

# **Navigating the AIDS Industry: Being Positive and Poor in Tanzania**

**Jelke Boesten**

## **Abstract**

This article shows how poor people living with HIV/AIDS in Tanzania navigate the aid provided by a myriad of actors, agencies and organizations in order to survive. This article focuses on the manner in which community-based organizations establish networks of care that people connect with to receive care, treatment and financial support. Such organizations help poor HIV positive people navigate their way through the maze of governmental and nongovernmental interventions that are otherwise difficult to access. A case study of a roadside town in Tanzania illustrates that these community-based networks of care, which are essential to the survival of many, are the partly the product of AIDS industry, as it has encouraged community based organizations and voluntary service delivery instead of more formalized care systems. However, community-based organizations are so poorly supported that they often deploy self-destructive strategies. The need to strategically navigate the AIDS industry in order to survive creates tension and even conflict among HIV positive activists, the people they represent and the wider community — thus undermining, rather than strengthening, community-based interventions. Whilst the AIDS industry promises inclusion of HIV positive people in the response to HIV/AIDS, it does so only partially, with the result that it may potentially do more harm than good.

## **Navigating the AIDS industry: Being HIV Positive and Poor in Tanzania**

In September 2008, after a year of absence, I returned to the roadside town of Migule along the main road between Dar Es Salaam and Arusha.<sup>1</sup> Between 2005 and 2007,

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<sup>1</sup> This research is the result of collaboration on two research projects. In that context I would like to thank a number of individuals and institutions. In 2005/06, I worked on a project, 'Community-driven Development: Understanding the Interlinkages', funded by DfID and headed by Frances Cleaver and Anna Mdee from the University of Bradford. In 2006, the ESRC/NGPA programme financed the second research project under the guidance of Jenny

during which most of the fieldwork was conducted, I actively participated in seeking funding and support for one particular community-based organization (CBO) for people living with HIV, Kikumi. This was relatively successful, and when I returned in 2008, Kikumi had obtained a building that housed 13 orphans, a paid staff member to take care of them, electricity supplied via a solar panel and the organization could count on continuous support from a small NGO based some 100 km north of Migule. My association with this NGO alongside my position as a researcher made for an ambiguous role within the studied community. It nevertheless allowed me to study the strategies groups of people living with HIV/AIDS employ to gain access to resources made available by the AIDS industry, which I, as both researcher and member of an NGO, represented while in town.<sup>2</sup> The return visit struck me. Although I had been away for over a year, several (poor and HIV-positive) people immediately approached me on the street with urgent matters. The urgent matters concerned the allocation of World Food Programme foodstuffs and access to other benefits. The struggle over access to such benefits was continuous, and had been subject of community-wide tensions for some time. However, when I asked the most prominent man in the community, Dr Godson, about the continuous complaints of aid beneficiaries, he angrily answered ‘AIDS is not a project’.

This article discusses AIDS as a project. While AIDS may be a project (or programme or intervention) for international development practitioners and researchers, it is generally not perceived to be acceptable that it becomes a project to HIV positive people. For Dr Godson the continuous demand for AIDS benefits on the part of poor community members had made a disease into a livelihood strategy. Being the main physician in Migule, health officer in the district council and elected ward chairman, Dr Godson argued that using AIDS in such an instrumental way was not good for the fight against disease or for the development of alternative livelihood strategies.

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Pearce, also from Bradford. The project focussed on AIDS Activism, Stigma and Violence. Janet Bujra and Nadine Beckmann have been pivotal to the development and outcomes of that project. In the field, Anna Mdee was a great support. The NGO, Village to Village, played a central role in facilitating activities and contacts. Without the social and linguistic skills of Reuben Marisa, Mariam Kinabo, Maria Gilbert, Mbazi Elidaima, Sarah Omwenga and Anneth Madiwa this research would not have been possible. The 2008 return trip was funded by the British Academy, for which I am grateful. I am also grateful for the helpful comments made by two anonymous reviewers of this article.

<sup>2</sup> The methodological challenges this dual role creates for fieldwork, especially regarding AIDS and poverty, is discussed in Boesten (2008).

However, as this case study will demonstrate, the structure of the AIDS industry, which is based on principles of competition over resources and a strict distinction between professionals and experts on the one hand, and volunteers and beneficiaries on the other hand, encourages people to use their health status and suffering to obtain certain benefits.

As Nadine Beckmann shows (2011), the emphasis on privatization and cost sharing that has dominated health sector reform has led to treatment and healing being structured by markets rather than mutual support between citizens and their rights and responsibilities vis a vis the state. In addition, neoliberal economic restructuring championed by the International Financial Institutions leaves the aid industry to fill the gaps left by privatization, which, in turn, channels expectations, rather than sufficient levels of funding, to community-based organizations (Boesten, Mdee and Cleaver, 2011; Dilger, 2009; Kelly and Birdsall, 2010,). In these structures of aid, poor people living with HIV have to adapt to the expectations of the AIDS industry, for example by organizing themselves in a certain way (community-based, identifiable groups such as women, people living with HIV/AIDS, the elderly), and to participate according to certain principles (voluntarily, accountable to both funders and beneficiaries). The increased marketization of health and healing combined with the demands imposed upon community-based organizations, including organizations of people living with HIV/AIDS, in the provision of services neglected by a deficient health system, encourages proliferation and fragmentation (Dilger, 2009; Kelly and Birdsall, 2010). While the industry speaks of ‘participation’, ‘ownership’, ‘cost-effectiveness’ and ‘sustainability’ in relation to community-based interventions, and expects poor HIV positive people to mobilize for the common good, they simultaneously demand from seriously ill and desperately poor people to pay for their own health care. As I argue below, these structures of the AIDS industry encourages opportunism and instrumentalism which leads to social tensions, competition and conflict over access to scarce resources, and ultimately, the erosion of community-based responses to HIV.

