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From “medical miracles” to normal(ised) medicine: AIDS treatment, activism and citizenship in the UK and South Africa

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Steven Robins is Professor of Social Anthropology, University of Stellenbosch, South Africa. These two papers (also 'Rights passages from "near death" to "new life": AIDS activism and treatment testimonies in South Africa', *IDS Working Paper* 251) were written as inputs to the IDS, DRC programme on Citizenship, Participation and Accountability. The papers benefited from discussions held amongst participants in the Science and Citizenship cluster of the DRC. This cluster was convened by Ian Scoones and Melissa Leach, both Fellows at IDS. Melissa Leach and Linda Waldman provided written comments which helped revising earlier drafts. Further comments are welcome and can be sent to robins@netactive.co.za.

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Summary

This paper compares and contrasts the cultures of activism and illness and treatment experiences of UK and South African AIDS activists. By the 1990s AIDS public health discourse in the UK, and elsewhere in the West, was reconfiguring AIDS as a manageable chronic illness that could be treated much like diabetes. By contrast, the introduction of anti-retroviral therapy (ART) in the South African public health sector in 2000 was described using quasi-religious phrases and narratives: “the Lazarus effect” and “God’s gift of life.” The paper is concerned with investigating these significant differences between Northern and Southern experiences and responses to ARV treatment. It is specifically interested in the ways in which relatively easy access to treatment in the UK has, in certain cases, contributed towards the individualisation, medicalisation and “normalisation” of HIV/AIDS. For example, some of the UK activists I interviewed claimed that the availability of ART through the NHS had “killed activism”. The paper shows how the individualising and depoliticising medicalisation processes associated with NHS treatment programmes stand in stark contrast to South Africa, where the ongoing legal and political struggles for treatment access continue to strengthen and sustain collective forms of social activism and mobilisation. The paper explores the implications of these strikingly different treatment contexts, experiences and responses. These include differences in the availability and quality of treatment and health services, infection and mortality rates, socio-economic profile of PWAs, political cultures of activism, and contrasting government and activist responses to the pandemic. In sum, individualising and normalising processes of “medicalisation” associated with the NHS are increasingly, it would seem, becoming obstacles to collectivist forms of mobilisation.

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Preface: DRC working paper series on citizens, science and mobilisation

Rapid advances in science and technology are accompanied by changing forms of public engagement, with implications for citizenship. There is evidence both of apparent crises of public confidence in science, linked to the emergence of new risks, uncertainties and threats thrown up by science, technology and its application. At the same time, certain local knowledge is being re-worked as citizen science, in which the public conducts research and engages critically with expert perspectives on scientific and technological issues.

The Citizens and Science Programme of the Citizenship DRC has been exploring emergent engagements between citizens and public issues involving science, and the processes of rights-claiming and participation involved. This inquiry has moved beyond institutionally-orchestrated attempts at public participation in science to look at more spontaneous forms of citizen mobilisation and activism around scientific and technological issues. Across a diversity of issues and contexts and drawing together perspectives from social movement theory and science studies, the Programme has asked:

- Who mobilises and who does not, and why?
- What are the patterns of experience, profiles and identities of activists?
- Within what spaces do debates about science and policy take place, and what processes of inclusion and exclusion exist?
- What forms of knowledge – including values, perceptions and experiences - frame these public engagements and movements?
- How are activist networks constituted, and what diverse forms do they take?
- How do science and scientists become enrolled in these networks?

Working Papers in the series include:

‘MMR mobilisation: citizens and science in a British vaccine controversy’, by Melissa Leach.

‘The science of water scarcity management and social mobilisation on water and the environment in South Africa’s Western Cape Province’, by Lisa Thompson.

‘Contentious politics, contentious knowledge: mobilising against genetically-modified crops in India, South Africa and Brazil’, by Ian Scoones.

‘When social movements bypass the poor: asbestos pollution, international litigation and Griqua cultural identity’, by Linda Waldman.

‘Rights passages from “near death” to “new life”: AIDS activism and treatment testimonies in South Africa’, by Steven Robins.

‘The formation of the Brazilian environmental movement’, by Angela Alonso, Valeriano Costa and Débora Maciel.

'Contesting scarcity', by Lyla Mehta and Lisa Thompson.

'From "medical miracles" to normal(ised) medicine: aids treatment, activism and citizenship in the UK and South Africa', by Steven Robins.

1 Introduction

In the early 1990s, the South African photographer Gideon Mendel exhibited devastating images of Africans dying of AIDS. These photographs of wasting bodies were taken before antiretroviral (ARV) therapy was even on the horizon for millions of HIV-positive Africans. At the 2002 launch of Mendel's new book, *A Broken Landscape*, held at the South African National Gallery, Cape Town, Mendel also exhibited his more recent photographs which comprised of healthy looking and "upbeat" Treatment Action Campaign (TAC) activists. The latter were part of the more than one thousand HIV-positive people who participated in the *Medicins sans Frontieres* (MSF) ARV treatment programme that began in Khayelitsha, Cape Town in 2000. These optimistic images of people living with AIDS (PWAs) told a powerful story of the empowering possibilities that the availability of ARVs presented for people living with AIDS. They also told the story of one of the most successful post-apartheid social movements, the Treatment Action Campaign (TAC).

While these images of "medical miracles" were widespread in Europe and the United States in the mid-1980s when ARVs first appeared, by the 1990s AIDS public health discourse in the West was reconfiguring AIDS as a manageable chronic illness that could be treated much like diabetes. By contrast, successful ARV treatment in South Africa continues to be described using quasi-religious phrases and narratives: "the Lazarus effect", "God's gift of life", *wukile* ["he awoke" from near death] and so on. So how should we understand the "extraordinary" character of South African treatment experiences, and what are the implications of this for AIDS activism and mobilisation? How has the recent availability of treatment impacted on AIDS activism, and how does this compare with the UK experience, where activists claim that "treatment killed activism"? Finally, what are the limits and possibilities of access to ARV treatment in South Africa, and will South Africa follow a similar path to the UK and the US, where AIDS is widely perceived to be "normalised" as a chronic illness?

I recall being stunned by the statement by an AIDS activist I met in London in 2004 who told me that the availability of treatment through the National Health Service (NHS) in the mid-1990s had 'killed AIDS activism'.¹ Yet, the more I began to understand the story of AIDS and treatment in the UK, the more this statement began to make sense. It appeared that contrary to the situation in South Africa, ARV treatment in the NHS had become thoroughly medicalised, normalised and bureaucratised. The South African AIDS treatment story, I will argue, is anything but mundane.

This paper is an attempt to compare and contrast the illness and treatment experiences of UK and South African AIDS activists. It is part of a comparative research project on AIDS, activism and citizenship. It does not claim to tell the whole story of HIV/AIDS or treatment activism in South Africa, the UK or anywhere else in the world. It is based on a limited number of interviews and is cautious about generalising and extrapolating beyond these few cases. Instead, it is concerned with highlighting issues that have been neglected in mainstream social movement theory and research, namely the role of social movements in radically transforming subjectivities and identities. The study focuses specifically on the role

¹ Although activists I spoke to were willing to have their accounts of their experiences tape-recorded and published, I have decided to protect their privacy and identities by giving them pseudonyms.

of illness, treatment and activism in producing new subjectivities and forms of health/biological citizenship. It is concerned with the following questions: How does AIDS treatment strengthen or undermine commitment to social activism, and what are the implications of treatment for the construction of HIV-positive identities, subjectivities and forms of social activism and citizenship?

2 Social movements and citizen science

Elsewhere I have written about the extraordinary AIDS activism that has accompanied the struggles for access to antiretroviral therapy (ART) in South Africa (Robins 2004; see also Friedman and Mottiar 2004). In grassroots and global struggles, AIDS activists belonging to TAC and MSF drew on the courts, mass action, mass media, internet, and grassroots mobilisation. These forms of TAC mobilisation involved legal challenges and street demonstrations against AIDS dissidents, the global pharmaceutical industry and a South African government that was initially reluctant to provide ARVs in the public health sector (Robins 2004). Studies of AIDS activism and “citizen science” (Irwin 1995) address a broad range of questions relating to identity-based illness movements (Denzin 1987; Epstein 1996; Petryna 2002), “biological citizenship” (Petryna 2002), and “lay expertification” (Epstein 1996). They also addressed issues relating to “risk society” (Beck 1992; Giddens 1991) and the perceived failure of governments and scientists to address environmental and health hazards has contributed to citizens’ increasing scepticism and distrust of science. As Leach, Scoones and Wynne (2005) have pointed out, these developments have also contributed towards ongoing contestation over “scientific facts” and the framing of debates on scientific matters. According to Scoones (forthcoming),

The way [scientific] debates are framed defines relationships between political contests, identities and ways of knowing. Indeed, as discussed below, many contests over knowledge – characterised by the struggles of “new” social movements (Offe 1985) – are less about “facts”, but more about values and symbols (Melucci 1985), “ways of life” (cf. Touraine 1992) and identities (cf. Melucci 1989; Castells 1997).

