



Praxis Note No. 43

Seeing with perspective

Using 'insider- outsider' dynamics to reflect on the civil society response to HIV/AIDS

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August 2008

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International NGO Training and Research Centre

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We need to look at HIV/AIDS from different perspectives. Disputes arise in both learning and practical action when we view HIV/AIDS from a single angle. In this article Snelder and Kerkhoven¹ argue that to learn effectively and avoid bias we need to look at HIV/AIDS as both ‘insiders’ and ‘outsiders’. They also advise addressing HIV/AIDS as both a health and as a developmental issue; as both an issue to mainstream in external programmes as well as internally in organisations. Looking at HIV/AIDS from different viewpoints – programmes, organisations and context, we can gain and retain perspective. This will help us respond to HIV/AIDS with insight and vision.

Who are we?

This article is the product of many years professional engagement with HIV/AIDS. We have worked with a range of civil society organisations (CSOs) in the North and South. In doing so we have been grappling with a set of basic questions²:

- How is CSOs capacity impacted by HIV/AIDS?

¹ This article is adapted from a longer article. A copy of the full version can be obtained from the authors. Both authors were formerly employed at the [PSO Knowledge and Learning Centre](#). Roel Snelder now works as a process facilitator at [Agri-ProFocus](#). Russell works at the [International Reference Centre](#) on Water and Sanitation as Head of Information and Communication.

² Interestingly, these questions are now much clearer to us than at the start of our learning curve. In fact they may even be more of a product than a predefined set.

- How are funding agencies and southern CSOs dealing with the impact of HIV/AIDS on their work, on their organisational capacities?
- What are the consequences of this impact for CSOs’ position?
- What are important matters and lessons of concern?
- And what are relevant questions we need to keep asking ourselves?

HIV continues to spread in most of Africa and Asia and in the most affected countries, like Zimbabwe, Botswana and South Africa, it is clear that we are not yet in control of the epidemic. We do not have the ‘answers’ yet. But we have learnt considerably along the way. To better address HIV/AIDS in the future, we need to learn from our experiences and share them with others. This is our contribution.

Insider – outsider learning dynamics

We have found the notion of being an ‘insider’ and an ‘outsider’ to working with HIV/AIDS a revealing model. Insiders are those whose central focus is dealing with HIV/AIDS, mostly AIDS service-oriented organisations and AIDS service professionals. Outsiders are those professionals (and organisations) that come across HIV/AIDS in their work and who are exploring how they should respond.

Russell is an ‘insider’. He has been directly involved with HIV/AIDS and employment issues in Zimbabwe and Southern Africa. This included initiatives for and assistance to the formulation of SADC and national HIV/AIDS

and employment policies in the mid nineties.³ He helped design and develop INGO HIV/AIDS policies in the Netherlands. He researched on HIV/AIDS in the internal workplace amongst Dutch civil society organisations working in international development.

He then joined PSO⁴ to assist them develop their organisational response, looking at its own HRM policy as well as starting a learning trajectory on HIV/AIDS and capacity building for is Dutch member NGOs. At PSO he encountered Roel.

Roel is an HIV/AIDS 'outsider'. As a learning facilitator with PSO and with a long-term involvement with capacity building of CSOs, Roel stepped into a new and 'highly contentious field'. Discovering the variety of positions and experiences in HIV/AIDS, he was sceptical of ready-made solutions applicable to and acceptable for all civil society organisations⁵.

From the beginning the insider–outsider positions among ourselves created a productive tension, which we used as a design principle.

Through dialogue and avoiding getting submerged by HIV/AIDS content, we 'treasured' the contrasting position and resulting dynamic. Such dialogue led to, at times, heated exchange on issues, such as power, relationship development, and organisational competencies, coming as we did from different perspectives.

³ The National Employment code on HIV/AIDS in Zimbabwe was developed by a multi-sectoral committee (this code inspired the development and adoption of a SADC AIDS and Employment code in 1997).

⁴ PSO, is a Dutch association of over 50 civil society organisations, that operate internationally and share a focus on capacity development.