The case study discussed is based on long-term (though intermittent) fieldwork in a roadside town<sup>3</sup> which I call Migule, and focused on the dynamics of the persistence of HIV in the context of increased responsiveness at global, national and local levels. The town does not benefit from any specific donor-funded project such as those studied by Catherine Campbell in South Africa (2003), or Karen Booth in Kenya (2004). Rather, Migule is an ‘average’ town with similar access to funding and project interventions as others, and a postcolonial history of urbanization and population growth in poverty. Population growth and mobility are not matched by a growth in urban infrastructure with the result that towns are characterized by a mixed economy of agriculture and trade, with few services to meet people’s needs. Migule has an active community of people living with or affected by HIV/AIDS, the organization of which is a recent development. In 2002, HIV positive people and their family members set up an organization called Kikumi, partly under the influence of increased national and international attention to HIV and partly because of the presence of a capable, pro-active and charismatic leadership. This study focuses particularly on the strategies employed by the leadership of Kikumi, Mr and Mrs Msangi, to establish and maintain networks of care with external funding. Their strategies can genuinely be described as navigating an industry not particularly favourable to them. Between 2005 and 2009, the HIV-positive community in Migule underwent a radical change from solidarity and success to conflict and disintegration. As will be illustrated through this case study, the fragmentation of local intervention and its vulnerability to conflict over access to resources and benefits is strongly linked to the expectations and demands that the AIDS industry places upon community-based organizations and individual HIV-positive people.

Thus, before I proceed to discuss the specifics of ‘AIDS as a project’ in Migule, I will first briefly outline the discursive and policy background to the role of aid in the response to HIV/AIDS. Two trends are highlighted: first, the emphasis on

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<sup>3</sup> In fact, the research was carried out in two towns and several annexing villages. The second town and the villages provided an added perspective on the issues studied, as participants in the study often move between such places. To a certain extent, the second town and villages were a source of triangulation; they also pointed out differences and particularities that made the focus of this study, Migule, stand out. Where relevant, this is indicated; otherwise the specificities of the research process are blurred into one narrative in order to facilitate analysis and to protect individuals involved in the research. All names of places, individuals and organizations have been changed unless otherwise indicated.

‘community-driven or -based development’, and second, the idea of greater involvement of people living with HIV/AIDS. It is at the intersection of these two approaches in development practice that poor people living with HIV have to find their way, which is the focus of this article. I will conclude with an analysis of the relationship between the different AIDS projects, how they might constrain each other and what lessons we can learn from the policies that influence poor people living with HIV/AIDS.

### **The Aid Industry and HIV/AIDS**

There is little doubt that international aid has become an industry in which commercial and political interests and professional expertise, moral outrage and notions of social justice, and bureaucratic processes interlock. Criticism of the way in which aid works, what it does and does not do, are widespread and the literature is growing. Whilst this is not the place to discuss these criticisms extensively, Sophie Harman’s analysis of the World Bank’s policy towards HIV/AIDS offers valuable insight into the manner in which AIDS funding at community level functions.

In an extensive study focusing on Kenya, Uganda and Tanzania, Harman argues that the World Bank seriously infringes upon national sovereignty through the creation of competition between the state and civil society and nongovernmental organizations in the delivery of services and access to funds (2007, 2009). It has achieved this by imposing structures of (HIV/AIDS) governance as a condition for receiving Multi-country AIDS Programme (MAP) funding. Since 2000, countries receiving MAP funding, including Tanzania, have had to set up a decentralized system of HIV management, which includes community, district, regional and national AIDS councils comprised of multi-sectoral stakeholders. National AIDS Councils set up under MAP often bypass existing AIDS councils and Ministries of Health and are instead directly responsible to the president and funded through the Ministry of Finance. The councils have a coordinating function and are expected to oversee, mobilize, monitor and allocate funding to governmental, nongovernmental and civil society organizations on the ground. The ‘old guard’ (Harman, 2009), e.g. the professional Tanzanians, Kenyans and Ugandans who set up the first national

response in the 1980s and 1990s, are housed in Ministries of Health and are allocated a limited task, namely, the medical side of HIV, including data gathering. In Tanzania, this shifting of responsibilities was felt at national and local levels alike. While the director of the long established National AIDS Control Programme (NACP, established in 1987) is widely known and respected, even in the relatively marginal town of Migule, the staff at the Tanzanian Commission for AIDS (TACAIDS, set up in 2001 with MAP funding), were largely distrusted. Interviewees with council and CBO members at district, ward and village levels indicated that the role of TACAIDS was unclear, and its staff remote, invisible and not engaged with them as stakeholders. Some of TACAIDS problems have been resolved through trial and error over the last ten years, but the mistrust generated by its initial imposition of unclear and unbeneficial rules and regulations regarding policy and funding has not entirely disappeared.

As Harman observes, staff in National Aids Councils (NACs) operate according to the discourses of the World Bank and the wider world of international development organizations (especially UNDP and UNAIDS, institutions with important coordinating roles, see also Swidler, 2007) as they are trained under the rubric of ‘capacity building’. While capacity building is meant to be empowering, in practice it has a disciplining effect (Gould and Ojamen, 2003; Fraser, 2005, Harman, 2009). This results in a discursive field that is technocratic at best, and depoliticizes policy making. This is reflected in the alienation that representatives of district, ward and village councils as well as CBOs experienced in their engagement with TACAIDS, as they did not necessarily speak the technocratic language of intervention when interviewed in 2005–2007.

The key concept in the approach to HIV governance is ‘multi-sectorality’. Multi-sectorality refers to collaboration between state, INGOs, civil society and community organizations who are all supposed to be represented in coordinating committees at all decentralized levels of governance. The terms of engagement for the participants in these committees are laid out by the World Bank and imposed through capacity building, limiting the possibility for context-sensitive organization and policy making. These terms of engagement include competition over resources ‘as a means of promoting efficiency and low-cost delivery’ (Harman, 2009: 363). In practice, access

to funding is facilitated by knowing the right people, speaking the right language, including knowing how to fill out certain forms. For many community-based organizations, access to funding is difficult unless a person willing and able to carry out such tasks is available. For Kikumi, computer access is a daily challenge and access to an English speaker to apply for funding is not readily available either. Competition for funding also largely eliminates questioning the funding body and, by extension, the organizational structure and policy framework imposed. In addition, larger national NGOs often compete for the same funds, which are generally well versed in the required argot. Consequently, local CSOs are not empowered and are once again at the mercy of the benevolence of more powerful international actors whilst being in competition with their own state institutions. As we will see below, competition over external funding severely undermines political action and voice, as both civil society and the state are forced into complying with the terms of engagement imposed by these structures of governance.

