africa during the bleakest years of the pandemic (1995 – 2006). Little by little, even the action of the camera came to be directed by the subjects themselves so that the person with AIDS is no longer simply the mute recipient of well-meaning but voyeuristic empathy.

'Positive Living' attempted to provide viewers with visual milestones to map this trajectory. Titles and captions have always been a tool in the critical armoury of documentary photographers in South Africa with both David Goldblatt and Gideon Mendel deploying narrative captions to locate their subjects 'in their own words'. Mendel's 1995 black and white photo from the series *A Broken Landscape* entitled 'Josaphat at Nazareth House, a home for abandoned children in Cape Town. He died shortly after this photograph was taken', was shown in the exhibition along with the extended caption – a quote from one of the nursing sisters working at Nazareth House. (Fig. 1) Far better than any gloss I could have supplied as the curator, these words convey the humanity of the staff and the tragic circumstances in which they were working at a time when certain death was the only outcome for the children in their care,

This picture shows Josaphat who came to us in the last stages of AIDS after being abandoned in hospital. Here he is enjoying a massage from a volunteer aromatherapist. Unfortunately she had to wear gloves as his body was covered in a fungal infection. In general we believe in giving our children as much physical contact as possible without the use of gloves. We concentrate on helping children live as normal, happy and healthy a childhood as possible. For most of our children, this is the only home they will ever know so we must make sure that this is a real home full of love and joy.

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<sup>19</sup> A. Weinand, 'Portraits, Publics and Politics: Gisele Wulfsohn's Photographs of HIV/AIDS, 1987-2007', *Kronos*, 38, 1 (January 2012), pp. 177 – 203.

When the time comes for a child to pass away we strongly believe in letting them die with dignity in familiar surroundings and not in a hospital. It is important that the caregiver with whom the child has the strongest bond is there with the child to hold him or her during their last moments.<sup>20</sup>

However, as the curator, I was also keen to ensure that Josaphat's pain was not the only legacy of his life's story. Consequently at the launch of the exhibition one of the survivors from Nazareth House, who had benefited from One to One Children's Fund provision of ARVs showed a film about her life and spoke movingly about her survival and subsequent adoption .

Mendel's colour photograph of sisters holding their memory boxes (2007) also came with their own words attached as an integrated caption. (Fig. 2) This is a consistent aspect of Mendel's practice and is indicative of his attempts to deliberately mediate his own photographs through the words of those who are represented in them, as a strategy of rendering back a measure of control and agency to (in this case) the sisters;

'I am Pinky Zondi. Both our mother and our older sister had HIV ...It was hard for me and Zandile to see both our mother and our older sister sick...I made the memory box in June this year...I made the box using paint of different colours. The box is a special thing for me by bringing the memories of my mother and sister and it is important because my identity document is kept safely in it.' The narrative of the caption reinforces the sisters' precarious existence and the way that care roles have been devolved to other members of an extended family as sixteen year old Pinky explains how an aunt takes care of her now and that her sister pays her school fees. But Zondi refuses the role of victim in this image and her words are also a reminder that some young people have successfully taken on greater responsibilities for their own health and the final sentence is optimistic in the scope of its ambition, 'I have learned about HIV during life-skills classes at school. I understand how it spreads and how to avoid it. I want to

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<sup>20</sup> Gideon Mendel, extended caption for 'Josaphat at Nazareth House.' (1995)

study more and become a doctor, to help my community. I want to help other HIV-positive people and help them not to suffer.'<sup>21</sup>

Mendel is one of those photographers whose work moved fluidly between documentary and fine art registers during the worst period of AIDS denialism in South Africa and in 2002 he lent his skills to Treatment Action Campaign. With a series of 13 posters designed to simultaneously tell the story of TAC's work but also to self-consciously create a photographic idiom, Mendel's series (in the best Brechtian tradition) makes explicit the variety of conventions of documentary and portraiture photography thus inviting the viewer and the subject to recognize how the different conventions might intervene in the production of meaning.<sup>22</sup> ( Fig. 3) They were also intended and used as a pedagogic tool, widely distributed and cheaply produced, disseminating a positive attitude, mutual respect, safe sex and information to help facilitate compliance with complex drug regimes. HIV-positive activists were encouraged to participate in the process of representing their own stories. In some photos a 'frame' of black masking tape is filled with objects and images that stand in for a 'portrait' of the narrator in those cases where anonymity was desired. Other individuals chose to challenge the stigma attached to disclosure by facing the camera directly and their stories of diagnosis and living with HIV are told in their own words beneath their photographic portrait.

Mendel's subsequent series dealing with HIV and the culmination of 20 years engaging with the representation of the virus is, 'Through Positive Eyes'. The series is produced in partnership with the UCLA Art and Global Health Center and Gere's Make Art/Stop AIDS and in collaboration with HIV positive individuals living in global metropolitan centres including London, Bangkok, Los Angeles, Mexico City, Mumbai, Rio de Janeiro and Washington DC . Key to the

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<sup>21</sup> Pinky Zondi cited by Gideon Mendel on the caption for his work, 'Pinky Zondi, aged 16 and her sister Zandile holding Memory Boxes, Murchison Township, KwaZulu Natal', 2007.

<sup>22</sup> Gideon Mendel's TAC poster series were produced with support and in collaboration with TAC, Médecins Sans Frontières South Africa, ActionAid, Wellcome Trust, SIDA, Perinatal HIV Research Unit, Positive Lives and Network Photographers, and the South African National Gallery.

success of the project is that those holding the camera (still or video) are themselves HIV positive. The stories they tell are their own in the images and words they select themselves. The larger aim of the project is to give '...voice to people living with HIV in major cities around the world. It is based on the belief that HIV-positive people should pick up their own cameras and make their own artistic statements. In doing so they create powerful tools for combating stigma, which is one of the most formidable barriers in reducing the spread of AIDS today.' (<http://throughpositiveeyes.org/>)

One of the most moving films is produced by a participant 'Gugu' from Johannesburg . Gugu speaks of her rape in 1994 when she found out that she was both HIV positive and pregnant, having been in a coma for three months following her ordeal. She was 14 years old at the time. When she gave birth her daughter tested HIV-negative. The film is essentially about the power of honesty and love – about the bond that has developed between the mother and daughter despite the stigma and guilt that Gugu describes following her rape and the abuse she received at the hands of some family members once her status was known. She decided to tell her daughter how she was conceived and then tells another story,

At school one day, the teachers set the children as assignment, 'Write something about heroes, like Mandela.' When I was checking my daughter's books, I saw that she had written about me. I said, 'Why do you write that I'm a hero, not Mandela or Jacob Zuma?' She said, 'No. They are not my heroes. My hero is you. Whatever difficulty I have in my life, you are always there for me. You are my hero. I will never talk about some far away person. I want to talk about you.' That's why I love her so much.<sup>23</sup>

Promoting such extraordinarily hopeful and courageous first-hand accounts through the eyes and words of those directly affected and in this case, an importantly trans-generational example, is a powerful counter to the images of victimhood and powerlessness that has so often been the primary message of representations of HIV diagnoses.

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<sup>23</sup> <http://throughpositiveeyes.org/> Johannesburg, Gugu's story.