It is within this context of contestation that citizen science movements are emerging in Europe and North America. Globally connected AIDS social movements in South Africa and Brazil have emerged in somewhat different settings but have in many instances followed similar activist trajectories. This paper is specifically concerned with the role of AIDS activism in producing new social subjects.

In recent decades there has been a proliferation of studies on social movements but only recently have they begun to address questions of subjectivity and identity. Marc Edelman (2001: 285), in an extensive review of the social movements literature, notes that theories of collective action have undergone a number of paradigm shifts from “mass behaviour” to “resource mobilisation”, “political process”, and “new social movements”. Edelman identifies these paradigm shifts with the four major theoretical approaches to understanding collective action in the twentieth century, and draws attention to the conceptual limits of these theories. Firstly, functionalist frameworks (Smelser 1962) viewed collective

behaviour as irrational mass responses to societal breakdown, but could not explain events such as the counterculture movements of the 1960s that took place in the midst of almost unprecedented affluence and political stability in North America. Secondly, rational actor approaches (Olson 1965) understood social movements as the sum of participants' strategic individually oriented choices, but could not account for seemingly altruistic decisions by students and hippies to "drop out" of middle class career trajectories. Thirdly, traditional Marxist approaches viewed the bourgeoisie and the proletariat as the central antagonists in capitalist societies, yet many of these movements focused on issues other than class and had leaders from middle class backgrounds as well as multi-class constituencies. In the 1970s theorists of "new social movements" (NSM) sought to address these conceptual conundrums and theoretical blindspots.

Edelman identifies Alain Touraine (1992) as one of the first scholars to theorise the emergence in Europe in the 1970s and 1980s of environmentalist, peace and anti-nuclear, women's, gay liberation, minority rights, and student and youth movements (Melucci 1989). Since then the list of new movements has grown to include struggles for human rights and democratisation, the rights of indigenous peoples, AIDS, and the needs of the rural landless and urban slum dwellers. Edelman seeks to make sense of this proliferation of "causes" by considering the classification of "old" and "new" movements. In terms of this conceptual grid, the "old" social movements were those concerned with "old" labour or working class struggles in terms of which class was the central social divide, category of analysis, principle of organisation and political issues (Edelman 2001: 417). The "new" movements, by contrast, rejected class as the master category and sought to achieve their goals outside of existing institutional channels and party political structures. These new movements were more concerned with questions of "cultural struggles" over meanings, symbols, collective identities and rights to difference (Edelman 2001: 416–7). Edelman (ibid) notes that in line of the emerging postmodern and poststructuralist paradigm, 'movement participants, often termed "new social subjects," have multiple "social locations" or "positions" and their political activity can, therefore, not be derived *a priori* from a single principle of identity or a particular structurally defined "interest," especially a material one' (Laclau and Mouffe 1985: 27). While Ernesto Laclau has provided important theoretical insights into the production of the "new social subjects" through participation in social movements, there have been very few ethnographic descriptions of these processes of subject formation. It is this gap in the literature that this paper seeks to address. Citizen science and AIDS activist movements fall into this relatively new category of NSMs.

3 AIDS activism and "new social subjects" in South Africa

While the linking of biology and health to identity is certainly not new, what is new are the ways in which biological identities, and the interest groups formed in their name, are emerging in different parts of the world (Petryna 2002: 14). These movements have had important implications in terms of creating new forms of citizenship and political subjectivity. In South Africa, for example, there has been a recent call for public health experts for a "new contract" between provider and client (see Coetzee and Schneider 2004). The advocates of this contract suggest that the passive and paternalistic surveillance model of direct

observation therapy (DOT) TB treatment is not a viable solution for life-long ARV treatment. Instead what is needed, they argue, is a highly motivated, “responsibilised” and knowledgeable HIV-positive client-citizen: a new social subject. According to David Coetzee and Helen Schneider (2004: 1), a “public health revolution” is necessary if ART is to succeed.

Alternative approaches to the traditional management of chronic diseases, such as “directly observed therapy”, are needed if the stringent adherence requirements of ART are to be achieved. The evidence from pilot projects is that high levels of adherence stem from *a new kind of contract between providers and clients*. The contract is premised on very high levels of understanding, treatment literacy and preparation on the part of users, the establishment of explicit support systems around users, and community advocacy processes that promote the rights of people living with HIV/AIDS. The responsibility for adherence is given to the client within a clear framework of empowerment and support. This is very different to the traditional paternalistic and passive relationship between health care workers and patients – changing this represents the key innovation challenge of an ART programme.

The idea of a “contract” between providers and clients is not new in the public health field. However, the nature and scale of the AIDS pandemic, along with the requirement of life-long treatment, reinvigorated calls for a change in the paternalistic culture associated with conventional public health interventions. These calls took place in a context in which the national Health Minister had conceded that DOT programmes were failing, largely because of ‘insufficient human resources to supervise and monitor implementation’, culminating in a declining cure rate for TB of only 53 per cent (*Cape Times*, 12 October 2004). In terms of this call for a paradigm shift, clients would be entitled to free government health care, including anti-retroviral drugs, but they would also need to show that they were “responsibilised clients”, i.e., through demonstrating treatment adherence, disclosing their HIV status, using condoms, abstaining from alcohol abuse and smoking and so on.

These calls from South African public health professionals for a “new contract” between clients and providers also resonate with MSF’s own ideas about the “responsibilised” citizen-patient. Both draw on the importance of creating empowered HIV-positive identities and non-hierarchical relations between providers and clients, experts and patients. However, neither of these models of health promotion and rights-based mobilisation adequately acknowledge the profoundly traumatic character of illness experiences; nor do they recognise the complex mix of religious, communal and activist discourses, interpretations and mediations of these illness experiences. Yet, it is precisely the discursive power of these interpretive frames of illness that facilitate the making of new HIV-positive identities and “responsibilised” subjects. Rationalist and liberal individualist conceptions of the modern citizen as a rights-bearing subject are inadequate for understanding the transformative character of these new biosocial identities. Merely providing information and education about rights and responsibilities, I argue, are insufficient for creating this “responsibilised citizen”.

In a companion working paper in this series, I have written about the empowering effects of the “combination therapy” of ARV treatment and AIDS activism, and how this can create the conditions for production of new subjectivities and collective meanings out of the traumatic experiences of illness and stigmatisation of individual AIDS sufferers (Robins 2005). I describe this process as a “rights passage” from “near death” to “new life”. It is precisely the extremity of “near death” experiences of full-blown AIDS, and the profound stigma and “social death” associated with the later stages of the disease, that can produce the conditions for AIDS survivors’ commitment to “new life”, social activism and “responsibilised citizenship”.

These processes can be distinguished from more mundane and medicalised forms of AIDS treatment in the public health sector, where treatment is shaped by the conventional doctor-patient dyad and highly technician and depoliticised modes of biomedical intervention in the private spaces of doctors’ consultancy rooms. By contrast, TAC activism creates the conditions for collectivist responses to HIV and treatment. Whereas public health practitioners report that most of their HIV/AIDS patients wish to retain anonymity and invisibility at all costs, TAC successfully advocates the transformation of the stigma of AIDS into a “badge of pride” that is publicly displayed on T-shirts at township funerals, demonstrations, workshops and other public spaces. It is through these activist discourses that it becomes possible for the social reintegration and revitalisation of isolated and stigmatised AIDS sufferers into a social movement and a caring community.

These profound transformations at the level of subjectivity and identity seem to occur when PWAs personally experience, or witness, the “near death” to “new life” transitions that are possible with ARV treatment. These “miraculous” transitions throw light on the social status shifts that may take place when the stigmatised and isolated sick recover and become reintegrated as healthy and socially active members of society. Drawing on illness narratives and treatment testimonies, it was possible to understand how these radical shifts in subjectivity could produce the kinds of “positive” HIV-positive identities and activist commitments that I discuss later in relation to the experiences of UK AIDS activists. But before doing this it is necessary to briefly discuss the very different treatment setting in South Africa.