### *Community-driven development (CDD)*

The emphasis on civil society and community organizations follows a trend in development policy and practice of the last ten years or so, which is to support ‘community-driven or -based development’.<sup>4</sup> This approach fits the idea that participatory development empowers people and communities (Chambers, 1983, 1997),<sup>5</sup> while it also suits a more neoliberal agenda of cost-effectiveness, decentralization and privatization (Boesten, Mdee and Cleaver, 2011). Under the rubric of community-driven development, the international aid community encourages the use of community-based workers to support a whole range of otherwise poorly staffed and resourced services. In doing so, the logic of the international development discourse of participation, ownership, sustainability and inclusion coincides with the

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<sup>4</sup> Community-driven and community-based suggest different levels of autonomy for the community in question. In practice, the majority of such projects are community-based, not driven.

<sup>5</sup> Tellingly, Robert Chambers, advocate of participatory approaches to development, strongly criticised the World Bank’s approach to community-based development in a CDD evaluation report and called for harm reduction in existing projects and a moratorium on new ones, see Chambers in World Bank (2005:153).

neoliberal logic of decentralisation, cost-effectiveness and privatization (or ‘self-help’ in some cases).

Community-driven development, or CDD, is championed by the World Bank as it seeks to decentralize power and resources to the local level in order to make interventions more responsive and equitable and efficient in serving the needs of the poor (Binswanger-Mkhize, et al., 2009, Mansuri and Rao, 2004). In addition, CDD is ‘increasingly seen as a nexus between bottom-up and top-down approaches to improved governance and service provision’ (World Bank Briefing, 2009). In practice, it means that funding and capacity building are allocated to existing or newly set up community-based organizations. CBOs are then assigned the responsibility to deliver a) a particular development objective (such as coordinating the implementation of a plan through a multi-sectoral AIDS committee), or b) a particular service (such as providing home-based care to chronically ill patients). This approach to the implementation of development interventions is not only promoted by the World Bank, but such community development is also central to the approach of the Tanzanian state, its poverty reduction strategy and National Multisectoral Framework for HIV/AIDS (TACAIDS, 2002; NSGRP, 2005; TACAIDS, 2007).<sup>6</sup>

Thus, the socially engaged discourse of community-driven development is absorbed into the neoliberal political economic practice promoted by international financial institutions. In fact, the trajectory of CDD offers a good example of how the World Bank can highjack an idea, mould it to fit a neoliberal model and elevate it to the level of universal blueprint for developing countries. National states and INGOs are almost automatically drawn into the rhetoric and repeat the mantra with limited opportunity for critical questioning. The result is poorly staffed, insufficiently supported (institutionally, financially, and politically) structures that put tremendous pressure upon a small group of very dedicated community workers. As we shall see in the case study below, the lack of institutionalization also feeds into a range of issues that create, rather than solve, problems. The proliferation of contradictory messages and perpetuation of conflicts over access to and control over scarce resources may actually

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<sup>6</sup> TACAIDS receives funding from the Global Fund, the US Government, MAP and other donors. The budget increased from US\$ 31.4 million in 2002/03 to US\$ 272 million in 2006/07. Around 85 per cent of the budget is funded by donors (TACAIDS, 2007:32).

do more harm to HIV care and prevention in Migule than what a few committed community-based workers can absorb (see Boesten, Mdee, and Cleaver, 2011 for a comparative perspective).

### *Greater involvement of people living with HIV/AIDS (GIPA)*

A central tenet of the multi-sectoral approach is the notion that HIV positive people should be active partners in the global response to HIV/AIDS. This is due to the belief that inclusion of HIV positive people in interventions can enhance the quality of the global response, promoted since the late 1980s by AIDS activists in the US and Canada (Epstein, 1996; Smith and Siplon, 2006). In policy jargon, this idea became known as an intention to promote ‘greater involvement of people with AIDS’, or GIPA, and was adopted by all major players in the field in the late 1990s, notably the UN and the World Bank — it also fits the logic of community-driven development of course, especially if HIV-positive people are perceived to belong to a ‘community’ based on health status. However, this presumption of identity and solidarity based on health status is grounded in particular histories of AIDS activism elsewhere. In the case of Tanzania, and indeed much of Eastern and Southern Africa, poverty prevents a positive identification with such a highly stigmatized condition as HIV (Beckmann and Bujra, 2010). As South African and global activists and observers claim, after the initial excitement about a constructive platform for action, GIPA was found to be tokenistic (APN+ 2004; Global Movement, 2005; Manchester, 2004; Robins, 2005). According to such criticisms, people living with AIDS were often called upon to set an example, to put a face on the problem and to tell personal stories. Rarely were they seriously engaged for their views (see also Beckmann, 2011).

Despite the condescending nature of GIPA as a concept and its tokenism in practice, some organizations and networks of people living with HIV/AIDS have successfully engaged with the global response to AIDS, notably in the US and South Africa. As Smith and Siplon (2006) show for the US case, and Robins (2004) for South Africa, organizations such as ActUp and TAC have been successful in challenging the top-down governance of HIV as shown by multiple epidemiological and UN agencies,

and pharmaceutical companies, and appropriated knowledge and expertise for the benefit for the wider community of people living with HIV. The greatly improved access to treatment and the reduction in pricing of vital drugs have likewise been the result of international activism, negotiation, and lobbying. However, these successes are largely the result of the particular histories of AIDS activism rather than policy interventions. In Tanzania, as elsewhere in the region, loosely defined organizations of people living with HIV/AIDS have existed since the late 1990s.<sup>7</sup> Such organizations and networks tended to provide mutual support and information, and some engaged in pooling care services, or what Joao Biehl (2007) calls the provision of ‘circuits of care’. Biehl (2007: 110) argues that groups and networks can help disenfranchised and ‘socially abandoned AIDS patients’ navigate through the maze of governmental and nongovernmental interventions that are otherwise difficult to access. Such circuits of care are not unique to Tanzania, or Brazil, where Biehl’s work is situated, but are observed everywhere where care and support is difficult to access or absent.<sup>8</sup> What this case study shows, however, is the level of strategic navigation through the aid industry that HIV positive activists deploy in order to provide basic care for the families of those involved — the members of said community groups, plus the individuals and families that continuously knock on the doors of those members.