Fine artists including David Goldblatt, Penny Siopis and Sue Williamson participated in international art exhibitions around the world to raise awareness of the plight of South Africans living with the virus in the face of their government's unwillingness to provide adequate health care and antiretroviral drugs. Williamson in particular, staged provocative public interventions with brave individuals who were willing to openly declare their HIV positive status, often risking violent consequences.

As with so many of Sue Williamson's artworks, 'From the Inside : Busi Maqungo' (pigment inks on archival paper, 2000) is essentially a collaborative project. (Fig.4) Part of a large series where signed statements about living with HIV by individuals prepared to publicly declare their positive status – in this case, Busi Maqungo – were initially produced using vinyl lettering and then in later versions of the same series, painted freehand, on to walls in prominent locations around Johannesburg and Cape Town. For the gallery version of the work the graffiti statements were then combined with a formal black and white portrait of the speaker. Williamson says that she made this series with participants to break the silence surrounding people who were HIV positive.<sup>24</sup> Busi Maqungo had been part of the women's march on parliament in 2000 to demand access to HIV/AIDS medication. Her statement on the wall and as part of the composite work reads: 'It should be taken as a crime if someone doesn't wear a condom and he makes you go to bed. Busi HIV Positive.' To those who recognised the pre-existing graffiti on the wall as that belonging to the Cape Town gang the Sexy Boys, Maqungo's message had an additional poignancy since the gang's initiation rites included raping virgins.<sup>25</sup>

In another memorable portrait from the series 'From the Inside: Johannes Bukhali, with parents' (2002), the wall text reads, ' HIV/AIDS is no longer only for people who are infected, it's everyone's task to help, Johannes HIV Positive'. Johannes

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<sup>24</sup> See Centre d'Art Contemporain, Brussels, *Sue Williamson: Selected Works*, (Cape Town, Double Storey, 2003) for more examples in this series.

<sup>25</sup> Personal email correspondence to Coombes from Sue Williamson, 27 October 2015.

painted his statement on a wall in Daveyton, near Johannesburg but the composite portrait with statement and family group in black and white as well as being part of a gallery show, gained further visibility by being enlarged as a huge banner and hung on the Turbine Building in Johannesburg as part of the 'Art City Project'. By taking over public spaces and writing on the built infrastructure of the city including underpasses, walls and flyovers 'From the Inside' became highly visible and almost unavoidable. Appropriating a combination of both the language of the streets ( for example, graffiti and advertising) *and* the intimacy of a private confessional or testimonial, is intrinsic to the effectiveness of the series which transformed Cape Town and Johannesburg into showcases for highly personal expressions about living with HIV from named individuals. It is important to remember that only two years earlier in 1998, Gugu Dlamini who had worked so hard to promote AIDS awareness in communities around Durban, was assaulted and murdered by members of those same communities after she had disclosed her HIV positive status on local radio as part of a campaign of Acceptance and Disclosure.<sup>26</sup> Over the period of the making of Williamson's 'From the Inside' public disclosure of HIV status was hardly risk free and demanded considerable courage. For example, in a series of film portraits following up on the lives of those involved in the 2002 Khayelitsha body mapping project, Bongiwe Mba speaks movingly to camera about how difficult it was for her to disclose her status to her church after her diagnosis in 2001, 'People were very scared to come out of the closet...and there are people who are still [in 2011] in the closet.'<sup>27</sup> As she paints the portrait that she made as part of a later series of workshops with UK artist Rachel Gadsden during the lead up to the Cultural Paralympics in London in 2012 she insists that 'By doing this painting, I want to tell the world out there that there are other people living with this disease. It is not the end of the road. Life goes on.'<sup>28</sup>

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<sup>26</sup> A. E. Coombes, *History After Apartheid: Visual Culture and Public Memory in a Democratic South Africa*, (Durham, Duke University Press, 2003), pp. 112- 113. This also discusses the memorial park and accompanying memorial dedicated to Gugu Dlamini in Durban. I was honoured to be able to attend her funeral.

<sup>27</sup> *Film Portraits, (Bongiwe Mba )*, (Cape Town, 2011). Film Editor: Deborah May, Camera: Cliff Bestall, Director: Rachel Gadsden.

<sup>28</sup> Ibid.

While Mendel and Williamson's early HIV photographic interventions borrowed language (however mediated) from a familiarity (their own and the viewers') with documentary photography, I selected Penny Siopis' 'Red Baby' (1996) because of the deliberate ways in which her photograph de-natured the genre. (Fig. 5) Siopis' series successfully appropriated the outward appearance of documentary reportage while flouting its conventions. Her 'Red Baby' series of colour photographs made use of an anatomically accurate doll which mimicked the appearance of a newborn child.<sup>29</sup> In some photographs the doll's proximity to the unborn foetus was unnerving. Siopis explained that she, '...wanted to emphatically connect the universal AIDS ribbon to the body of a baby so that the ribbon becomes less symbol, motif, logo than a representation of flesh and blood.'<sup>30</sup> In the series, and in this single image, it also seems to me that Siopis has exploited the iconic AIDS ribbon to suggest both threat and nurture. In a consciously ambivalent gesture, the ribbon has become simultaneously suggestive of a beautifully wrapped gift, of a child's swaddling clothes, of a wound dressing and of a restraint. The ethnicity of the baby is deliberately ambiguous thus drawing attention to HIV/AIDS as a global problem that knows no boundaries.

### **Narrating memory : the power of print-making**

While South Africa's fine artists and photographers were central to the fight to gain recognition for the struggle for ARVs particularly from an international community, I was also concerned with exploring visual activism's capacity to lend agency to women in those communities most directly affected by the pandemic. In some communities, visual art was enlisted to deliver effective therapeutic treatments for those with HIV/AIDS, enabling proactive memory work to be performed as a legacy for bereaved families and children. Many of these initiatives, such as the memory box and body map projects addressed in this research, have subsequently been adapted to other medical and mental health contexts globally. While, in each case, art has been enlisted for public health initiatives, economic empowerment and therapy, the models and delivery have been distinctive in important ways. Something which characterises those initiatives which were more successful in promoting

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<sup>29</sup> Penny Siopis personal email correspondence with Coombes, 20 October 2015.

<sup>30</sup> Penny Siopis cited in *Not Alone: An International Project of Make Art/Stop AIDS* (2008), p.42.



awareness, encouraging disclosure, testing and adherence, is that, as Kim Berman points out ‘... they did not function as bureaucratic structures’<sup>31</sup> but rather harnessed local knowledge and inventiveness so that the strategy seems to have been clearly ‘owned’ by the participants who experienced themselves less as ‘subjects’ of an experiment and more as agents of change in their own lives. In all cases the results were far more than just the diligent compliance with the instructions of either the experts from the print studio or collaborating NGOs and the selections in Positive Living were chosen to highlight this fact.

The ‘Paper Prayers’ initiative is one of the longest running projects delivered with the participation of communities from all over South Africa. It was designed to both raise awareness in an accessible and practical way about the biomedical context and to provide a safe environment to acknowledge and combat the stigma associated with HIV/AIDS. This printmaking project emerged from workshops initiated in 1998 by Artist Proof Studio (a non-profit participative community-based printmaking studio and training centre in the heart of Johannesburg co-founded in 1991 by Kim Berman and Nhlanhla Xaba) with funding from the Department of Arts, Culture, Science and Technology as part of a national cultural strategy for HIV education and awareness. Participants working with artists and printmakers, were encouraged to use pared down images as visual metaphors expressing their response to the AIDS crisis as they experienced it personally in their own lives. The stories and narratives which explained their choice of image were later transcribed and became an integral part of the ‘prayer’.