3.1 *Aluta continua: South African struggles for treatment continue*

The struggle for ARV treatment began in earnest in South Africa in the late 1990s. In October 2004, following sustained activist pressure on the pharmaceutical industry and government that included court cases and mass mobilisation, a national ARV programme was launched in the public health sector. South Africa now has one of the most ambitious AIDS treatment programmes in the world, yet by May 2005, only approximately 33,000 of the estimated 600,000 people needing treatment were receiving ARVs

through the public health sector, while another 45,000 accessed treatment in the private sector (*Cape Times*, 15 April 2005). This limited access to treatment was particularly worrying given estimates that there were between 4–6 million HIV-positive South Africans.²

Even with the arrival of treatment, AIDS activists have still had to challenge forms of AIDS denial and dissidents within and outside of government. In addition, access to testing and treatment programmes seemed to be stymied by AIDS myths, misinformation, denial, fear, shame and silence within the general population. In May 2005, the TAC found itself yet again in court, this time challenging what it claimed were the misinformation campaigns of multi-vitamin manufacturer and AIDS dissident Mathias Rath. The Rath Foundation had distributed thousands of leaflets and posters in working class townships claiming that TAC, as a front for the pharmaceutical industry, was peddling toxic drugs. Rath claimed that his multi-vitamins were safer and more effective in preventing AIDS than ARVs. AIDS activists and public health practitioners responded by claiming that instead of using legal and non-legal methods to counteract Rath's "disinformation campaigns", the Health Minister, Manto Tshabalala-Msimang, was giving legitimacy to the dangerous misconception that vitamins were alternatives to ARVs. So, notwithstanding the introduction of a massive national ARV programme, activists belonging to the Treatment Action Campaign (TAC) found themselves having to continue to challenge AIDS dissidents who persisted in questioning the link between HIV and AIDS, the scale of the AIDS pandemic and the efficacy and safety of antiretroviral therapy (see Robins 2004). Activists were also involved in ongoing litigation that challenged the global pharmaceutical industry's patents policies, monopolies and pricing structures, as well as the national leadership's perceived lack of political will when it came to ARV treatment. As a result, ARV treatment in South Africa was anything but mundane, routinised and "normalised". These ongoing controversies and the persistent politicisation of AIDS ensured that AIDS activism remained alive and kicking.

South African AIDS activism has been extraordinarily successful in its challenges to the global pharmaceutical giants and the South African Government. These legal struggles and modes of mobilisation straddled local, national and global levels in ways that can be best described as "grassroots globalisation" or "globalisation from below" (see Appadurai 2000, 2001). This mobilisation took place in multiple spaces including the streets of Cape Town, Rio and New York, the South African Constitutional Court, international AIDS forums, the mass media and the Internet (see Robins 2004). This paper, however, focuses on a specific dimension of AIDS activism in South Africa, namely its capacity to create the conditions for the production of new subjectivities and identities out of the traumatic experiences of

² See Dorrington, Bourne, Bradshaw, Laubscher and Timaeus (2001: 6). Estimates drawn from Department of Health surveys based on blood tests of pregnant women in antenatal clinics throughout the country indicated that by 2000 over 4.7 million South Africans were infected with HIV, and that this figure was likely to double by 2010. Since 1990, the national Department of Health has conducted annual anonymous surveys of blood tests of pregnant women in antenatal clinics around the country. At the end of 2000 the seropositive rate for HIV amongst pregnant women was 24.5 per cent. The current estimates of HIV-positive South Africans stand at between 4.3 and 7 million. In October 2002, a study by the University of Natal's health economics and HIV/AIDS research division found that the pandemic would rob three million children of their parents in the next ten years (*Sunday Independent*, 6 October 2002).

illness and stigmatisation of individual AIDS sufferers. It contrasts these “extraordinary” processes with the shift in the 1990s in the UK and North America to more medicalised and “normalised” treatment regimes that were perceived to have “killed off” possibilities for grassroots AIDS activism. The study focuses on the ways in which experiences of illness, treatment and activism can, under certain circumstances, contribute towards profound changes in the lives of people with HIV/AIDS.

ARVs are often interpreted by people living with AIDS as miraculous medical technologies, and recovery is often narrated as a biosocial and quasi-religious passage from “near death” to “new life” (see Robins 2005). This “miraculous” recovery from traumatic experiences of AIDS-related illnesses is often viewed by people living with AIDS as a “gift from God”. These interpretations are qualitatively different from the experiences of those exposed to “normalised” medicine. However, by focusing on the illness narratives and treatment testimonies of two UK AIDS activists who were diagnosed in the 1980s before ARV treatment became available, it will be argued that the experiences of these UK activists were in certain respects quite similar to people living with AIDS in developing countries, where ARVs continue to be out of reach for millions who need them.³ Before proceeding to discuss the UK setting, it is necessary to establish why questions relating to the rights, responsibilities and subjectivities of PWAs have become so important in South Africa.

Section I

4 Rights and responsibilities in a time of AIDS: South African ethical and treatment conundrums

After almost two decades of ARV treatment within the NHS, it appears that most people living with AIDS are able to access relatively high quality treatment without experiencing serious problems. Most people needing ARVs through the NHS appear to be in a position to access and adhere to treatment. Moreover, the NHS, together with community based organisations and NGOs, have provided special psychological and social services for those who encounter adherence problems. While such services are indeed available for better-off South Africans who have private medical insurance, it is certainly not an option for the majority, who have to rely on an overstretched and under-resourced public health system. This situation is exacerbated in South Africa where chronic poverty, fear, shame, denial and stigma have conspired to make treatment access and adherence exceptionally difficult. This has prompted some South African public health practitioners to call for a balance between individual rights and the responsibility of

³ The paper is wary of presenting ARVs, especially in developing countries, as a “magic bullet” for a number of reasons, including the following: millions of the almost 30 million HIV-positive Africans (an estimated 90 per cent of the world’s HIV-positive population) are likely to continue to be denied access to AIDS treatment for decades to come; many will arrive at clinics too late for treatment to be effective, and millions will fail to seek out treatment due to a lack of access to drugs and information or because stigma, denial and AIDS myths will continue to be obstacles in the path of treatment access. In addition, many people on ARVs are likely to encounter treatment adherence and resistance problems. Finally, poverty, patriarchal traditions, wars, famine and natural disasters are likely to conspire to complicate, if not prevent, millions of Africans from accessing to treatment.

the state to protect society, i.e., by making HIV testing compulsory and make AIDS a notifiable disease. These arguments for prescription and compulsion are often supported with reference to the poor adherence and treatment statistics for South African TB patients. Given these difficulties, it is not surprising that South African public health professionals are grappling for solutions that will improve treatment access and adherence in contexts characterised by stigma, fear and denial.

In his book *Witness to AIDS*, Judge Edwin Cameron (2005) provides a moving account of how the knowledge of one's HIV-positive status can produce overwhelming feelings of fear, self-blame and self-loathing (*Sunday Independent*, 3 April 2005). Cameron, an internationally respected human rights lawyer and Judge who was actively involved in AIDS policy issues in the 1990s, was diagnosed in 1986. Yet it took him almost 12 years to publicly disclose his status. His courageous account of the agony of living in silence and shame provides a cautionary note to those who glibly claim that it is the responsibility of everyone to test for HIV and disclose their status. Cameron experienced these feelings of shame as a middle class, anti-apartheid lawyer who moved in progressive circles and who had a very supportive family and circle of friends. His story draws attention to how fear, stigma and denial can conspire to produce silence and denial about this devastating pandemic.

In 2005, barely two years after the announcement of the national ARV programme, a number of questions were being raised concerning ethical and pragmatic grounds for prescriptive measures to deal with HIV/AIDS. Professor Solly Benatar, Professor of Medicine and director of the Bioethics Centre at the University of Cape Town, suggested in a newspaper article that the prevention of multi-drug resistant HIV 'may justify over-riding individual rights to treatment for those who may not be able to adhere to treatment' (*Cape Times*, 15 April 2005). Benatar called for a balance between the rights of individuals and the public health needs of society. To maximise adherence to ARV treatment, he argued, required that patients take some responsibility for their own health. Dr Udo Schuklenk, a bioethics professor at Wits University, took Benatar's argument much further. He claimed that the high infection rate of the AIDS pandemic warranted the introduction of compulsory HIV testing and counselling of pregnant women in the public health sector (*Mail & Guardian*, 1 April 2005). Schuklenk claimed that compulsory testing would give pregnant women knowledge of their status and allow them to participate in prevention of mother-to-child transmission (PMTCT) programmes. Schuklenk's call for more prescriptive approaches to counselling was based on the argument that there needed to be a more equal balance between women's reproductive rights and their responsibility to give newborn children "a fair shot at life". Dr Ruth Rabinowitz, an opposition Inkatha Freedom Party Member of Parliament, also called for compulsory HIV tests, notwithstanding women's rights and rights to privacy (*Cape Times*, 18 August 2004). These views shared the belief that the rights of the individual may, under certain circumstances, be compromised by the state's responsibility to "protect" the public, including unborn children and HIV-negative citizens.