The idea of GIPA plus the multi-sectoral/CDD approach in the response to HIV gave a boost to the idea of community-based organizations of people living with HIV/AIDS. Funding, if only small amounts, became available and both INGOs and government showed interest in working with such groups — largely as part of multi-sectoral committees or as service providers. In 2001, the Tanzania Network of Organizations of People living with HIV/AIDS (TANOPHA) was set up in Dar es Salaam. TANOPHA links community-based groups and assists in coordinating the sharing of information, capacity building and advice about access to funding. Conversations with staff at the headquarters of the network disclosed the difficulties involved in coordinating a large number of diverse and generally poor groups — all

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<sup>7</sup> SHEDEPHA, the first Tanzanian organization for and by people living with HIV/AIDS, was established in 1993.

<sup>8</sup> See the wide literature on community activism in the US during the earlier days of HIV (e.g. Altmann, 1994; Brown, 1997; Epstein, 1996) and in contemporary Africa (e.g. Nguyen, 2005a and 2005b; Robins, 2005; Manchester, 2004) and India (Das, 2006).

competing for scarce funding. At national level, this competition led to conflicts over leadership, and consequently, the fragmentation of initiatives. The establishment of a national umbrella for people living with HIV/AIDS that could represent the interests of individuals, groups, organizations and networks of people living with HIV/AIDS at the high-level governmental and multilateral multi-sectoral committees is an ongoing battle. Several attempts have been made, but the initiative suffers from in-fighting, fragmentation, weak capacity and too little funding. At local level, similar processes take place, although small successes should not be underrated. In the following section the tensions in how individuals, groups and networks of people living with HIV/AIDS navigate the aid industry in order to access small amounts of money or resources, is discussed.

### Survival and HIV in Migule

Poor people living with HIV/AIDS in Migule develop a range of livelihood strategies which have to be taken into account in order to understand their relationship with the aid industry. The main sources of income for the majority of Migule's residents are agriculture (beans and maize), livestock (goats) and poultry (chicken and duck). However, harvests are unpredictable and farming is hard work. Of the fifty people living with HIV/AIDS interviewed, the majority participated in some form of agriculture, although not always on their own land. Business activities such as selling home-made goods (food and carpentry) are often difficult to maintain, as customers often disappeared when the health status of the seller became known. This, of course, indicates the difficulty of being openly HIV positive and being involved in service delivery or local-level policy work. Worse still, families hardest hit by HIV, i.e., families that have lost their main breadwinner, that care for school-going children and where one or more adults and/or children are often ill and in need of medicine and care, had often sold their land and animals and depended on kinship networks and odd jobs when health allowed. Many such families sink into cycles of immiseration and fail to survive as a household (Rugalema, 2000). Kinship networks can function as a safety net, but they can also be exploitative: girls are sent to richer households in the extended family to do housework, boys may be sent out to sell their labour or goods on the street. Nevertheless, parents, siblings or cousins may help to feed a destitute family and care for ill relatives. For example, one interviewee, Maria, receives great

support from her sister-in-law and her family. She and her teenage son depend on this family network when Maria gets ill or has no income. The family is helping Maria's son through secondary school, instead of demanding that he earns his and his mother's livelihood. But long-term dependence on wider kinship networks also heightens people's awareness of their vulnerability and may result in tensions (Beckmann, forthcoming). When possible, people try to avoid too much dependency.

Maria's situation, receiving great support from her sister-in-law, is an exception. The majority of female interviewees in this study faced many difficulties surviving with HIV. Women who are widowed due to AIDS are vulnerable to the anger of their family-in-law and may be thrown out of their house and ostracized. For example, Rehema, a woman in her late thirties and mother of four, was ostracized by her family-in-law after her abusive husband died of AIDS. She lost the house she lived in and the land they cultivated. When we met, Rehema, her four children, Rehema's sister and her baby lived in a rented room with one bed and were desperate for access to food and clean water. The sisters' own family was not mentioned at all as married women tend to move close to the husband's family and often do not own the house they live in. But many women and men also experienced hostility from their own parents and siblings. For some interviewed people, this meant complete estrangement from their own family, as in the case of Mariamu whose mother shut her out when she disclosed her HIV status. Many households affected by HIV do not cope, but dissolve, disintegrate, as Rugalema observes (2000). Some surviving family members may be absorbed into other poor households, such as Rehema's sister and her young baby, but it is difficult to speak of 'managing' in their case. In most cases, family support needs to be negotiated and renegotiated on a daily basis. The burden of care that falls mainly on women, plus their economic dependency on men, makes them very vulnerable in the face of HIV/AIDS. As I discuss elsewhere (Boesten, 2009), poverty and gender inequality also feeds into unsafe sexual behaviour among women in Migule, such as having multiple sexual partners, not using condoms and not disclosing HIV status to new sexual partners.

ART has changed the outlook of survival and suffering for HIV positive people in Migule. Between 2005 and 2007, the population of Migule got access to ART via the hospital programme in the district capital. However, the response to ART from the

general population has been mixed. Many people believe that the lives of HIV-positive people should not be extended as it would increase the likelihood of the infection spreading, thus keeping HIV in the community. Some religious leaders in Migule echoed this view to their parishioners. Such viewpoints not only reinforce the stigma and discrimination attached to HIV, but ultimately discourage people to come out, test and seek access to treatment. Persistent aggression towards HIV-positive people also means that people who do seek treatment do so in secret, and often try to conceal their health status. For example, Flora, a woman who was openly positive and part of community-based organizations when we met in 2005, had turned secretive about her health in 2007. The difference was the ART: now that she was physically much stronger because of the drugs, she was keen to show her family, her neighbours, and, most importantly, any potential employer, that she was fit and healthy and did not need any support. For her, ‘living positive’, i.e., openly HIV positive in order to reduce the stigma and encourage others to be tested<sup>9</sup> serves little purpose if the stigma itself impedes full participation in work and society. When we met in 2005, she said she felt ‘prematurely dead’, ostracized by the community, including her own family. In 2007, ART offered her the opportunity to work again which facilitated her reintegration into the community. Thus, for some HIV positive people, ART offers an opportunity to resume a ‘normal’ life, to adapt back into society instead of continuously facing discrimination due to the stigma attached to HIV/AIDS.