For ‘Positive Living’ I selected paper prayers which demonstrated the scope of the images and texts and which gave an insight into the poetics but also sometimes the pragmatism of the makers. Both of these qualities seemed to me to be crucial in different ways as forms of support for those living with HIV or those caring for others with the virus. The prints were also selected to demonstrate individuation and the human being behind the ‘prayer’. For example the outline of a fragile pair of oval wire-rimmed glasses – typically

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<sup>31</sup> Berman, *Finding Voice*, p. 58.

associated with the image of an idealistic intellectual or poet (dated 8 February 2007) included a text which was as much a poem as a prayer, 'Please take this glasses (sic.) and look through far away which it will take your mind to that state and think positively and live long. There is a hope with HIV and AIDS.' (Fig. 6) A print of vegetables, drugs (pills and capsule) and vitamins (carrots, squashes and fruits) on handmade paper was less a poetic entreaty and more a road map with detailed dietary advice for the viewer, 'A person who is HIV positive can be given ARVs only if their CD4 count is less than 200 to maintain their immune system. They can also be given supplement such as selenium, amino acids, and vitamin C to maintain a balance diet.' ( Fig. 7) Three luminous green trees printed on handmade paper came with a moving plea to a friend, 'My friend, I remember you my friend, sitting down under the tree, talking about your sickness. That's why I remember you. On your way don't forget I am still your friend, From Thembu.' (Fig. 8)

Another important and related project devised by Artist Proof Studio involved producing etched portraits combined with a narrative tribute commemorating a personal friend, or family member they perceived as a mentor who had died of HIV/AIDS ('100 Artists 100 Tributes', etchings on paper 2006). The etchings fall into various categories: a figurative portrait; a 'metaphorical' portrait where perhaps an object or article of clothing stands in for the loved one and in some cases a witty caricature. In each instance the makers were given three headings to elaborate the reasons for their choice of individual. Having examined the entire series of 100 etchings and accompanying statements I was struck by the strong personalisation of the Tributes both visually and textually. For 'Positive Living' I deliberately selected three which would reinforce the variety of visual representations, from the sensitively drawn figurative portrait of Zitha's aunt, to the graphic lack of sentimentality displayed by Ngulube's uncle in his naked emaciation seemingly dead on the street, and the enigmatic glimpse of a cap to stand in for Mafrara's friend.

It was also important to me to highlight the diversity of ways in which the tributes were expressed and the range of narratives which justified the print-

makers' choices. They are worth reproducing in full here. Part of the significance of the testimonies is that they prompt our awareness of the complications of people's lives and of the conflicted emotions generated by the commemorated individuals. They also demonstrate an extraordinary ability to set aside personal moral judgments in favour of spare, bald statements which have the additional effect of exposing the lived contradictions of precarious existences. So, for example, a heavy drinker who was only able to come home once a month from his job in a rural area, might also be a 'loving person'.

Thomas Ngulube, Tribute Number 11 out of 100: (Fig. 9)

Tribute: Uncle

Why Honour the Uncle:

'He was the closest family member to pass away from this pandemic. I HONOUR (sic) him to break the silence.'

About the Uncle:

'He was a headmaster at a rural area. (sic) He came home once a month. He was a loving persons with two kids and a stay at home wife. He was a heavy drinker.'

About the Project:

'It is liberating and will help bring me closer, as I never expressed my views on his death by the virus.'

Another tribute explains how someone who '...became so famous for the bad behaviour ' and '... liked to come to Joburg to look for something to live by stealing and cheating people,' could also be 'a role model' from whom one could discover 'treasures' and learn 'good things'.

Manuel Mafara, Number 8 out of 100 Tributes: (Fig. 10)

Tribute: Friend

Why Honour Him:

'He was very (sic.) quiet person, people never understood him. They thought he was a loner and someone who was full of bad secrets. I took him as a role model because I discovered a treasure from him. I learned good things from him.'

About the friend:

'He was a last born in his family. His life deteriorated after the death of his father. He started bringing girls every time at his home and hang up with gang companies that were always on the street, smoking and drinking. He became so famous for the bad behaviour. He liked to come to Joburg to look for something to live by stealing and cheating people. He never had any body from his family who stands up for him for guidance. I think he was doing these things to make people pay attention on his outcry (sic).'

About the project:

'I found the project as challenging and fun at the same time, because I learnt to deal with serious issues. It is like beating two birds with one stone.'

Eustacia Zitha produced a tribute to her aunt (Number 76 out of 100 Tributes) represented by a sensitively drawn portrait, and characterized in less contradictory terms as unequivocally loving and kind-hearted. But her precarious situation slips through the cracks in the narrative in the frequent references to her multiple jobs so that 'she never got time to rest'. (Fig. 11)

Tribute: Aunt

Why Honour Aunt:

'She had a good heart and was caring. I loved her as a mother to me who did everything from the heart.'

About the Aunt:

' My aunt was the 3<sup>rd</sup> child of my grandparents. She used to work as a tea lady and cleaner at the office of the Mpumalanga premier. She started getting sick in 1995 and struggled to fight her sickness in 2005 where she died. She was a hard worker who was kindhearted and giving. Her hobbies were growing vegetables and loved cooking. (sic.) She never got time to rest as she worked all day long. That is why I loved her dearly.'

About the Project:

'I feel really great as I never had the chance to say goodbye to my second mother.'

Kim Berman while having a firm belief in the value of art-based projects as socially transformative, crucially also emphasizes the importance of flexibility

and responsiveness to specific conditions, individual's and community needs and the necessity of giving time to any process.

' Like any such project, Paper Prayers needed to be able to reflect on and respond to these different needs in order to be sustainable and continue to revisit its initial objectives. No community-based art project can afford to lack such adaptability if it hopes to have the time needed for the communities it serves to gain agency. The one-off intervention of a three-hour Paper Prayers workshop can only introduce a new language for and way of integrating painful and complex issues. For meaningful change to be sustainable, time and an ongoing, engaged and participatory process using a phased approach is necessary for inculcating agency.'<sup>32</sup>

The degree of variety and personalisation of the Tributes and Paper Prayers both visually and textually suggests that the Artist Proof Studio printmaking workshops had the power to elicit genuinely self –reflective responses rather than the mechanical adherence to a useful formula which would normally generate highly conventionalized and fairly similar imagery. The rich variety of responses (in both narrative and visual terms) makes clear that participating in the workshops enabled individuals to access highly personal responses did far more than reiterate a pedagogic message. This is surely a measure of effectiveness in any therapeutic process and suggests the kind of agency advocated by Berman.

### **Embodied narrative : body mapping**

Like the Paper Prayers workshops 'body mapping' has often been used in health and other contexts as a pedagogic tool, transforming excessively complex medical and social data into accessible information through an heuristic process - learning through experience - in this case, specifically through collaborative making and the conversations it provokes.<sup>33</sup> In 2002 Médecins Sans Frontières and the AIDS and

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<sup>32</sup> Berman, *Finding Voice*, pp.s 69 – 70.