Benatar, Schuklenk and Rabinowitz, like many South African public health practitioners, argue that citizens have both rights and responsibilities. They also make the assumption that citizens are in a position to make responsible health-related decisions based on scientific information and "rational" decision-making procedures. The problem with this view is that it assumes that everyone is capable of acting from

this position of rational choice and individual agency. However, if AIDS has taught us anything it has shown that millions of women in South Africa do not have bodily autonomy and free choice when it comes to health matters. They cannot simply decide to go for an HIV test or participate in prevention of mother-to-child-transmission programmes without incurring the wrath of their male partners. Should they disclose their HIV-positive status this can result in possible beatings and eviction from the household.

These gendered realities were recently highlighted in the case of SM, an HIV-positive woman who tried to commit suicide by setting herself alight after her HIV-positive status was revealed in Independent Democrats leader Patricia de Lille's autobiography. SM claimed that she decided to commit suicide by pouring paraffin over her body in response to her husband's rage when he discovered that she had publicly revealed her HIV status (*Cape Times*, 19 April 2005). These accounts reveal the limits of liberal individualist conceptions of rights and responsibilities. They also suggest that it is problematic to abstract the individual rights bearing citizen from his or her social and cultural milieu. The issue of rights and responsibilities is further complicated by the negative social constructions of HIV/AIDS and the profound fear, blame and shame that this can produce. So what are the implications of all of this for HIV testing, prevention and treatment?

As was mentioned earlier, in recent years there has been a call from South African public health experts for a "new contract" between provider and client. The advocates of this contract suggest that the passive, authoritarian and paternalistic surveillance model of direct observation therapy (DOT) TB treatment is not a viable solution for life-long ARV treatment.⁴ Instead what is needed, they argue, are highly motivated, "responsibilised" and knowledgeable clients and persons living with AIDS. The argument is that citizens have rights to health care but they also have responsibilities, and that for ARV treatment to work, clients will have to be active empowered citizens rather than passive patients of the "nanny state". The term "responsibilised citizens" is also used by some of the MSF doctors involved in ARV programmes in Cape Town.

It is perhaps not entirely coincidental that the concept of "responsibilisation" also appears in the recent work of political theorists writing about contemporary liberal rationalities of government in the UK and Europe. Nikolas Rose and his colleagues (1996), drawing on the writings of Michel Foucault, use the term to refer to the ways in which, under contemporary versions of liberalism, citizens are encouraged to "govern themselves". For instance, instead of burdening the public health system, they should take care of themselves through healthier diets, lifestyles and exercise. In other words, citizens are meant to become

⁴ These concerns about the paternalism of DOT approaches resonate with Foucauldian critiques of biomedicine's role in the processes of medicalisation and "normalisation." These critiques are concerned with the pathologising discourses of "social deviance" that are associated with the medicalisation of society that began in late nineteenth century. Following the work of Foucault, many critics of biomedicine have 'treated medicalization as an aspect of the rationalization of society through the dominance of scientific categories' (see Turner 1996: 206). According to Bryan Turner, 'since sickness can be regarded as a form of social deviance, the medical profession has a policing function within society. Medicine as a form of social control involves the standardization of illness in phenomena that can be managed by bureaucratic agencies' (Turner 1996: 206.)

responsible for issues previously held to be the responsibility of the state and public health authorities. Should this model of governance be used to encourage people living with AIDS to become “responsibilised clients”?

Social movements such as the TAC and MSF provide striking examples of ways of inculcating a stress on both health rights and responsibilities. For many TAC and MSF activists living with AIDS, their experiences of full-blown AIDS, and the profound stigma and “social death” associated with the later stages of the disease created the conditions for their commitment to treatment adherence, “responsible” lifestyles, and social activism. ARV treatment, together with TAC and MSF’s provision of support and social solidarity for people living with AIDS transformed the traumatic experiences of stigmatised illness into new forms of social commitment, empowerment and citizenship. For some, it was a combination of treatment and AIDS activism that created the possibility for transforming the negativity of AIDS stigma into a “badge of pride” and a new positive HIV-positive identity. These experiences also produced a strong sense of social belonging that was expressed in statements such as ‘TAC is my mother, MSF is my father’ and ‘Zackie and Mandla are like my brothers’.⁵

While TAC and MSF are obviously not the only avenues for creating these empowering outcomes and commitments to treatment adherence and responsible sexual and health behaviour, they are nonetheless powerful examples of how a new “contract” could be forged between health providers and clients. These examples suggest that what is required is not simply access to more AIDS awareness information and better medical surveillance systems, but rather transformations in the subjectivities and identities of people living with AIDS. It is here that TAC and MSF have been successful in creating new and empowering forms of health/biological citizenship that challenge the paternalism and prescriptive approaches of DOT methods for treating TB.

TAC and MSF appeared to have improved the lives of many of its members to the degree that one often hears from TAC activists that “AIDS was a blessing in disguise”. Many of the young female activists I interviewed spoke of traumatic experiences of rape, illness, AIDS stigma and expulsion from their homes and communities. Upon joining TAC they found a “new family” and close-knit community of activists. These organisations are clearly concerned with much more than lifesaving ARVs. They are also concerned with creating social capital and facilitating radical transformations in selfhood and subjectivity. These transformations come from the ability of MSF’s treatment programmes to address both biological disease and the social, cultural and psychological dynamics associated with stigmatised identities. These are worlds apart from the mundane, bureaucratic and “normalised” encounters between NHS “providers” and “clients.”

Edwin Cameron’s *Witness to AIDS* (2005) is a powerful account of the devastating power of AIDS stigma, shame and denial. It helps account for why treatment is not a “normalised” medical intervention, and why so many people living with AIDS are staying away from testing and treatment centres. Cameron’s testimony also suggests that prescriptive methods of compulsory testing and HIV status notification could

⁵ These are two national leaders of TAC, Zackie Achmat and Mandla Majola.

push the disease further underground. In addition, it suggests that treatment adherence is unlikely to succeed using traditional DOT methods. Instead, what is required is a profound change in individuals' sense of self-worth and dignity. This is likely to have more positive treatment outcomes than prescriptive methods of intervention.

TAC and MSF have created particularly powerful social processes for transforming stigmatised AIDS sufferers into “responsibilised” and empowered activist-citizens (see Robins 2004). Other equally effective approaches are being developed in various parts of South Africa. These approaches, rather than relying on compulsion and prescription, draw on the extraordinary and almost magical healing powers of ARVs. They also draw on the creative capacities of individuals to make sense of their traumatic passage from “near death” to “near life”. This quasi-spiritual interpretation of healing goes a long way to explain why, for many people, AIDS treatment is unlikely to become a mundane, medicalised condition like diabetes. Similarly, given the enormity of the AIDS challenges facing South Africa, activism is unlikely to die a quiet death now that treatment has become available. Commitments will continue to be fuelled by the very real threats to human lives posed by HIV/AIDS. AIDS dissident theories, stigma and denial, are also likely to continue to animate activism in South Africa. For these reasons, the paper will argue that AIDS treatment and activism in South Africa continues to look very different to the UK situation.

Section II

5 From “miracle drugs” to normal(ised) medicine: the UK perspective

Most studies of social movements assume the prior existence of stable political identities and subjectivities and that it is simply a matter of mobilising and organising around shared interests. This study, however, suggests that the political identities and subjectivities of HIV-positive activists are often the outcome of profoundly transformative experiences of illness and treatment. It also suggests that experiences of highly medicalised and bureaucratised treatment processes may produce very different outcomes that can end up depoliticising AIDS and undermining activist commitments and social movements. The discussion above drew attention to “extraordinary” treatment circumstances in South Africa that produced a profound sense of having a “new status” and “new life”, as well as empowering possibilities for belonging, solidarity and citizenship. It also alluded to another possible treatment scenario: the demobilisation of illness-based movements.

Some would argue that HIV/AIDS in Europe and the UK has indeed become “just like any other chronic illness”. The availability of relatively high quality treatment and health care through the NHS has, it is often argued, rendered AIDS activism virtually redundant; it is now perceived to be up to individual client-patients to access these health services and make sure that they behave responsibly in relation to treatment adherence and healthy lifestyles. So what are the implications of these normalising and individualising processes, and what similarities and differences can we expect in relation to the social consequences of AIDS treatment in the UK and South Africa?