This transition from being vulnerable and dependent to fit and independent is, however, not always long term. As Nadine Beckmann observes (forthcoming), adherence can become a problem as people get used to feeling good again or the treatment itself can place a strain upon the body — widely known as treatment fatigue. In addition, people may drop out of treatment because of other reasons — more immediate threats to livelihoods, for example, a lack of food, funding and time to undertake trips to the hospital. Taking drugs for survival could well be meaningless when living with seven people in one bedroom without sufficient income for food or access to clean water, as in the case of Rehema and her sister. While Rehema’s situation is extreme, all interviewed people were struggling to survive on a daily basis. Most had different narratives about their survival strategies over time, as did Flora.

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<sup>9</sup> The idea of ‘living positive’ and how this may influence people’s identities and citizenship is discussed elsewhere (Boesten, under review).

Situations change as opportunities come and go and health deteriorates or improves. It is at the intersection between regained health and independence and the responsibility for a vulnerable household in adverse circumstances that people get entangled in the AIDS industry. Most people who were involved in Kikumi had become involved when they were reasonably healthy and had sufficient time and energy to spend on community work and to learn the procedures involved in navigating the industry. The leadership of Kikumi spent much time talking to relevant parties, such as doctors, nurses, district officials and representatives of NGOs and CSOs, in order to find ways to fund activities, food baskets and housing for orphans. This strategic navigation took time but also gained them experience, and in the long run, access to resources. For some members of Kikumi this became a daily activity and a means to survive. For others, active membership of such an organization was temporary when in desperate need or involvement may be only from a distance, in anticipation of worse times to come. Of course, people's initial need, both in terms of health as well as in terms of livelihoods made them the intended beneficiaries of this industry in the first place. Unfortunately, this is not how it turns out for most HIV positive people struggling to survive on a daily basis.

### **People Living with HIV/AIDS and Community-based Organizations**

The number of government and third sector organizations and institutions that directly or indirectly influence the response to HIV/AIDS in Migule is vast. A whole range of government institutions are involved: TACAIDS, NACP and a series of decentralized multi-sectoral committees at regional, district, ward and village levels. All operate according to the terms of engagement laid out by the MAP. Multilateral organizations (Global Fund, World Bank, UNDP, AMREF, WFP) also fund NGOs and large-scale programmes and support different types of capacity building initiatives throughout Tanzania. Universities that conduct AIDS research on regional and district hospitals influence access to treatment and care and sometimes also provide training for local healthcare personnel. Nurses employed by the dispensary in Migule have attended these courses. Bi-lateral donors, international NGOs and faith-based organizations fund community-based projects and national NGOs. All of these initiatives, the funding flows, knowledge and the 'experts' involved together represent the AIDS

industry in Migule and directly or indirectly influence the response to HIV in the town and the wider district. Several organizations provide direct support to poor families in Migule: World Vision provides school fees and uniforms for vulnerable children, parishes and mosques often provide small amounts of money for medical bills or food, WFP provides food, and a US-based Christian organization, Compassion, has a ‘sponsor-a-child’ programme in the district. While this seems like a lot of support, it was not sufficient to cover all people who needed aid.<sup>10</sup>

In practice, few representatives of the aid industry were accessible to beneficiaries and much aid was delivered by local CBOs. Funding, training, resources and institutional support offered by national and international agencies to CBOs were not sufficient and often contradictory (see Boesten, Mdee and Cleaver, 2011), reinforcing existing patronage relationships between local leaders and the population. Competition among beneficiaries over access to scarce resources provided by CBOs could be fierce: for example, a continuous conflict over WFP food baskets distributed by the local women’s organization played out in Migule between 2005 and 2007. The issue was impossible to resolve: too few food baskets for too many people placed the needy at the mercy of an elite that was given the task of selecting beneficiaries. Competition over access went hand in hand with accusations of corruption and withholding information; well-meaning community members became villains in the eyes of some, and villains sought strategies to control access to food in the eyes of others. It turned into a messy conflict over daily survival and community support. The precariousness of life in a context of poverty and disease did not make people more generous towards each other. On the contrary, it led to a competition of ‘who suffered most’ in order to access scarce resources. A lack of clarity regarding who is in charge — local government, local community leaders of CBOs, INGOs or multilateral organizations —, and competition over scarce resources created much trouble for community initiatives (Boesten, Mdee and Cleaver, 2011). The roll-out of ARVs may have worsened the situation. As Kalofonos (2010) observes with regard to Mozambique, the need for a decent diet when taking ARVs and the lack of a simultaneous scale-up

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<sup>10</sup> The Director of District and Community Response of TACAIDS expressed her serious concern about the concentration of aid in this region, as opposed to the relative abandonment of other, perhaps even poorer, regions in Tanzania. Interview September 2008.

of food support creates a situation of competition over food handouts, which, both in Tanzania and Mozambique, undermined the potential for community solidarity.