<sup>33</sup> One of the most detailed accounts of the different stages of a body mapping project in South Africa is found in, A. Weinand, 'Visual Approaches to HIV Literacy in South Africa' in Barz and Cohen (eds), *The Culture of AIDS in Africa* (New York, Oxford University Press, 2011), pp. 94 – 110.

Society Research Unit (ASRU) at UCT initiated the body mapping memory workshops in Khayelitsha, in collaboration with twelve HIV positive women (the Bambanani Womens' Group).<sup>34</sup> The Khayelitsha body maps which used a canvas ground to support (literally and symbolically) marks, gestures and words expressing the participants' experience of diagnosis and the challenges and implications of living with HIV/AIDS have been well documented by those involved in the early workshops including Kylie Thomas<sup>35</sup> and Beth Mills and Hayley MacGregor who conducted follow up interviews in 2008.<sup>36</sup>

Body mapping has been widely adopted with economically marginalized communities across Africa (Kenya, Tanzania, Zambia) and internationally (Thailand, India) sometimes in relation to health issues other than HIV for example, asbestosis in Canada and in relation to adolescent schizophrenia in Australia.<sup>37</sup> As a therapeutic process it has not been without its critics however, and some research suggests that those who have suffered trauma may become further distressed by increased awareness of embodied experience. However it seems that in the South African context, perhaps because of counselling and other support systems that were put in place for participants in for example the Khayelitsha workshops, participants have been able to turn body mapping into a tool for their own agendas and thus wrest a degree of agency from the process. TAC activist Thobani Ncapai who had left his 2002 body map unfinished due to heavy work commitments for TAC who were in the thick of their campaign, went on to produce a completed body map in 2011 in a

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<sup>34</sup> J. Morgan and the Bambanani Womens' Group, *Long Life: Positive HIV Stories* (Melbourne, Spinifex Press, 2003).

<sup>35</sup> K. Thomas, *Impossible Mourning*.

<sup>36</sup> H. MacGregor, 'Mapping the body: tracing the personal and the political dimensions of HIV/AIDS in Khayelitsha, South Africa', *Anthropology and Medicine*, 16, 1, (April, 2009), pp. 85-95. See also H. MacGregor, and E. Mills, 'Framing Rights and Responsibilities: Accounts of Women with a History of AIDS Activism', *BMC International Health and Human Rights*, 11 (Suppl.3), S7 (2011), pp. 53-57.

<sup>37</sup> A. de Jager, A. Tewson, B. Ludlow and K. Boydell, 'Embodied Ways of Storying the Self: A Systematic Review of Body-Mapping', *Forum Qualitative Sozialforschung/Forum; Qualitative Social Research*, 17, 2, (May 2016), pp.1-31, 6.5 available at <http://www.qualitative-research.net/index.php/fqs/article/view/2526/3986#g65>. They argue that although body mapping holds great potential the technique so far has lacked more empirical evaluation of its effects.

workshop facilitated again by Jane Solomon.<sup>38</sup> His map follows the technique of the earlier workshops in 2002 including the background body silhouette representing his personal supporters. The 'map' shows evidence of the operation on his broken leg following a car accident and carries the legend, 'Face it – Life is a Challenge'. (Fig. 12) In different encounters with Thobani including an invitation to speak at Birkbeck (with Nondumiso Hlwele and UK artist Rachel Gadsden) as part of the 2012 Cultural Paralympics, he has always insisted on the importance of taking responsibility for one's own health. His body map reiterates this message (consistent with TAC's own) with the statement, 'ARV is a long life treatment. Your health is your responsibility.' "The time we were doing workshops with Rachel", he says, "I was emphasizing the ups and downs of life that I have been facing through since I was diagnosed with HIV in 1997. My aims to do the visual arts with Rachel was to tell other people out there who have other chronic illnesses that, if you believe in yourself and don't give up you can go through with your life."<sup>39</sup>

It would be superfluous to rehearse the details of the Khayelitsha project again here although there are a few points worth reiterating in the context of evaluating the impact of body mapping as a visual activist strategy in relation to HIV in South Africa. A piece I wrote in 2011 compared the Khayelitsha body maps to other forms of women's story-telling as testimony in South Africa and in the context of the significance of narrative forms as a means of developing women's agency.<sup>40</sup> In that article, I drew on the important research of Fiona Ross on the nature of women's testimony during the TRC and how the almost incidental detail of the hardships and complexities of their own lives emerged while they gave testimony on behalf of

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<sup>38</sup> This became known as the 'Khayelitsha Hospital Project' because three of the completed body maps were recreated by Lovell Friedman and her team to decorate three wards at the new hospital there. Thanks to Jane Solomon who supplied this information in personal email communication, 6 October 2018.

<sup>39</sup> Thobani Ncapai in personal email correspondence with Coombes, 3 October 2018.

<sup>40</sup> A. E. Coombes, 'Witnessing History/Embodying Testimony: Gender and Memory in Post-Apartheid South Africa', *Journal of the Royal Anthropological Institute (N.S.) Special Issue 2011*, (2011), pp. S92-S112.

others.<sup>41</sup> Having done further research, it seems to me that this is borne out by other examples though not solely in relation to women, such as the Paper Prayers and Tributes initiatives discussed above, and that visual strategies that enable the production of narrative accounts are of critical importance both as a process and also incidentally as a means of better understanding the structure of people's lives, particularly those lived in precarious economic circumstances.

As with the prints, one cannot help being struck by the diversity of expressions and creative interpretations in instances of body mapping. This is especially remarkable since the body mapping process, devised in South Africa by the artist Jane Solomon, sets out a fairly strict formula, but one which nonetheless seems not to inhibit deeply personal responses to the effects and impact of living with HIV which translate into highly individual visualisations. For some, like the activist Nondumiso Hlwele, body maps can also act as a visual diary charting the different phases of her experience of living with HIV and she went on to complete two other body maps at later dates. In her 2011 body map instead of representing the virus inside her body as she had in the Khayelitsha workshop she explains, "...I showed it outside my body because it has given me opportunities to go overseas. The flower on my Body Map, is a leaf from a maple tree. I travelled to Canada twice, just to talk about my experiences and the process of how I did the bodymapping. The colour around my body, purple, for me is my strength so through all of this I feel fine, myself, that I am a woman of strength."

<sup>42</sup> (Fig. 13) By 2014 in another body map, she represents herself through the colour orange which "...represents the sun. There are a lot of things that are happening in my life which I would like to achieve in a short space of time. I feel like I am rushing, so the sun keeps me calm and warm and comfortable. Yes, there is no stopping you just keep on going, you keep on going." "Life is beautiful", she says, "We need to enjoy it and appreciate it." But despite the great joy of having given birth to her son (nine

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<sup>41</sup> F. Ross, 'Speech and Silence: Women's Testimony in the First Five Weeks of Public Hearings of the South African Truth and Reconciliation Commission', in (eds.) V. Das, A. Kleinman, M. Lock, M. Ramphela and P. Reynolds, *Remaking a World: Violence, Social Suffering and Recovery*, (Berkeley, University of California Press, 2001), pp. 250–279.

<sup>42</sup> Nondumiso Hlwele in personal email correspondence with Coombes, 20 September 2018. This is taken from the transcript of a talk she has entitled 'Bambanani Stories Nondumiso March 2012'. My thanks to Nondumiso for sharing these with me and for reading my drafts concerning her body maps.



years old by 2014 ) she has also been concerned about the continuing spread of HIV in South Africa particularly amongst young people. “ I listen”, she says, “and I find that education about HIV has been there but somehow did not reach certain kinds of people. For example how HIV is contracted. Somehow many people are still not sure, even though they know people who died from HIV they are treating it casually.