5.1 'Treatment killed activism': ARVs and the unmaking of AIDS activism in the UK

Although the UK study is still at a very preliminary stage, it does seem to confirm the widespread perception that AIDS in the “First World” has become a manageable chronic illness. AIDS in the UK has been historically associated with “high risk” groups such as drug users, sex workers and gay men. Yet, UK AIDS activists are increasingly concerned with the growing numbers of HIV-positive heterosexual youth and the increase in the STI rates amongst young people. In addition, the presence in the UK of significant numbers of HIV-positive refugees and immigrants from the Third World is also beginning to challenge complacent attitudes towards HIV/AIDS in the UK. Although there is some activism and lobbying surrounding the rights of refugees⁶ to access AIDS treatment through the NHS, the overall prognosis for citizen participation and AIDS activism in the UK was perceived to be bleak.

One of the key findings of my brief research visit to the UK was that one of the unintended outcomes of a relatively effective treatment response by the NHS was the depoliticisation of treatment issues. Users of the NHS were described as “consumer-citizens” who were able to access relatively good health services without having to lobby, organise or mobilise. Statements such as ‘AIDS treatment killed activism’⁷ and ‘people aren’t angry enough about the NHS to get involved in any activism’⁸ reflected this depoliticised form of health consumerism. From the interviews, it was not clear whether these forms of “depoliticisation” were a response to normalised treatment regimes, or whether, in the UK treatment context, AIDS activism no longer had any real “causes” and difficulties around which to mobilise. Interviewees such as David did, however, draw attention to the writing-off of people’s difficult experiences with adherence and side effects.⁹ Similarly, the psycho-medical labelling processes – in terms of which those who could not cope with treatment were designated as “dysfunctional” – was another source of anger, although it was unlikely that this would emerge as an issue around which to mobilise.

Notwithstanding the pervasiveness of these normalising and medicalising processes, I visited a number of highly effective community-based AIDS organisations. Yet, as will become clear below, these organisations were generally involved in service delivery rather than AIDS activism.¹⁰ The following section draws attention to the Janus-faced character of these interventions, which involve providing services to those who “fall between the cracks”.

⁶ Respondents told me that African refugees in the UK were increasingly being told that since ARV treatment was now available in African countries they ought to return home for treatment. This served as a catalyst for NGO litigation and lobbying on behalf of refugees who were being denied access to the NHS.

⁷ Interview with David, 27 November 2004.

⁸ Interview with Chris Pearce, Terrance Higgins Trust, 26 November 2004.

⁹ I am grateful to Melissa Leach for encouraging me to explore in greater depth this subterranean source of anger.

¹⁰ Interview with Nick Boston from Open Door, a community support organisation in Brighton.

6 “Falling between the cracks”: the “medicalisation” of AIDS patients

There are numerous striking differences between the contexts of HIV/AIDS in the US, UK and South Africa. These include differences in the availability of treatment and health services, infection and mortality rates, the socio-economic profile of PWAs, and contrasting government and activist responses to the pandemic. Whereas HIV-positive people in the US and the UK have had relatively good access to treatment for almost a decade, ARVs are a relatively recent development in South Africa’s public health sector. Another marked contrast lies in the quality of psychological services provided to HIV-positive people. Whereas in South Africa such services are virtually absent for the poor, in the UK they are relatively advanced and freely available through the NHS. It is also becoming increasingly clear that psychological/psychiatric services are targeting those who have “fallen through the cracks”. It is this category of “dysfunctional” PWAs that are most exposed to the individualising and normalising discourses of the NHS. These processes of “medicalisation” are increasingly, it would seem, becoming obstacles to more collectivist forms of mobilisation. They are widening the gap between individual-based psychological therapies and the more collectivist, community-based forms of AIDS activism.

Jackie Titley, an HIV/AIDS Community Services Manager at the Sussex Beacon, Brighton,¹¹ is a trained specialist mental health nurse who joined Sussex Beacon (SB) 11 years ago when it was still a hospice. During this pre-treatment period there used to be a mortuary at SB, which was subsequently converted into an office. With the arrival of ARV treatment in the mid-1990s, SB had to find a new purpose and rationale. It dramatically altered its programmes and transformed itself into the only all-purpose HIV centre in the UK, and perhaps even Europe. Through fundraising it was able to expand a section of the building for use by HIV-positive women and children. Sussex Beacon has become a continuing care unit for men and women with HIV/AIDS who require convalescence care, monitoring and maintenance of health, treatment support, palliative/terminal care, and rehabilitation, as well as a range of respite care. The care provided is meant to focus on the “holistic needs of clients”: medical and nursing care needs together with social, educational, emotional, psychological, spiritual and cultural needs. However, Jackie spoke of how medication (ART) had ‘turned things around in the UK’: ‘It’s become very medicalised. Before it was more holistic – you treated someone physically, mentally, emotionally, and spiritually. HIV has become more medicalised [with] sophisticated measures of viral loads, resistance, and CD4 counts’. Yet, while the medical advances in treatment regimes provide patients with a better chance of living longer, some treatment users experience serious side effects and some are dying from heart conditions rather than HIV/AIDS.

We have to help them to go onto special diets to reduce cholesterol. People can look very good on paper from a medical point of view but psychologically they’re not feeling good. They have muscle

¹¹ Interview, Brighton, Monday 22 November 2004.

wasting and now they have to make changes to their diet because of cholesterol. Then they need more drugs to lower the cholesterol levels. It is this group of “problem patients” that Sussex Beacon caters for.

According to Jackie, the majority of patients on ARVs do relatively well on the drugs and cope with the side effects: ‘They deal well with the medical, biological and psychological aspects of HIV. For them it is a long term manageable chronic illness.’ Sussex Beacon is specifically concerned with the group that does not cope well with treatment:

The group of people we see here are those that don’t do well on treatment. There are those that don’t do well from a bodily or physiological point of view, and there are those that don’t do well psychologically – they struggle to have to take their pills for everyday of their lives and they often end up a residential treatment support unit. They’re identified by clinical staff as not psychologically strong enough to deal with taking the drugs everyday of their lives, they fear the side effects and they feel they don’t have the confidence to take the drugs . . . We want to support these people so they can go back in the home environment in the community. We’ve had to retrain nurses; their skills have had to change. They often feel de-skilled if they feel they’re not giving ARV drugs and not doing palliative care, they feel they’re not doing proper medicine. So we try and show the nurses that every conversation they have has a therapeutic element to it. One way we’re trying to re-skill our nurses is to give them motivational interview training which comes from addiction therapy theory. It involves cycle of change methodologies of contemplation and action. It’s about anticipating the adaptations necessary for treatment. If a person thinks I’ve got to take the medication because the doctor told me so, this may not work because the person drinks heavily on the weekend because of his party lifestyle. You need to anticipate all the obstacles that could be in the way e.g., alcohol and weekend party lifestyle etc . . . Some of the people my colleagues are seeing are at their last chance of combination therapy because of failing so many times. And this is not only happening in HIV; treatment support issues also apply to patients at the renal unit and in psychiatry. We had this with other patients who weren’t taking their drugs. But now the drugs companies are responding to this by trying to make combination therapy as simple as possible. But there are still problems – often unconscious feelings of lack of self-worth can result in failure to take drugs properly. So, for some, ARVs and HIV have become a life saver, for another group it’s become something to deal with, another problematic area in their lives.

Jackie also identified key social factors – unstable social structure, unemployment and welfare dependency (“the benefits trap”) – that usually contribute towards failure to cope with treatment:

Usually people who do well on the combinations are people who are more recently diagnosed, they’re part of a stable social structure and a stable relationship. A core group of our clients consist of those who were diagnosed at least 10 years ago, and because they’ve been diagnosed ten years

they've lost a lot of social standing. They're all on benefits, and this is the benefits trap that we talk about, that people are afraid to go back to work. So there is a core group of people with low esteem because they can't back to work. They've been on benefits for so long that they don't have qualifications to get jobs. Being older, in their forties and fifties, makes it even more difficult to find jobs. For those that have been diagnosed more recently, their social lifestyle revolves around recreational drinking and drugs – they often don't have jobs and are on benefits. As a group of people they don't have stability, *they haven't been normalised*.