However, external support is essential for poor people living with HIV considering the impoverishment of many people live and the speed at which whole families disappear and households dissolve. In Migule, a group of people living with HIV/AIDS established community-based organizations in order to get direct access to resources — circumventing community patronage systems such as those played out in the distribution of WFP food baskets. The emphasis on CDD and GIPA in the wider aid industry makes this possible and even desirable. Indeed, the group was advised to create an organization by people who were well connected to the aid industry at national level. At this level, people living with HIV/AIDS have been encouraged to establish organizations since the early 2000s. The leadership and members of these CBOs in Migule were not political elites and did not have social standing in the community other than through their own merit and among their peers. Thus, the aid industry offers disenfranchised HIV-positive people new opportunities through community work and the idea of inclusion. However, similar to the feelings of tokenism among international AIDS activists, HIV-positive community leaders, such as Mr Msangi in Migule, expressed their disappointment and cynicism about participation in governmental and nongovernmental committees at town, district and regional levels. The condescending attitudes of experts and professionals in such committees, most notably expressed in the remuneration level of those officially regarded as ‘experts’ and ‘beneficiaries’, in particular, was an affront. It seemed that often people living with HIV/AIDS were invited to join committees so that the experts could tick the ‘participation’ box, but often without serious consideration of the knowledge and experience of the invitees. The ‘consolation’ is that in Tanzania, the custom is not only to reimburse transport costs and provide food, but often to pay participants ‘sitting fees’— an allowance for showing up. So despite the lack of a feeling of appreciation, sitting on boards and committees has become an income-generating activity for several HIV-positive leaders in Migule. In addition, the creation of CBOs for and by people living with HIV/AIDS attracts funding and some people have made use of this opportunity.

For example, Mr Msangi, widely known just as ‘Msangi’, is in his late twenties. He is

married to Joyce and has two children. Joyce and Msangi were both active in youth organizations when they tested positive in 2003. As they had experience of community organizations, setting up and being active in CBOs for people living with HIV/AIDS followed automatically. Settling in Migule in 2003, they became members of the recently established organization, Kikumi. Charismatic and well-connected, Msangi has since chaired the organization, making it a widely known and successful CBO by and for people living with HIV/AIDS. Kikumi received three sewing machines from World Vision, and more sewing equipment and carpeting tools from the McKnight Foundation (Minnesota) and from a regional NGO. These were used to set up sewing and carpeting workshops for girls and boys who would, according to Kikumi, otherwise have had to earn their living on the streets. The sewing workshops for girls were relatively successful; carpeting for boys appeared more difficult. Caring for children is central to Kikumi's objectives; considering that all members have or had small children, and most care for deceased relatives' children as well, this is a priority. Educating the children about the risks of sex, keeping them off the streets (girls involved in sex work, and boys, albeit seldom discussed, (see Lockhart, 2002) is a real concern), sending them to school if possible, giving them a home and, in doing so, securing a future for them, serve as motivation for most of the HIV positive parents who are active in Kikumi. The Msangis have taken in six other orphaned children of relatives and with one of the grandmothers they are a household of thirteen. Msangi owns a camera and presents himself as photographer whilst Joyce helps him in this profession. However, the people of Migule rarely require the services of a photographer, and when they do, the profit margin is very small. Hence, the family's main income is generated by growing an acre of maize. Again, this is not enough to maintain their extended family, and both Joyce and Msangi are frail and often too ill to work the land. Over the years, applying their leadership skills in the organization has become their main income-generating activity.

Kikumi offers the Msangi family the possibility to earn a bit for themselves and for several children they care for through the tailoring workshop the organization has. This is a collective enterprise as the tailoring activities absorb children that other families cannot support; hence, the community is supportive of Kikumi and its caring capacity and the vocational training they offer. Not only the Msangis benefit: the children and their relatives benefit, and earnings are also used in other community

activities. Besides the Msangis, Kikumi has a secretary and a treasurer, plus thirteen other members. These members all have a stake in HIV in Migule, either because of their profession (a nurse is member), because they care for orphaned children, because their family is heavily affected by HIV, or because they themselves are HIV positive. Kikumi has a constitution and is registered as a CBO, a requirement to obtain government funding. Besides vocational training, in 2005 the organization also provided home care, gave talks at schools and clubs, distributed information (leaflets) and condoms to women working in and men frequenting bars, did outreach work among families and individuals at risk and provided tailored seminars for orphaned teenagers.

When I met the Kikumi members in 2005 the organization was strong. They were popular and well known among the population of Migule and also among governmental and nongovernmental agencies at district and regional level. While Msangi said that government (especially the district council) was only interested in them showing up at meetings and carrying out voluntary work, he thought NGOs were more generous and did provide assistance. Apart from World Vision and the one-off donation from McKnight, Kikumi worked closely with four other NGOs and networks and received medicines and condoms from the dispensary, albeit on an irregular basis. One year later, Kikumi also received funding from the District Council and the Regional Facilitating Agent (which allocated TACAIDS funding, i.e., multilateral), indicating that by 2006, government funding was also starting to reach the targeted communities. As mentioned at the beginning of this article, the British-Tanzanian NGO, Village to Village, with funding from Rotary Netherlands, sponsored the building of a Kikumi community house for those affected by HIV, especially children, which was finished in 2008.

In return, Kikumi provided support to many vulnerable adults and children in Migule. The organization allocated transport money to people who needed to go to the district hospital, took in orphans, distributed food baskets (from government) when available, and provided the above-mentioned services of HBC, outreach and information and education to the wider community. Of the sixteen active members, not all members could be equally active as most members were preoccupied with income-generating jobs or heavy caring duties, thus having less time for involvement in time-consuming

activities such as HBC, outreach work and seminars. However, all of these members provided some intellectual, financial or practical input. A small group of about three to four people led Kikumi and were most active. These included the Msangis, plus the secretary of the group, Mr Msuya. A distinction can thus be drawn between ‘active members’, consisting of leaders and other members, and ‘non-active’ members, those who benefit directly or indirectly from the organization’s services. The beneficiaries are largely very vulnerable people without a regular income and who have difficulty accessing food, schooling and healthcare. Considering that the majority of the population do not have formal employment — apart from those in education, health and law enforcement of course — and the impoverishment of most families due to high medical bills, loss of income and increased caring responsibilities, the demand for the support provided by Kikumi was huge. Of course, not only the very poor, but some working in the public sector, also contracted HIV. However, as they enjoyed a steady income and certain status in the community, these people generally did not disclose their HIV positive status and are not members of support organizations. In this sense, material support available does reach the most vulnerable as few people would come out as HIV positive to access aid unless really necessary.<sup>11</sup>