⁵ A short inspiring view of 'sceptical' can be found in: The quicksand of quick fixes: the vexing temptation to make AIDS manageable, Hein Marais, 2004 (www.aids.org.za/?q=book/view/206)

Organisational perspectives – the boxing myth

As we consulted on what PSO's role should be in HIV/AIDS, we were met with initial hesitance and even suspicion from the insiders in the HIV/AIDS community. We were an 'outsider'. We also had no wish to become an HIV-specialist organisation. We did not want to be in competition with insiders. But we did not want this lack of HIV/AIDS specialism to be interpreted as saying 'HIV/AIDS does not affect us'. We wanted to become AIDS-competent. We wanted to add something positive to the situation and do so in a collaborative manner.

We wanted to 'add value' to the response by focussing on something important, but something different – the 'human resource dimension of HIV/AIDS'. Our starting question was - How is civil society organisations' capacity impacted by HIV/AIDS and what are the consequences for their position? This niche fitted well with PSO's extensive experience with capacity building. It was an area where limited work had been done and we together with many others were at the start of a learning curve.

Breaking through closed language

We found that the human resource side of the epidemic is understood differently by insiders and outsiders. Some see HIV/AIDS foremost as a hugely debilitating factor to development at large. This means that any professional (working in high prevalence areas) needs to factor it in; especially those working in capacity building. In working on HIV/AIDS the 'HR side' should be viewed as an approach, as opposed to an intervention area. Insiders (those directly involved in HIV/AIDS work or 'living' in its context) generally translate the 'human resource side' less in methodical/conceptual terms and more in a direct, people, sense. It's about colleagues getting sick, dying; to them the issue appeals at a much more personal and emotional level.

"A telling example is a reaction I (Roel) got from an activist at an INTRAC conference in Johannesburg, where I had the role of, and presented myself as, a relative outsider 'looking

in'. I was scorned for not identifying enough with those suffering from HIV/AIDS with the remark: 'anyone working with organisations from South Africa should be an HIV/AIDS expert'. At first I felt this was beside the point as I wanted to make clear we needed to look at the bigger picture. Lately I have come to observe that this is a very significant feature of how HIV/AIDS affects development professionals."

"A much earlier – similar – illustration of this was my (Russell) experience with the South African AIDS Consortium in 1997, where a professor of communication who attended the South African AIDS Conference, observed after three days that 'we' the HIV-groupies and AIDS-activists clearly understood each other with heated debate going on, but that as an outsider to this 'community' it had been totally impossible for him to understand what it was all about. And that as a result he had not been able to enter into a reasonable conversation with anybody."

Both examples reveal that closed language implies HIV/AIDS can only be really understood by 'those in the know'. This dynamic has consequences for how professionals practically respond and for how they learn with others. Consequently when working on HIV/AIDS it is important to continuously explore the meaning of language in order to avoid misunderstanding and encourage learning. This starts with understanding your position and your individual or organisational comparative advantage in becoming engaged with HIV/AIDS.

Learning from different angles

To address our central questions – How is the CSO capacity impacted by HIV/AIDS? What are the consequences for their position? – PSO contracted two pieces of research to feed into a seminar for members.

INTRAC was commissioned to look at evolving practice and to build shared understanding of the issues involved. This work focused on HIV workplace issues⁶. The lead researcher for

⁶ See: Rewriting the rules? Capacity building in times of HIV/AIDS, 2004, PSO, R. James

INTRAC, Rick James, took an insider's perspective. He was deeply immersed with Malawian NGOs who were dealing with the internal consequences of HIV/AIDS on a massive scale. Rick approached the issue from a people's perspective (visualising what HIV/AIDS does to staff within an organisation). This resulted in the research focussing predominantly on the 'internal' functioning of southern NGOs containing a lot of valuable detail.

To counterbalance this, Alan Fowler, a specialist in civil society capacity building issues – and in his own words rather uneducated on HIV/AIDS – was contracted to articulate a broader (outsider) perspective. His 'thinkpiece' (Civil society capacity building and the HIV/AIDS pandemic: A development capital perspective⁷) takes the angle of human capital.

Both articles were used as input for a seminar with PSO members. Participant reactions fitted the perspectives they brought. People tended to look at the issue through a single eye. For the insiders, the human capital approach was felt to be too abstract. But they identified with Rick's work and articulated a clear sense of urgency for action now. The 'outsider' generalist agencies reacted rather defensively to the suggestions that they should get involved at the level of the work place. But dialogue was underway.