By contrast, those coping with treatment seldom access services such as those offered by Sussex Beacon. They simply “vanish” into anonymity and access the NHS independently. Neither of these groups – those making use of services and those who melt into the anonymity of the NHS – are very amenable to AIDS activist mobilisation. From Jackie's description of SB's client base, it would seem that it is this “medicalised” group that seeks out institutional support and services that is least likely to avail itself to AIDS activism:

The people who are on top of treatment often don't come to the Sussex Beacon. The people we see here are those with problematic elements in their lives, they find it difficult to take the regular treatment. There are some people with good jobs and good support networks that don't do well physiologically and that's when they come here for support to deal with the side effects. They may feel low and are very sick from the treatment so they come here for support. We have 10 beds, and they're able to stay 7–10 days for treatment . . . Some people may be despondent about the fact that their whole lives revolve around HIV. Some of them have been on treatment for 15 years. They don't actually identify as part of an HIV-positive community.

While members of this group seldom openly identify themselves as part of an HIV-positive community, Jackie suggests that they do openly identify as belonging to a tightly knit Brighton gay culture. Jackie also suggests that this deep sense of belonging can, under certain circumstances, contribute towards creating a “ghetto mentality” that can result in dysfunctional forms of risk-avoidance behaviour. It can also kill any prospect for activism:

Because of the epidemiology of the disease in Brighton, the majority of those who come to the day services are gay men, they've got a culture in Brighton to identify with, and this group of people seem to socialise together. If they're not working, they will tend to spend time in the Brighton gay community and identify with it. And sometimes that can be difficult because it becomes difficult to convince them to take more risks, to perhaps take a college course. They will often say ‘We would rather you bring the computers here so we can do the course at the Sussex Beacon.’ So what we try to do is build their confidence and esteem. We've had a couple of successes in getting people to do courses. Some [gay] people fear that they will be the objects of prejudice. They fear that people will know they're gay and, because there's so much homophobia, they will also say that if they know I am

gay they will think I'm HIV-positive. So they prefer the safety and comfort of the Brighton gay community. Some people have turned being gay into pride but others haven't – it's been mixed . . . But others will stress the prejudice and they will remember the gay bashings that happened at the seafront and not see beyond these events. A lot of our work is when people say the world is homophobic we point out that this is not true everywhere and for everybody. If people feel threatened inside, they'll see the threat outside . . . There are large numbers of people who are on treatment and not experiencing these problems – a large group of peer mentors came to Sussex Beacon for a workshop and I didn't know one of them. There are clearly people who are functioning well on ARVs. They were very positive about their illness and how they were living with it – they've really turned it into a positive experience.

It appears that the medicalisation processes associated with the NHS's ARV treatment programmes have created a bifurcated system for categorising PWAs as either "responsibilised citizens" or "dysfunctional patients". This treatment scenario is clearly not very conducive to AIDS activism and social mobilisation. The following section follows the story of David and shows how he arrived at his social commitment to AIDS activism. It also discusses David's perspectives on the implications of the availability of treatment for the future of AIDS activism in the UK.

6.1 From tears to commitment

David discovered his HIV-positive status 18 years ago. He recalled how there was no treatment in the UK at the time he was diagnosed. He received no counselling, and was simply told that he had six months to live. It was a traumatic experience, and it took him about 18 months to recover psychologically from this devastating discovery of his seropositive status:

My activism comes from that trauma and anger of being treated horrendously . . . There were times when my wife went into counselling, to see the person who's supposed to be supporting us, and came home in tears because the counselling was so dreadful. And we said we can do better ourselves. We'll find out how to sort ourselves out, so we did [laughing softly].

David and his wife started an AIDS self-group and began to read up on treatment options. They managed to establish an extensive web of self-help support groups and treatment information networks throughout the UK. David managed to acquire AIDS science literacy and read research reports on treatment developments.

DAVID: I have been involved in [AIDS activism] since I was diagnosed. I was diagnosed 18 years ago, and at the time when there was nothing in the UK, nothing anywhere . . . Most of the doctors told me I've six months, twelve months if I was lucky. A good job I didn't believe them [laughter]. To be honest it took us a good 18 months to recover from the information on a personal level . . . I went through quite a horrendous time when I was diagnosed. We cried a lot . . . So my experience is

actually in a sense much closer to the experience of people in developing countries than it is to people who get diagnosed in the UK now, where they've got it [treatment]. So I was diagnosed, and then my wife and I, after recovering from the shock, felt that we needed to meet other HIV positive people. And because of the stigma that there was around in the UK then, we weren't meeting anybody. So we set up our own self help group which is still running . . . We then moved into running the national self-help network in the UK. All this time I never needed treatment, and even when AZT was being promoted, I didn't take it because it didn't work [chuckle]. You learn to read the research notes . . . We were – in a sense – ploughing a lone furrow in our areas. We recognised that knowledge was power and we needed to understand what was happening. Body Positive started producing a newsletter so we started accessing that. Then we found an organisation called Positively Healthy which ran seminars on 'Learn to love your virus' . . . Some of these organisations were much more political. They had begun looking into the drug company procedures and through accessing their information we realised some of the shenanigans that were going on within drug companies at the time. So that then led us on to the national aids manual, which is pretty much a bible in the UK for HIV activists in terms of keeping up to date between things like that.

David described how, when treatment arrived in the UK in 1996, community-based responses to AIDS went into sharp decline. Although it has become commonplace to hear that ARV treatment in the UK has turned AIDS from a “death sentence” into a manageable chronic illness, this account of AIDS treatment is not nearly as straightforward as it would appear. For example, David spoke of the frustration and anger he felt when people portrayed AIDS as a mere chronic illness, like diabetes and hypertension. He claimed that antiretroviral therapy is an extremely complicated life-long treatment process and poor adherence was creating serious problems of drug resistance in the UK. While he blamed some people living with AIDS (PWAs) for being ‘sloppy with their discipline’ and not taking drug adherence sufficiently seriously, he also acknowledged that treatment adherence was anything but easy. According to David, while ‘treatment killed activism’, it did not come anywhere near to solving all the health and adherence difficulties faced by PWAs:

DAVID: It takes a hell of a lot of discipline to do the treatments properly and people need to be prepared to move from being the person living with HIV to be a person who is going to be on pills for the rest of their life. And then they also need coaching on how to manage the side effects. I mean I was fortunate, when I eventually went for treatment, I've been on treatment four years, I only had three months of side effects . . . I know people who have had [side-effects for] much longer. And I'm extremely disciplined, I mean I'm sure I'm 95 per cent compliant, I'm very disciplined. But it took me 12 months to make my mind up to go on treatment, even though I was getting ill because I wanted to be sure I could be disciplined and I was happy psychologically to be in that different place. What we're finding is a lot of people are running out of treatment options because they weren't properly prepared, so they haven't been compliant, so they built up resistance [and] then they had to change

treatments. They've been sloppy with their discipline again, or they've stopped taking them because in the first three months or six months it's been horrible and that kind of thing. So we're seeing a lot of people now . . . just having no options left . . . Yeah they were on fourth line [treatment regimens] sometimes, and I think that's storing up problems for the future, unless something new comes on.

David and other interviewees are convinced that the availability of ARVs through the NHS since the mid-1990s has had many unfortunate unforeseen consequences, including “killing activism”.

[Generally] people have realised that they're getting their lives back where they didn't think they were going to have a life. And that has killed their activism because they realise they can actually manage their health, relationships and work and do what they love doing rather than being an HIV activist. This really has killed activism. (London, November 2004)

While the free availability of ARVs through the NHS had undermined activism, David spoke of how his own ongoing commitment to activism grew out of his traumatic experiences of being diagnosed and being told he had six to twelve months to live. He believed that these experiences – which occurred before AIDS came to be seen in the UK as a manageable “chronic disease” – ultimately made him stronger and proud that he had survived:

Yeah, that's why I say when I was diagnosed [in 1986] it was more like people nowadays in developing countries, than it is for a lot of people in our own country are experiencing [HIV/AIDS]. And the other thing, it is quite empowering to be told you're dying and not to crumble but to come back stronger. You learn an awful lot, and you can gain an awful lot of pride . . . I'm much stronger than I ever thought I was. I came back much, much stronger and I'm quite proud of it. (London, November 2004)

Sue, a founder member of 'Positive Women' and the International Coalition for Women (ICW), is a person living with AIDS (PWA). Like David, she also spoke of her isolation and the trauma of being diagnosed before treatment and counselling services became available. As a former intravenous (IV) drug user she was also exposed to the negative and stigmatising responses of distrust and blame she encountered from donors and NGOs as well as the general public. Like David, she felt that the traumatic experience of being told, upon her diagnosis, that she ought to prepare for death contributed towards her determination to establish a support group:

Okay it was back in the beginning of 1987 and around the time of my own diagnosis [that] I got shingles quite badly. I approached my doctor again and he got me tested. And I was the first woman I think in that hospital they found living with HIV. They told me just go away [because] there's nothing we can do, you can come back when you're ill. And that was about it really, there was very little information available . . . It was a small North London hospital. They couldn't give me any information, they couldn't put me in touch with any support organisation or network, no proper

counselling or anything. So it was a real shock . . . But I was desperate to meet other people living with HIV, especially women and really, really struggled . . . I lived with a group of gay men but there were issues that I wanted to talk about that I couldn't really talk about. I'd been told I could never have children. Yeah, there're all kinds of issues. So I wanted to talk about it to a woman. I happened to see an advert placed in *City Limits* saying that two women wanted to set up a support group of women living with HIV, contact this number, so I did. Yeah, that must have been about February or March 1987, a long time ago. So I went to meet these two women. I don't know quite what I expected, because you know – even I sort of internalised some of these images that we had of people with AIDS at that stage, you know. And I walked into this woman, she was kind of bouncy [laughing], eating cake and drinking tea, and between the three of us we set up this support group.