According to beneficiaries and activists, Kikumi was more accessible than other CBOs in Migule that were linked to government or otherwise existing structures of patronage. There were two such initiatives for people living with HIV in Migule. One was a system of ‘Village Health Workers’, i.e. volunteers trained by multiple external agencies and loosely linked to the local dispensary who were assigned to deliver home-based care to chronically ill people, including AIDS patients. However, few HIV-positive people sought their help, as the profile of health workers was perceived to be too public due to their ties to government and religious organizations. A second initiative came from a women’s group, which provided home-based care and distributed food baskets. The women’s group was generally perceived to be less accessible due to their relative elite status in the community based on class, age (largely elderly women), education and ties to government. Again, these were not the

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<sup>11</sup> Accusations that people ‘fake’ HIV status in order to access aid are widespread among Tanzanians. This may be true, but if so, only for very vulnerable people who do need the support. The stigma attached to HIV is likely to be too damaging for people to fake it if they do not need the material support that becomes available when disclosing HIV positive status.

people that most vulnerable and poor HIV-positive people felt comfortable confiding in, although material support was certainly sought from them. Kikumi offered a different kind of support: stigma is absent, they offer social and emotional support from experience, have a personal stake in confidentiality and they approach people with a strong and realistic focus on the future — even if that involves imminent death.

Thus, despite the multiple direct or indirect links between the institutionalized AIDS industry and the affected population there are no clear and accessible structures that allow vulnerable people and households to access services. Nevertheless, CBOs such as Kikumi provide the networks of care envisioned by the aid industry in the approach of community-driven development and greater involvement of people with HIV/AIDS. These CBOs are then an essential component of the aid industry that provide the link between the funding made available and the most vulnerable, without which the industry would not be able to decentralize and delegate so much. The discussed CBOs carry out the hard work of providing care, basic treatment and organizing prevention activities at community level which national and international organizations and agencies are willing to fund. This could be called cost-effective community-based development through the greater involvement of people living with HIV/AIDS. However, there are multiple problems with such an analysis compared to what actually happens on the ground. As the infected and affected people in poor countries are ‘helped to help themselves’, they do not receive the professional support, education and salaries that other participants in the industry receive. Instead, they are confronted with a fragmented aid industry that offers unpredictable and never sufficient support — all too often delivered in a condescending manner. To compete for funding, CBOs have to submit written project proposals which require a certain skill at writing and framing them. This is time-consuming and competition and fragmentation demands that CBOs submit various proposals simultaneously in order to fund different ‘bits’ of a project (e.g. one for food support, another for transport, children, housing, health care, and so on). Funding was insecure, and one year’s funding — or project-length funding — is not a guarantee for future funding. In addition, the CBOs were in charge of deciding who the beneficiaries would be. With always more families and individuals in need than support available, this often led to conflicts between potential beneficiaries and leaders of CBOs and to very real problems with regard to the sustainability of networks of care.

When one NGO agreed to fund specific underfunded aspects of Kikumi, things temporarily seemed to be going well. When the organization finally obtained a building, beds, mosquito nets, electricity and a playground, a child minder had to be appointed to ensure proper care for the Kikumi children, which the NGO paid for. After a few months of a seemingly smoothly functioning ‘orphanage’,<sup>12</sup> some members of Kikumi started to complain that the organization was investing too much money in the orphanage and child minder, also taking care of the Msangi children. Why did Kikumi not spend more on other issues that might be of interest to other members? Other Kikumi members were resentful about the salary paid to the child minder; why she and not someone else? Why is the child minder paid but not the leadership, the secretary or those giving home-based care? These questions were impossible to answer. Is there a good reason to privilege one person over another? Does a market-based rationale work in these circumstances? Who is more needy, if so many HIV positive people in Migule have less than one dollar a day to live on and need is defined by access to water, food and medicines for survival?

### **AIDS as a Project**

The activists living with HIV/AIDS in Migule are aware of the capricious character of the aid industry and adapted to this by diversifying and proliferating their activities. In 2007, the number of CBOs had risen significantly and I counted eight established CBOs that directly targeted vulnerable people, people living with HIV/AIDS and orphans. The leadership and members of these organizations largely overlap. Five of the organizations had a combined membership of 78 members, half of which was ‘active’. The other half was (potential) beneficiaries. Three of the active members (the Msangis and Msuya) sat in the managing committee of all five groups. These CBOs differ in their aims and objectives in so far that they can link up to different ‘types’ of funding and focus on different target groups, such as orphaned children, women, people living with HIV/AIDS and the elderly. Technically, an umbrella group

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<sup>12</sup> Children were often called orphans even if only one of the parents had died. Other children may not be orphans at all, but abandoned all the same, and several of the children in Kikumi’s care were HIV positive and often ill.

represents all groups and by establishing links to trends in the aid industry, the leadership maximizes the likelihood of obtaining support.

For example, in 2006 Kikumi created a group for elderly people affected by HIV/AIDS. The group represented both HIV-positive elderly people and grandparents who cared for their grandchildren. The elderly are increasingly recognized by the aid industry as group needing special support, but also one that can be mobilized to carry out community work in the area of HIV such as HBC and prevention (HelpAge, 2004). One way to gain access to such valuable support is by becoming more visible as a group. In June 2007, a group of elderly connected to Kikumi performed plays before community and district leaders in an effort to raise awareness of their plight and affirm their commitment, but also in the hope of obtaining funding. Orphans and children living with HIV/AIDS are also mobilized to perform before potential benefactors and supporters. They perform songs and plays that communicate their vulnerability, need and gratitude. Another strategy to draw attention to need is showcasing people's suffering. For example, in early 2007, Msangi went on a mission to write down the stories of individual children in Kikumi's care, translate these into English and, accompanied by the saddest portraits, presented them to potential funders. This approach resembles the fund-raising strategy of any Western NGO that shows pictures of (particularly children's) suffering in an attempt to convince the public to donate money. However, as it exploits suffering, it also magnifies the perversity of such strategies. A couple of months later, with no funding immediately forthcoming, few children of the group Msangi had portrayed were still in Migule. Some had died, some had gone onto the streets and a few had been absorbed by the households of relatives or neighbours. The industry appeared not to be flexible and quick enough to respond to the immediate needs of groups of abandoned children, while the CBOs at whose doors the children arrive do not have the material or human resources to deal with them either. A strategy of organizational diversification that included a specific intervention for children seemed an obvious next step. In mid-2007, a Children's Trust focussing on fundraising for children was established in Migule. The Children's Trust was chaired by a person who was new to the scene of AIDS activism in Migule, but who was strongly allied to existing leaders and could rely on Joyce Msangi and Mr Msuya as secretary and community representative, respectively.