Maybe for them life would become boring if they become too careful when it comes to sex. I also see that there is a lot of teenage pregnancy this means there is not much condom use and no fear amongst young girls that they might be infected.”<sup>43</sup>

Nondumiso Hlwele’s body maps seem to enable a visual record-keeping of her progress in relationship to the HIV virus and to bear witness to the expansion of her dreams. Thus they are also the distillation of her knowledge about management of the virus that she has gleaned over time. In this sense they provide another crucial function in providing hope for those embarking on the same journey.

The Khayelitsha body mapping project has clearly had different kinds of impact both for those directly involved in their making or in the sense that there have been a variety of afterlives for the project either through appropriating the process or the images themselves. Warren Smit and his team used body mapping in other areas of Khayelitsha as a means of testing out the extent to which residents felt that the built environment had any impact on non-communicable diseases.<sup>44</sup> The researchers ran the workshops over 5 days deploying a similar technique to those used in the original Bambanani group body maps, ‘...participants gradually worked on tracing the outlines of their body, drawing the organs inside as they knew them, and then annotating these drawings to represent different aspects of their health and wellbeing (for example, adding ‘scars to the skin’ and ‘scars under the skin’).’ In this instance participants were also asked to draw where they were born and what the area looked like and to use colour codes to indicate the kinds of emotions aroused by different areas (‘red for danger’). As with the original HIV workshops the body maps were

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<sup>43</sup> Nondumiso Hlwele in personal email correspondence with Coombes, 20 September 2018. This is taken from the transcript of a talk she has given, entitled ‘Life is beautiful body map 2014’.

<sup>44</sup> W. Smit, A. de Lannoy, R.V.H.Dover, E. V. Lambert, N. Levitt, V. Watson, ‘Making Unhealthy Places: The Built Environment and Non-Communicable Diseases in Khayelitsha, Cape Town, *Health & Place*, 39, (May 2016), pp. 196-203 available at <https://www.sciencedirect.com/science/article/pii/S1353829216300247>

then used as a way of initiating discussion in this case, around how the participants felt about where they lived in terms of health and wellbeing.

On another occasion, in 2007, the University of Cape Town commissioned Lovell Friedman, working with three local artists, Sandi Mdkazi, Sibongile Memani and Xolani Badli, to translate three of the original body maps (by Noloyiso, Nondumiso Hlwele and Nomawethu) into mosaics for the Anzio road wall of the Medical School Library. ( Fig. 14) Arguably their reinvention as mosaics attached to the Medical School gives them permanence and monumentality as part of the built environment. Such a strategy clearly valorises the work of these women and makes their body maps durable and highly visible to a much wider public than the original workshop group. And as with Williamson's project 'From the Inside', the re-making of such intimate and originally intensely private work into a public display on a busy road has an interesting effect on the viewer and transforms a personal history into a highly public and political statement. For Friedman it was a '...way of telling these women's stories of courage.'<sup>45</sup>

There have been questions raised about the 'ownership' of the original body map designs and discussions about how they have been re-appropriated and sold as digital prints. Kylie Thomas, who was one of the facilitators in the Bambanani Women's Group body mapping project, explains that the money from sales of the digitised print versions of the body maps was channelled through ASRU with a portion of the sum being distributed between the members of the Bambanani Women's Group members.<sup>46</sup> Instead of borrowing a body map from some institution and paying them the lending fee, for 'Positive Living' I decided to work directly with Nondumiso Hlwele and to pay her a fee, both as the maker/artist for her work as well as paying the costs of the digital printing - the process whereby the originals are now multiply reproduced. Another impact from the project is that some of the original participants have benefitted both from being trained as research assistants through ASRU (this is the case for both Nondumiso Hlwele and Thobani Ncapai) but also through their

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<sup>45</sup> <https://www.news.uct.ac.za/article/-2007-03-05-body-maps-of-hope-captured-in-mosaic>

<sup>46</sup> K. Thomas, *Impossible Mourning : HIV/AIDS and Visuality After Apartheid*, p. 23. See also footnote 16, p.32 where she discusses the fees that have been paid in various international and South African contexts.

exposure to a variety of international contexts, travel and networks which have opened up for them as a result of their original participation. It would be naïve to imagine that this kind of privilege does not also incur penalties. For example, neighbours in Khayelitsha may imagine the recipients to be in a more privileged financial position simply because they see them being whisked away on some fully-funded international tour for a period.<sup>47</sup> This can be the cause of some resentment. Conversely, returning home with no permanent change to their daily circumstances, recipients of international largesse can find themselves presented with other challenges.

### **Narrating the Past in the Service of the Future: Community Art Activism**

As a way of dealing with the experience of poverty exacerbated by illness and death from HIV and its related conditions, there have been a considerable number of community art projects in South Africa since the first democratic elections in 1994. All of these were initiated by NGOs and individuals with varying degrees of community consultation and thus varying degrees of tension between the NGOs and community activists.<sup>48</sup> The now well-established Philani printmaking project is a case in point. Set up originally as a nutrition and health peer-mentoring initiative for mothers and children in Crossroads township outside of Cape Town, Philani subsequently developed as an economic empowerment and skills acquisition project aimed at enabling women to start small businesses selling weaving, producing murals and from 1997, printmaking on textiles and paper. Kim Miller has convincingly charted the effective activist agenda of the collective's T-shirts and other textiles where the designs address issues such as domestic violence, school rape and physical harassment in the workplace.<sup>49</sup> By 2000 however, some of the core artists in the group had already

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<sup>47</sup> Conversation between A. E. Coombes and N. Hlwele, at Coombes' home in London, December 2015.

<sup>48</sup> For an important early book which gives detailed case histories and critically explores the making and marketing of work from community embroidery projects in South Africa and Zimbabwe is, B. Schmahmann, (ed.) *Material Matters* (Johannesburg, Witwatersrand University Press, 2000).

<sup>49</sup> K. Miller, 'T-Shirts, Testimony and Truth: Memories of Violence Made Visible', *Textile*, 3, 3, (2005), pp. 250-273.

been reported in the national press complaining about the lack of consultation and involvement in the day to day decision-making processes of the project.<sup>50</sup>

A number of highly effective creative initiatives, which might usually be deemed 'craft', have acquired such a high degree of international acclaim and national recognition (and in some cases considerable value in a collectors' market) that they now deny easy categorization. These projects, sometimes originated by middle-class white professional women, have ultimately produced important collaborations between black and white women from vastly differing social and educational backgrounds with a number of local beneficiaries. It is also true however, that the complex needs of historically disadvantaged local communities has meant that some of these initiatives have not escaped accusations of paternalism. However, their relative success and longevity as NGOs are important to acknowledge, while at the same time being mindful of the tensions which have necessarily arisen at various stages of their development.