6.2 Moral and psychological blame and the limits to grassroots mobilisation

Availability of treatment through the NHS from the mid-1990s also created the conditions for public responses that blamed and stigmatised HIV-positive people who experienced adherence difficulties and had social and psychological problems. Before the arrival of ARV treatment, the AIDS sufferer tended to be represented in the media as a victim and heroic figure. This changed with the availability of ARVs through the NHS. PWAs who required psychological support services increasingly came to be viewed as “dysfunctional” and unwilling to take responsibility for their health and lifestyles. Since high quality ARV treatment was available to all through the NHS, those HIV-positive people who could not manage their condition were deemed to be “abnormal” and “irresponsible”. In other words, HIV-positive people with adherence problems related to drug and alcohol abuse, depression or cognitive impairment – which is sometimes a result of HIV itself – were blamed for not being self-sufficient, self-motivated and “responsibilised”. These pathologising labelling processes also undermined the possibilities for grassroots community-based activism and mobilisation.

Chris, a psychological counsellor at Brighton's Terrance Higgins Trust (THT), also spoke of the enormous difficulties of getting HIV-positive people to become involved in community or civic action. ‘They will complain about having to wait half an hour at the clinic for a blood test, but they don't want to come to meetings. They have nothing to really get angry about.’ According to Chris, the NHS is sufficiently responsive to the needs of HIV-positive people to placate and pacify citizen-patients. This, it would seem, is one of the most striking contrasts to the South African situation where AIDS activists continue to struggle for treatment access.¹²

The accounts of Chris and David suggest that the provision of ARV treatment through a relatively effective public health system can unwittingly undermine community organisational strength, citizen participation and local activism. For example, a number of UK AIDS support groups and AIDS activist

¹² By April 2005, 33,000 of the estimated 600,000 who needed treatment were receiving ARVs through the public health system. This was the result of numerous factors including logistical, resource, political and managerial problems and blockages within the public health system. These problems are likely to continue to fuel AIDS activism in South Africa (see Robins 2004).

organisations were not able to adjust to the new treatment environment, and subsequently closed down. They were not able to transform themselves into service providers, a process that required entering into service provision contracts with the NHS and developing sound “business plans” that met budgetary guidelines and that involved highly bureaucratic auditing, evaluation and monitoring capacities. In addition, with the devolution of service delivery to the local government level through the establishment of primary health trusts (health councils), it soon became apparent that HIV-positive people would not become directly involved in these institutions. The highly technical language of such consultation forums played a part in keeping people out of these institutional settings. But it also became clear that many positive people did not want to participate in these forums. Interviewees such as Chris and David indicated that many HIV-positive people were quite content to be represented by NGO service providers. In addition, according to David, ordinary “rank-and-file” HIV-positive people seldom had the confidence to engage with these bureaucratic institutions. Drawing on his personal experience of the Luton support group, where the vast majority of members were African women, he was convinced that most HIV-positive immigrants were intimidated by officialdom. He believed that they did not have the necessary confidence, cultural capital or immigration status security to be able to engage in these official spaces of participation. These observations draw attention to the limits of citizen participation in health forums.

A number of the NGO people I spoke to concurred that having a reasonably well-functioning NHS that catered for the majority of HIV-positive people in the UK meant that AIDS activists would continue to struggle to mobilise at the grassroots level. This did not mean, however, that there were no community issues around which to mobilise. Community based service organisations such as Brighton-based ‘Open Door’ and Terrance Higgins Trust (THT) represented the needs of a very specific section of the HIV positive population in the UK. Chris spoke about the difficulties of being caught in the middle between the need to represent their clients and being a state-funded service provider. This had stymied any real possibility for confrontational activism. In addition, according to David, ‘Confrontational activism is not a very English thing to do. We have to learn to do it.’

The choices of community based service organisations in the UK were limited by a combination of state control through funding, medicalised forms of dependency on the NHS and service providers, and the gradual erosion of a vibrant culture of community-based activism. As Chris from THT put it, ‘I get angry that the community is so passive and dependent on us. They want us to do everything for them . . . *The problem is that they do not have sufficient reasons to get angry and get actively involved in AIDS activism.*’ Notwithstanding these constraints, some organisations were able to lobby for and represent their user communities quite effectively. ‘Open Door’, for example, provided HIV-positive people with a variety of services including peer support, meals, access to welfare services and a variety of other social resources. African women were becoming an increasingly important clientele base. This raised numerous challenges. For example, it was initially thought that it would be difficult to integrate African women and white gay men in the same programmes. Yet, both Chris and David found that this was not a problem. In fact, their common experiences of HIV/AIDS, and the everyday forms of discrimination that both groups encountered, seemed to have brought them closer to each other. Despite the openness with which these

groups interacted with each other, members were seldom willing to publicly disclose. Stigma, discrimination and silence were clearly major barriers for any active expression of citizen participation. Most of these community-based organisations were situated in buildings in alleys off main roads in order to accommodate visitors' desires for anonymity.

6.3 Confidence building and "normalised" treatment

One of the key interventions of these service organisations was to provide psychological counselling to build self-esteem and confidence. Jackie Titley, a community supporter and psychiatric nurse, from Sussex Beacon, stressed the need for these interventions. Jackie spoke of her organisation's shift from being a hospice to an organisation that provides psychological services to HIV-positive people. She mentioned that a number of HIV-positive people who had been diagnosed during pre-treatment period had withdrawn from the work environment, signed up for disability benefits and prepared themselves for death. When treatment arrived they found themselves unprepared, psychologically and in terms of job skills, to resume work. They had been out of the job market for a lengthy period and did not have the confidence to re-enter this highly competitive market. Many developed the equivalent of "the dole syndrome": substance abuse and depression. Others suffered from ARV side-effects and could not work.

David was far less sympathetic than Jackie about HIV-positive people who found themselves in this predicament. He felt that they were "free riders": 'They took the disability benefits and chose not to work because it was the easy option. Now they are complaining about being out of the job market all this time.' He pointed to the many HIV-positive community activists who had worked very hard with no pay; 'I have a jaundiced view on all of this. These people who are now complaining about depression and not being able to get back into the work environment don't deserve that much sympathy. They chose to go into a life of welfare benefits and now they realise that they want to work because the benefits are declining'. David, a house painter by profession, never stopped working throughout his illness.

It seemed that HIV/AIDS and ARV treatment have indeed become "normalised" and those who did not manage their lives as "positive people" were pathologised, stigmatised and labelled as "free riders" and "dysfunctional". This labelling process was not something that emerged overtly from the NHS, the general public or HIV-positive people themselves. Instead it was a subtle and insidious process that emerged in a context where ARV treatment had become a universally accessible medical technology and AIDS was deemed to be a manageable chronic illness. Yet, David told me that he became extremely angry when people referred to AIDS as a "manageable disease". 'I could tell them how difficult it is to manage with this disease. They know nothing about it.' Yet, at the same time David acknowledged that he sometimes used this normalising language in certain contexts and forums to drive home the point that AIDS is no longer a "death sentence". David was nonetheless concerned about recent efforts to "normalise AIDS", to "mainstream" it, thereby eliminating its special status. This pressure, David claimed, came from within the NHS as well as illness-based movements that claimed that AIDS had special status that gave it privileged access to health resources: 'They should do the same as we have and fight for resources. It's not right to try and reduce our resources because they haven't fought for theirs.'