Whilst the objective of the proliferation of groups representing people living with HIV/AIDS is to expand the possibilities for access to funding for the vulnerable, it nevertheless generates resentment among those CBOs and beneficiaries who feel left out. By 2007, the Msangis and their friend Msuya had a fulltime job managing these circuits of care, including the funding that is received. The fact that the three main strategists of this fragmentary approach also benefited the most generated much suspicion among beneficiaries, other CBOs, town leaders and funding agencies. However, care networks are greatly advantaged by the knowledge of the leaders. The networking they do at district, regional, national and global levels raises awareness among current and future sponsors. But while the leaders receive a reasonable income through the attendance of seminars and courses, sitting on boards and carrying out paid outreach work for NGOs, the beneficiaries in Migule sit and wait in the hope that the leaders succeed at gaining access to programmes that provide transport money or food baskets. By mid-2007, the beneficiaries of the CBOs accused leaders of stealing funds, while government and nongovernmental professionals viewed both leaders and beneficiaries as opportunists fighting over material support. As we saw at the beginning of this article, well-placed members of the community accused less well-placed people of opportunism and even of using AIDS 'as a project' in their attempt to gain access to as much resources as possible. In-fighting, caused by increasing tensions over leadership, accountability and responsibility, combined with tensions within the community over access to resources, led to the disintegration of the once successful CBO Kikumi.

## **Conclusion**

The roadside town in this paper is linked to the global AIDS industry through a myriad of institutions and interventions. However, these institutions are often largely invisible and difficult to penetrate, while interventions are often fragmented and insufficient. Groups of people living with HIV/AIDS help establish contacts between vulnerable people and the AIDS industry via care networks. However, individuals' participation in these structures of funding and AIDS governance is not based on equality or inclusion, as discourses of participation, multi-sectorality and involvement

suggest, but on voluntarism. While development workers, researchers, health workers and bureaucrats are embedded in the institutional framework of the AIDS industry and earning decent salaries, people infected with and affected by HIV/AIDS are expected to mobilize themselves and provide services at little or no remuneration. They are expected to carry out the most vital of functions within the global response to HIV/AIDS, namely to maintain networks of care for the most vulnerable people. As the case study illustrates, community-based organizations can only do that with the support of a strong and creative leadership that have access to an income allowing them to dedicate time to community-level AIDS activism. The case study illustrates how people navigate the aid industry in order to fulfil those conditions, but also how these strategies of survival and care undermine networks of trust.

For well-connected individuals involved in CBOs for HIV/AIDS, fulfilling the role of leader can become an occupation and a livelihood strategy. Entire (extended) families survive on sitting fees. This money is often also used to care for vulnerable people close to the family, for example, orphans and/or someone in the organization who does voluntary work (see also Nguyen, 2005: 124). Kikumi organized a range of other activities that benefitted the community. Nevertheless, despite the large number of people who depended on the networks of care, such navigation through the seminar circuit of the AIDS industry was often resented. It is worth emphasizing once more that only the poorest, unemployed people tend to seek access to these networks of care, since it forces them to disclose their HIV status to at least a part of the community. While, arguably, this implies that richer people miss out on the social and emotional support provided through networks of care, it also means that the poor people are publicly identified as both HIV positive and poor. It is likely that such exposure fed into the resentment some beneficiaries felt about the relative economic 'prosperity' of leaders who had access to meetings with sitting fees and project money.

On the part of the donors who fund AIDS projects, criticism was directed at both beneficiaries and leaders of CBOs. CBOs with overlapping membership and the same leadership come across suspicious: as if leaders are setting up fake organizations in order to obtain more money. In international development jargon, this strategy can easily be classified as 'resource capture' and the 'proliferation of opportunistic

CBOs'. In development slang, such organizations are referred to as 'briefcase NGOs'. Such negative assessments of the recipients of aid are rarely mentioned in official reports and project evaluations of INGOs as this would put the funding agency in a bad light, but it is a widely acknowledged problem among international experts and development practitioners. Proliferation, however, is the result of the competitive structures of funding imposed by the industry and its tendency to provide partial and short-term funding. Funding opportunities are often tied to particular 'target groups' — women, the elderly, children — and often address only one aspect of the need, and not the rest. CBOs go to great lengths to gain access to such funding; they perform plays and make children sing and dance, they write reports and travel to make sure they are favoured by the funding organizations. And they set up organizations that match the demands and expectations of the AIDS industry. Hence, the fact that Kikumi — and others in the community — used 'AIDS as a project' is merely an effect of their compliance with the demands of the industry and its funding structures. Poor people living with HIV had to actively engage with the industry in order to gain access to resources which allowed them to maintain the networks of care. In the final analysis, one could say that this group of people living with HIV understood and navigated the industry quite well, regardless of the fact that it ultimately led to the disintegration of their organization(s).

There is one set of measures that would immediately improve the situation of CBOs responsible for maintaining networks of care 'on the ground'. First, CBOs should be professionalized and institutionalized. Leaders must be provided with proper training and monthly salaries, instead of repetitive seminars whose primary purpose is sitting fees. CBOs should be provided with institutional support and be given an actual say in community- and district-level HIV interventions. Second, if resources are allocated, they should be adequate — food baskets for all who need it and sufficient transport money and school fees. Care must be taken to ensure that allocation is fair and rules are followed that people can identify with. This can be achieved, for example, by allowing beneficiaries to participate in setting the rules for access to benefits. Support should also be consistent instead of unreliable and competitive. These two sets of measures would be easy to implement if the aid industry were reliable and consistent, well-coordinated and accountable to beneficiaries and if it was willing to incorporate their local partners into their economic and institutional structures in fair and equal

manner.

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Jelke Boesten is Senior Lecturer in Social Development and Human Security at the School for Politics and International Studies at University of Leeds. Apart from HIV/AIDS in East Africa, she is interested in gender, policy, and violence in the context of Latin America.