The work of the Keiskamma Art Project (part of the Keiskamma Trust) located in the Eastern Cape has had a significant impact both nationally and internationally in promoting HIV/AIDS awareness through their collaborative art projects. The Keiskamma Trust began life as an economic empowerment initiative to build self-esteem and a livelihood amongst local Xhosa women in a region disadvantaged by a legacy of discrimination from successive waves of colonial, apartheid and Bantustan governments. Conceived in 2000 by Dr. Carol Hofmeyr (a medical doctor and trained fine artist), the creative project soon found a new focus. Located in the village of Hamburg, in an area of the Eastern Cape decimated by HIV/AIDS, the Trust's Art Project has acquired an international reputation for large-scale multi-media artworks highlighting the challenges of living with the virus. Interviews with members of the Keiskamma community

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<sup>50</sup> See M. Esau, 'A participatory approach to political, social and economic freedom of the poor in South Africa: An approach that lends itself to real empowerment or one that perpetuates continued vulnerability of the poor,' (unpublished conference paper, Fukuoka Japan, July 2006). See also J. Mesi, *Die Burger*, 25 May 2000. The women were reportedly dissatisfied by lack of consultation though the co-ordinator at Philani, M. Mphathi Gocini, denied the allegation.

which I conducted in 2009, 2011 and 2013 highlight the misinformation around HIV and the prejudice against those who tested HIV positive.<sup>51</sup> During the period of AIDS denialism under former President Thabo Mbeki when antiretrovirals were withheld, death almost inevitably followed infection and fear was a constant companion.

Under these circumstances Hofmeyr retrained as an HIV specialist and set up a hospice and clinic (Umtha Welanga) in 2005, while enlisting the help of Eunice Mangwane, an HIV counsellor from the Western Cape. Between them and with the help of others they attempted to educate the community against the fear of testing and the inevitable stigma which followed disclosure of a positive status. Just as Halstead-Berning had felt the need to sidestep government restrictions, Hofmeyr similarly found other ways of supplying the community with ARVs and initially paid for them out of her own pocket from 2003. Ardmore Ceramics in the Midlands , KwaZulu-Natal , (which developed from the initial mentor/pupil relationship between art-school trained Fee Halstead-Berning and Bonnie Ntshalintshali into a dynamic creative partnership) shares a history of battling for ARV provision with both initiatives making the decision to accept this from whatever source was available. In the case of Ardmore this came in the form of the US President's Emergency Plan for AIDS Relief (PEPFAR).<sup>52</sup> These were controversial decisions in the face of Treatment Action Campaign's fight to secure government provision of ARVs, but are a measure of the desperation felt by those working closely with communities being torn apart by the virus.

Recognising that smaller craft items would be priced out of the market if the women were paid a reasonable wage for their efforts, Hofmeyr had the foresight

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<sup>51</sup> A. E. Coombes interview with Eunice Mangwane at Umtha Welanga, the Keiskamma hospice and treatment centre, 8 December 2009. In this long interview Eunice spoke movingly (and in tears) about how she was treated with great suspicion and hostility as an outsider working with a white doctor. She discusses the numerous myths about how AIDS was spread and contracted held by the community in Hamburg.

<sup>52</sup> F. Halsted, *Ardmore: We are Because of Others*, (Cape Town, Fernwood Press, 2012), p.xiii. Keiskamma were also the recipients of PEPFAR aid.

to concentrate on attempting to win large commissions.<sup>53</sup> Her idea was to work from concepts inspired by European masterpieces but reinterpret them as large-scale multi-media artworks, drawing on local crafts and skills, which spoke directly about the histories and lives of those in the Eastern Cape who produced them. One of their earliest works completed in May 2004, was the Keiskamma Tapestry whose structure mirrors that of the Bayeux Tapestry and depicts selected incidents from local and national histories. The Keiskamma version transforms the story on the original tapestry (the battle of Hastings in 1066) into 126 metres of embroidered and beaded panels recounting the Frontier Wars and cattle killings of the Eastern Cape and the later struggle against apartheid. The tapestry won Keiskamma national acclaim and was exhibited in the grounds of the new Constitutional Court Precinct in Johannesburg and is finally (having been bought by the Standard Bank collection) on permanent loan in the Parliament Buildings in Cape Town.<sup>54</sup>

The women who had collaborated on the project speak movingly about the impact it had on them personally, increasing their self esteem through an understanding of the local and national histories which they learnt as part of the design process and which had been denied them under the restrictions of Bantu education during apartheid,

The first time I started to learn about the history of my ancestors is ...when we were doing the Keiskamma Tapestry. It was so interesting. I had never known about all those wars and the reasons why they happened. I also did not know how my family came to be in Hamburg – all the Xhosa kept moving around, I learnt. Now I know where I come from, and where my ancestors come from. I know about the history of my people, it makes me

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<sup>53</sup> A. E. Coombes interview with Carol Hofmeyr at her home in Hamburg, 5 December 2009.

<sup>54</sup> B. Schmahmann, *The Keiskamma Art Project, Restoring Hope and Livelihoods*, (Cape Town, Print Matters Heritage, 2016).

feel good inside, and a little sad about all the bad things that happened, but we can make it right now.<sup>55</sup>

Even if the commissions were less economically rewarding than intended, the fact (evidenced by this quote) that the process of creating these large commissions clearly stimulated a direct engagement in local history from the women working on the project. This knowledge, which was a key component of the training on many projects undertaken at Hamburg, played a major role in fostering self esteem. All the women I interviewed emphasized the importance of education and training prospects offered by the project with a number being funded to train at Walter Sisulu University of Technology in East London in return for paid work on the project.<sup>56</sup>

Ultimately the devastating effects of HIV began to dominate the life of the small community. Like the memory box project, the art projects at Keiskamma needed to fulfil the demands of both mourning and of memorialisation. In addition, if the community was not to collapse under the weight of despair, they also needed to provide another more pro-active function – to affirm life and to inspire the community to take action against the disease as well as providing an income to support the living.

One of the works which has perhaps been most successful at meeting these requirements was the Keiskamma Altarpiece (2004 – 2005). Based on the Sixteenth Century 'Isenheim Altarpiece' by Matthias Grünewald and Niclaus of

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<sup>55</sup> A. Shelver, 'Offerings at the Altar: 'Life is to Share' – the Keiskamma Art Project, HIV/AIDS and Herstory' (Honours thesis, Rhodes University, 2006). My thanks to Amy Shelver for sharing this excellent thesis which contains some of the most detailed research on the Keiskamma Art Project available.

<sup>56</sup> Coombes interview with Nomfusi Nkani, at the Keiskamma Art Project shop in Hamburg, 18 February 2015. Nomfusi's ambition prior to working on the art project was to earn money from domestic work in either East London or Port Elizabeth because on qualifications were needed. Through the project she obtained government funding for Teknikon training in fine art, along with four others from Keiskamma. By the time of the interview Nomfusi was teaching basic skills in fine art at secondary school to Grade 9 pupils as part of a pilot project funded by the National Lottery and the Department of Arts, Culture and Education. Her new ambition was to teach full-time.