The “normalisation” of the condition of people living with AIDS (PWAs), and of HIV/AIDS treatment and care, can be an extremely ambiguous and paradoxical process. On the one hand, treatment addresses the reality of biological illness, the fear of dying and the stigma associated with a lethal disease. But at the same time, the transformation of AIDS into a manageable chronic illness can be part of a process whereby PWAs are tacitly instructed that they have no right to complain about their predicament: treatment is available, as are a vast array of additional health resources earmarked for HIV-sufferers. This can produce forms of denial and the suppression and displacement of the trauma of living with HIV. It can also further stigmatise those who are not coping because of depression, unemployment, homelessness, or because of the consequences of their illegal immigrant status and uncertainty about whether they can access the NHS. This category of HIV-positive people can quite seamlessly be constructed as “non-compliant”, “irresponsible free riders” and “welfare cases” that need to be taken care of by service organisations. This can create a sharp divide between the empowered and virtuous autonomous citizen and the welfare subject/non-compliant free rider. Ideas about the negative paternalism of the “nanny state” are also sometimes deployed in public health discourse in ways that sharpen this divide. These internal divisions are hardly conducive to creating a grassroots social movement.

One of the unintended consequences of these “normalising” processes is that HIV-positive professionals and employed people like David, may feel obliged to suppress difficulties they experience in order to conform to the image of the autonomous and functional citizen-patient. Self-monitoring and self-sufficiency can also of course become a convenient foil for a neoliberal state that wishes to “empower” its citizens by promoting, and fetishising, self-reliance, while simultaneously outsourcing “social problems” to service organisations. In this process, those who are perceived to be not coping are labelled as dysfunctional welfare subjects. While the British government appears to be committed to defending NHS and the welfare state from rightwing criticisms of the “nanny state”, this artificial dichotomy between the autonomous and self-regulating individual citizen and the dependent welfare subject can be used to legitimise rightsizing and the cutting back of health resources and social services. This outcome could be achieved by promoting the idea that citizens ought to be encouraged to become self-sufficient and “responsibilised” lest they become tempted into “free riding” and burdening the welfare system. Again, these divisive ideological discourses can systematically undermine efforts at grassroots mobilisation. Other divisions that have emerged include concerns about the possibility of “mainstreaming AIDS” and thereby downgrading its special status *vis-à-vis* other health conditions.

Clearly much has changed in the shift from the pre-treatment to the treatment phases. In the early years of the epidemic there were very few resources available for HIV-positive people. For example, David recalled that he was one of many HIV-positive people who decided to do his own research into treatment issues because he was not convinced about the safety and efficacy of AZT monotherapy. Although he struggled with some of the more technical research papers, he was able to gain access to information that he needed to make independent decisions about his treatment options. It was only in 2000 that he eventually decided to go onto triple therapy. All this time he was involved in self-help groups that were emerging throughout the UK. By the time he began treatment in 2000, many of these self-help

groups were already in the process of closing down. The availability of treatment through the NHS had taken its toll on community-based activism and mobilisation. The concluding section focuses on the possibilities of reinvigorating AIDS activism in the UK by connecting it to the global context, in particular the crisis of AIDS in Africa.

7 Provisional conclusions: connecting the “local” to the global: re-activating domestic AIDS activism

UK AIDS activists I interviewed spoke of having “rediscovered” and re-energised AIDS activism through their involvement in global AIDS issues. For example, Sue of Positive Women and ICW, spoke of how domestic AIDS activism was in gradual decline, but that her own work on global AIDS issues had reinvigorated her personal sense of activist commitment and engagement. This view was shared by David (see below) who, for similar reasons, called for the establishment of stronger links between UK domestic and global AIDS organisations. By “going global”, David and Sue believed it would be possible for domestic AIDS organisations to reinvent UK AIDS activism and resensitise the UK public to AIDS issues. The fact that HIV-positive Africans were living in relatively large numbers in the UK made it easier, they believed, for this global perspective to take root.

Together with his wife, David ran an HIV-positive support group in Luton, 30 kilometres North of London. Almost 90 per cent of those who attend are Africans. He mentioned that he could transfer the group to Zambia without making any changes to the ways in which it was run. David claimed that the presence of significant numbers of seropositive Africans in the UK was beginning to sensitise people in the UK to the global dimensions of the pandemic despite the tendency to shut out these realities. As David put it, ‘The closed, island mentality of the UK has prevented people from seeing the global epidemic.’ He believed a greater awareness of the global dimensions of the AIDS pandemic could potentially contribute towards resuscitating domestic AIDS activism and awareness in the UK. However, this had yet to happen on a significant scale.

At the time of the interviews, David and Sue were about to move to Geneva to work for UNAIDS and the Global Fund. Both spoke of the urgent need to link domestic and global AIDS issues.¹³ Both were concerned that AIDS awareness in the UK was waning and contributing towards complacency. David noted the dramatic contrast between AIDS awareness campaigns in South Africa, for example the *LoveLife* HIV/AIDS billboards, and the “conspiracy of silence” in the UK. He claimed that there were no sustained AIDS awareness and condom promotion campaigns in schools and universities. It was as if it is assumed that young people were already “responsible citizens” who knew the risks involved in unsafe sex. Yet, David was convinced that there was a “hidden epidemic” in the UK waiting to happen, especially amongst heterosexual youth. He attributed this part to the fact that young people believed that they did not need to fear AIDS because treatment was available. As a result, HIV and syphilis infection rates were increasing amongst young people. David personally knew of two young men who were HIV-positive and were sleeping around without practising safe sex. He hoped that this widespread complacency would be challenged as the global face of the pandemic became more visible in the UK. Perhaps South Africa’s experience could also become part of this globalisation of AIDS activism.

My earlier research on illness narratives and treatment testimonies revealed how “AIDS survivors” were able to make sense of their traumatic experiences by drawing on multiple and hybrid interpretative frames, including religious, communal, biomedical and liberal modernist rights-based discourses. I argued that the “responsibilised” citizen-patient that MSF and progressive public health professionals desired was not necessarily simply a product of modern, liberal individualist conceptions of the rights bearing citizen. Instead, I suggested that illness and treatment experiences could, under certain circumstances, contribute towards creating “new social subjects”, i.e. responsibilised people living with AIDS. The recipe for these empowering possibilities was a specific type of triple combination therapy: ARVs, AIDS activism and the individual experiences of the passage from “near death” to “new life”. However, what happens when treatment loses its “magical” properties and becomes a “normalised” and mundane medical intervention? These questions were reflected in the concern of David and Sue that there was a growing complacency about AIDS, a development they attributed to the relatively easy access to high quality AIDS treatment through the NHS. Social movement theories are generally incapable of appreciating the significance of these radical shifts in subjectivity.

¹³ A similar perspective emerged from my discussion with Mamioosa Rangers, the Project Support Officer (East and Southern Africa) for the UNAIDS-funded International HIV/AIDS Alliance based in Brighton. Mamioosa, who is originally from Madagascar, spoke of the urgent need to connect UK domestic and global work on AIDS. She personally knew of a number of African women who were HIV-positive and who struggled to access NHS services. This was partly because of their uncertain immigration status and partly because they did not have adequate information and knowledge about how to access these services. In addition, many of these women were unable to disclose their status to their partners and family members because of the stigma and silence about HIV in these communities. A similar perspective emerged from my discussion with Mamioosa Rangers, the Project Support Officer (East & Southern Africa) for the UNAIDS-funded International HIV/AIDS Alliance based in Brighton. Mamioosa spoke of the urgent need to connect UK domestic and global work on AIDS. She personally knew of a number of African women who were HIV-positive and who struggled to access NHS services. This was partly because of their uncertain immigration status and partly because they did not have adequate information and knowledge about how to access these services. In addition, many of these women were unable to disclose their status to their partners and family members because of the stigma and silence about HIV in these communities.

Finally, the UK AIDS activists who were diagnosed before ARVs were readily available through the NHS, spoke about their HIV-positive identities and illness and treatment experiences in ways that resonated with those of South African activists. These UK activist perspectives also revealed the problems associated with the medicalisation and normalisation of AIDS treatment. In concluding, it is still too early to tell what the long-term impact of ARV accessibility will have on treatment adherence, activism and construction of HIV-positive identities and subjectivities in the UK and South Africa. This study suggests that, given the limited and uneven access to ARV treatment in South Africa, struggles over access to ARV treatment will, in the foreseeable future, continue to fuel “extraordinary” forms of AIDS activism and grassroots mobilisation. This is one of the key differences between the UK and South African experience of AIDS, treatment and activism.

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