Haguenau, painted to celebrate deliverance from the Plague - it is no exaggeration to describe the Keiskamma version as truly monumental. Standing at 4 metres high and reaching about 6.8 metres wide when fully extended, it is a tour de force deploying older local traditions of beadwork and Xhosa pearl button work, wirework, photography, embroidery and appliqué. The artwork was highly effective as an international ambassador for South Africans raising awareness about the wider effects of the HIV pandemic on local communities. In 2006 it toured to a number of international venues, including a widely reviewed exhibition at the Fowler Museum at the University of California, Los Angeles (UCLA) where it was described as a 'present-day folk-art masterpiece'.<sup>57</sup> The tour took in several cathedrals including St. James Cathedral in Toronto, Canada and St. James Episcopal Cathedral in Chicago, USA and London's Southwark Cathedral where it was displayed until 30 October 2008.<sup>58</sup> As Amy Shelper has noted in her dissertation on the Altarpiece, it is one of the key Keiskamma artworks to incorporate identifiable individuals and their stories and is 'explicitly about Hamburg'.<sup>59</sup> In many ways (though not exclusively) it is a women's altarpiece – celebrating the role played by specific women in mitigating the effects of HIV/AIDS on this tight-knit community. The Altarpiece also invites the viewer to recognise the resilience of women in general, as nurturing forces in local communities across South Africa – as mothers and grandmothers who sustain the melded and extended families that have become a legacy of the AIDS pandemic.<sup>60</sup>

By 2009 (completed in 2010), Hofmeyr had extended the visual strategy of appropriating a well-known icon of European art to another ambitious project by re-making Pablo Picasso's 'Guernica' in the image of the community at Hamburg. (Fig. 15) The anguished masterpiece protesting Franco's massacre of innocent civilians on a busy market day during the Spanish Civil War was

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<sup>57</sup> <http://international.ucla.edu/africa/event/5701>)

<sup>58</sup> *The Telegraph*, 11 October 2008, reported fully on the event which coincided with a fund-raising drive for the Trust, as did a number of other sources.

<sup>59</sup> Shelper, 'Offerings at the Altar', p.61.

<sup>60</sup> The women involved in the Art Project are at pains to emphasise that not everyone in the community is HIV positive and that those whose health is not compromised by the virus play a crucial role as carers.



transposed onto the Eastern Cape to embody the community's harrowing struggle against HIV in an embroidered, beaded and felted version using Picasso's monumental scale, 349.3 cm x 776 cms. (Picasso's is 350 x782cms). For 'Positive Living', a smaller version of the large-scale 'Keiskamma Guernica' was commissioned and made in 2015 by Veronica Nkosanzana Betani and Nosiphiwo Magdswana.

To understand the impact of the Keiskamma Art Project's transformation of Picasso's masterwork, we need to know a little about the complex history and afterlife of *his* 'Guernica' and how its various appropriations are compounded to produce particularly powerful readings for the Keiskamma version.

The bombing of the Basque town of Gernika on 26 April 1937 was undertaken by German and Italian squadrons ordered by the Spanish Nationalist forces under General Francisco Franco. It is the first known instance of what later became familiar as 'carpet bombing' – the indiscriminate mass bombing of (in this instance) a civilian population - completely decimating the town and its inhabitants. At its inception Picasso's 'Guernica' was already a highly political statement, being the centrepiece of the Spanish Pavilion organized by the short-lived Republican government at the 1937 Paris World's Fair, at the very start of the Spanish Civil War against Franco's Nationalist forces.<sup>61</sup> Picasso himself recognized the potency of his work and when the Republicans lost the war, he refused to have the painting displayed in Spain until the end of Franco's Dictatorship and the restoration of democracy. The original remained in the Museum of Modern Art New York until it was brought 'home' to Spain in 1981 where it now resides in the National Museum - Reina Sofia - in Madrid.

The painting's significance as an iconic plea for peace was famously reinforced in the run up to the Iraq war in January 2003. On the corridor outside the United Nations Security Chamber a replica of 'Guernica' in tapestry form, became the backdrop to the regular press briefings given by John Negroponte, US

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<sup>61</sup> Guernica's relationship to the Republican cause was cemented when it was shown in the Whitechapel Art Gallery in 1939 to raise funds for the Republican cause.

Ambassador to the UN – until, that is, the tapestry was covered over with a blue cloth. Clearly the irony of attempting moral justifications for the war on Iraq in front of a painting dedicated to warnings about the moral unacceptability of war in the face of its horrors – was too much even for the US administration! As one UN delegate said at the time, ‘We may well live in the age of the so-called ‘smart bomb’, but the horror on the ground will be just the same as that visited upon the villagers of Gernika...and it won’t be possible to pull a curtain over that.’<sup>62</sup> Later in 2009-10, the artist Goshka Macuga’s installation ‘The Nature of the Beast’ at the Whitechapel Art Gallery would explicitly draw attention to this irony.

‘Guernica’ has subsequently been appropriated as a critical shorthand, in many contexts where atrocities have occurred – in particular those enacted upon civilian populations including most recently on the cover of *The Spectator*. This referred to the ‘Syrian nightmare’ of the siege of Aleppo with Morten Morland’s remaking of Picasso’s version with a Russian bear in place of Picasso’s bull (signalling the Russian bombing of Aleppo) and President Assad launching a missile on his own peoples.<sup>63</sup> ‘Guernica’ has become an iconic image of the horrors of mass killings seen as the inevitable result of war and is specifically used to expose the lie of the euphemism of ‘collateral damage’.<sup>64</sup>

Because of ‘Guernica’s’ historic legacy and because the image has clearly attained an iconic, universal quality, it seems a natural choice for Keiskamma to revisit and re-appropriate Picasso’s work. Those who produced the ‘Keiskamma Guernica’ are quick to point out the differences between the two versions however, since theirs ‘... depicts not an instant of horror but rather a slow eating

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<sup>62</sup> *The Independent*, 28 January 2009.

<sup>63</sup> *The Spectator*, 8 October 2016, cover. See also T.J. Clark, ‘Picasso and Tragedy’, *London Review of Books*, Vol 39, Number 16, 17<sup>th</sup> August 2017, p.33 where he lists Ramallah, Kolkata, Oaxaca and Belfast as contexts where Picasso’s ‘Guernica’ has been used to expose the lie, as he puts it of ‘collateral damage’.

<sup>64</sup> Nicola Ashmore and colleagues at the University of Brighton have been part of an ongoing research project, ‘Guernica Remakings’ which began life by making a protest banner closely drawing upon Picasso’s ‘Guernica’ between 2012 and 2014 with a group of artists and members of the public in England and India. The idea was to produce a banner to protest contemporary aerial attacks on civilian populations. See [www.guernicaremakings.com](http://www.guernicaremakings.com).

away at the whole fabric of a community. Each day another thread is lost, and suddenly an entire generation has disappeared. It has seemed that as we stitched in panic and in sorrow against this disintegration, more holes have appeared and gaps that could not be mended. While the foundations of a new wealthy and privileged society have been built up, we have dug countless graves.’<sup>65</sup>

Key to its success in the South African (and specifically Eastern Cape) context and to its appeal internationally, is that the Keiskamma version has successfully ‘Africanized’ the original ‘Guernica’. Where Picasso’s horse holds centre stage, they have introduced a cow, since cattle (specifically Nguni long-horn cattle) are so central to the political and economic wellbeing of the community, being implicated in lobola (bride price). It is also a reminder of the prophetess Nongqawuse’s disastrous but desperate insistence on how killing the stock of cattle (upon which the wealth of the community depended) would see off the colonizer and result in the return of ancestral lands to the Xhosa in the region. A group of mourners in traditional Xhosa mourning have been inserted into the bottom right hand side of the work and the words of those combating HIV have been embroidered into the very body of the central cow. Along the border of the work are beaded AIDS ribbons and square metal plaquettes with the names of those who have died in the years up to the completion of the ‘Keiskamma Guernica’.<sup>66</sup>

If Picasso’s ‘Guernica’ represents the massacre of civilians by Franco’s Nationalist forces in 1937, its monumental scale also contributes to the experience of the work as a memorial to those who were killed. The ‘Keiskamma Guernica’, through its association with Picasso’s and due to its own grand scale, forces the viewer to thus recognize the multiple massacres that have shaped this small fishing community. The local Xhosa population in Hamburg not only suffered its own version of Frontier Wars between 1779 and 1878 with a heavy death toll. It also suffered the decimation of its population as a result of the

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<sup>65</sup> Keiskamma Trust pamphlet on the ‘Keiskamma Guernica’, (2010).

<sup>66</sup> In the original commission, the felted, embroidered and beaded work was part of a larger installation which cemented a local reading and included a thorn bush kraal.

withholding of life-saving ARVs by Mbeki's government – a decision which resulted in more than 330,000 avoidable deaths nationwide. This too is akin to a massacre.<sup>67</sup> Consequently as in the case of Picasso's 'Guernica', the Hamburg 'Guernica' acts as both a warning to future governments and an effective peripatetic memorial to the unnecessary deaths of innocent civilians during the period of AIDS denialism and its aftermath in South Africa.

## **Conclusion**

All of those represented and participating in the many visual strategies analysed in this article and in the exhibition 'Positive Living' have expressed on many occasions, the fact that they do not wish to be always and inevitably identified solely in relation to the virus and that they have a life beyond this diagnosis. One of my imperatives in curating the exhibition was to reinforce the message of survival and resilience in the face of the challenges posed by living with HIV but to also give space to the everyday hopes and concerns of many of those represented and participating in the exhibition, As a consequence I included a film originally commissioned for the 'Unlimited' programme as part of the London 2012 Festival during the Paralympic Games that year, which celebrated the creative engagement with the challenges of living not only with HIV but also with major health issues and disabilities.<sup>68</sup> The film revisits the lives of the participants with a series of filmed portraits from the original Khayelitsha Body Mapping group. Nondumiso Hlwele, Bongiwé Mba and others from the Bamanani Women's Group together with Thobani Ncapai, speak movingly to camera about the moment of their diagnosis but also and importantly they share the changing priorities in their lives and their expanded dreams in a renewed future.

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<sup>67</sup> Simelela (2014) p.250, cited in Schmahmann, (2015) p.9 makes it clear that by 2010 when the 'Keiskamma Guernica' was completed, despite government-sponsored roll out of ARVs, only a small percentage of those eligible for ARVs under the government guidelines (55% of adults and 36% of children) were actually receiving them. Schmahmann recounts the additional difficulties facing Hamburg once distribution was limited to government clinics, since the available clinics involved complicated travel arrangements and long distances for the community.

<sup>68</sup> *Film Portraits* (Cape Town, 2011). Film Editor Deborah May, Camera Cliff Bestall, Directed by Rachel Gadsden, commissioned as part of a collaborative art and performance project conceived by UK artist Rachel Gadsden for 'Unlimited Global Alchemy' as part of the Unlimited Paralympics programme, London, 2012.

It is difficult to draw a neat conclusion which adequately summarizes the differential extent and impact of the range of visual strategies adopted by the campaign around HIV/AIDS awareness in South Africa and elsewhere. As always, any assessment would need to take account of who is making the address to whom (questions of agency) and how the different spaces of any address might already determine the kinds of audiences that could be reached and engaged. And I have attempted to keep this in view in my discussion of these strategies. From the early fine art conceptual and provocative experiments delivered in the relatively liberal and safe space of a designated art environment already associated with risk-taking (but nonetheless a critical form of intellectual and political engagement), we have seen how the same fine artists often moved out of their comfort zone to widen the reach of their work and the vital politics that drove it, sometimes taking their work to the streets.

Photographers and master printmakers have increasingly given over the tools of their trade to those directly affected by the virus, equipping them with means to develop their own visual languages to explore loss, anger and survival and to spread the messages that preoccupy them to those they want to reach. The most effective so-called 'community art' projects expanded the range of their activities over the period under discussion, by knowingly crossing the boundaries attributed to different genres so that local economic empowerment initiatives became international ambassadors for the cause of HIV awareness while still maintaining local valency. The domestic intimacy of embroidered, beaded, quilted piecework sewn at home has transmuted into the monumental expression of the AIDS Memorial Quilt and the 'Keiskamma Guernica' both of which have gained traction through their peripatetic displays around the globe.

Running through these examples and the processes which have produced them is the importance of narrative and the question of temporality – the pressure of time under periods of duress but equally, as Kim Berman has so poignantly emphasised, the urgency of making the time. Those collaborative strategies which have taken the time to work over a longer timeframe and even to revisit the visual project at a later date with the same participants, have left a legacy which now acts as a visual diary of a life's history, adding valuably nuanced levels of detail for later generations. In almost every case those projects which have engaged relevant constituencies most effectively, are projects which have facilitated the telling of personal narratives and which have

enabled the visualisation of these stories in ways which expand the formulas that inevitably form the necessarily pragmatic and sometimes universalising structure of many workshops. It is these personal narratives and their visualisation, as much as the workshop process itself that have had the ability to enhance the self-esteem of the narrator (who is often also the artist/maker) and to transform complex medical and social data into the accessible, transferable knowledge that ultimately saved lives.

These examples are surely evidence of the power of art, as a tool for advocacy, as a pedagogic inducement, as a means of articulating loss and as a creative practice with the license to raise sometimes uncomfortable and painful truths often occluded in the mainstream media. 'Positive Living' was also of course, evidence of the power of art to simply imagine otherwise.

#### ACKNOWLEDGEMENTS

The concerns of this research stem from personal experience and the generosity of a group of HIV positive gay men in London in the 1980s who welcomed me non-judgmentally into their therapy and healing sessions following the prospect of diagnosis with a life-threatening disease. The medical professions' advice to me was to 'grasp the nettle' and very little else. The men in that self-help group saved my sanity. Thank you and in particular to my old friend John Edgar who introduced me to the group but is no longer with us.

Thanks also to Veronica Nkosazana Betani, Nosiphiwo Magdswana, Nomfusi Nkani, Cebo Mvubu and Eunice Mangwane for generously allowing me to interview them in Hamburg in the course of this research. Carol and Justus Hofmeyr have always been the most welcoming of hosts and took time out from their crucial medical work to facilitate my research on Keiskamma. Thank you both.

Thank you to Nondumiso Hlwele who shared her time, expertise and friendship with me in South Africa and in London and to Thobani Ncapai for sharing his knowledge and personal experience with us at Birkbeck during the 2012 Paralympics cultural festival and subsequently. Thanks to Kim Berman at Artist Proof Studio for reading an earlier draft of this article, for making the Artist Proof archive available to me and for the important work she does as artist, activist and educator, training a new generation of print makers in South Africa. Thank you to Jane Solomon for allowing me to access her personal body mapping archive many years ago and for supplying

photographs and to Jean Brundrit who generously took photographs for me when I was unable to get to South Africa. Thanks to Rebekah Lee for her insightful comments on an earlier draft of this article and to my friend and colleague Hilary Sapire who was co-convenor of our conference 'Women and HIV/AIDS: Medicine, Art, Activism' and who is always generous with her time and critical advice.

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