Learning carousel

We observed that this learning dynamic of bringing 'insiders and outsiders' together for a more practical exchange was worthwhile. We designed a follow-up learning experience, but used a different process – a learning carousel in June 2005⁸. We explicitly shared ownership of the conference and invited all parties to present

(<http://extranet.pso.nl/asp/documentsite.asp?document=353>).

⁷ Civil society capacity building and the HIV/AIDS pandemic: A development capital perspective, 2004, PSO, A. Fowler

(<http://extranet.pso.nl/asp/documentsite.asp?document=354>).

⁸<http://extranet.pso.nl/knowledgecenter/agenda.asp?dossier=10>

their experience and 'state-of-the-art' methods to the wider development sector. Presenters were encouraged to use creative methods such as role play, individual reflection, and experimentation with different conceptual models.

Overall we saw that while generalist (OD practitioners, donor staff, and consultants) found it difficult to cross the divide between HIV/AIDS and development, those working in HIV/AIDS had a hard time letting go of their exclusive HIV/AIDS focus. The carousel also showed us that in terms of HIV/AIDS competencies both 'insiders' and 'outsiders' need to learn to:

- address their own biases
- work more from and with partner's experiences
- be very aware of using blueprint model
- have an open dialogue with various stakeholders
- experiment and look for cooperation and linking up with likeminded organisations.

These are key reference issues in relational facilitation⁹.

Strategic focus in HIV/AIDS work

As well as tending to learn from just one perspective – using one eye – we also have observed that we implement our HIV/AIDS work with a single perspective. There are two major areas of strategic tension, where taking a dual perspective can help:

- HIV as a health or a developmental issue
- Mainstreaming HIV internally and externally

HIV/AIDS – a health or development issue?

Many CSOs, including PSO, have taken a narrow response to HIV/AIDS. We have observed:

- The emphasis is on raising huge funding to support programmes aimed at care, including

the provision of antiretrovirals in settings with failing or semi-functional basic health services

- Especially non-HIV/AIDS organisations are adding 'stand alone' HIV/AIDS related projects to existing programme portfolios (such as work place policies projects) with the inherent danger of diluting their core business
- Many initiatives are working vertically (often through new channels) rather than integrating and investing in existing (health care) systems
- There is a constant (threat of) draining away of scarce capacities (human resources) from other priorities (e.g. in health care but also in other sectors)
- The agenda setting for these developments in the last analysis lies predominantly with northern donors.

Although it is professed not to be an emergency the interventionist and action-oriented frames of reference dominate¹⁰. Such responses are based on:

“we (in the north) have a responsibility; let's intervene/allocate directly for the most obvious problem: which is people are getting infected and dying”.

It shows the seductive lure of the 'desperately trying to contain the disease without exploring the context and history of the communities' focussed action-responses; without an understanding of the dynamics of the system in which the epidemic occurs. The immediate wish to actively engage with HIV/AIDS is understandable and seems to be one of the motives of jumping to action, with the danger of treating HIV/AIDS as a single intervention or vertical programme issue, and thus treat the symptoms and ignore the drivers or root causes.

PSO tried to help members take more and broader perspectives in deciding how to respond to HIV/AIDS. We believe that the concept of vulnerability is key to understanding HIV. Vulnerability to HIV is the absence of sufficient

⁹ See the PSO learning trajectories on balancing between advisor and funder, in collaboration with Frank D. Little. He currently conducts a shorter version with MDF.

¹⁰ See Helen Epstein, *The Invisible Cure: Africa, the West and the fight against AIDS*

power and the ability of choice of people, communities and organisations to minimise their risk of exposure to HIV infection and, once infected, to receive adequate care and support¹¹. HIV and related illnesses spread unevenly in any population. Those sections of the population that are less empowered through limited access to basic social services, (formal) employment or essential resources are more vulnerable. Similarly if there are extensive patterns of discrimination based on gender, ethnicity or sexuality, the spread of HIV/AIDS tends to follow these patterns. Vulnerability also extends to society at large; the social, economic and political sphere. HIV/AIDS also aggravates existing inequalities.

We believe that in responding to HIV, CSOs need to see HIV as both a medical and a developmental issue. It is about taking a both/and response, not an either/or view.

Mainstreaming – internal or external?

Responding to HIV/AIDS can be reduced to a choice between two jargon words: ‘internal and external mainstreaming’ (though Sue Holden’s useful work on mainstreaming HIV/AIDS¹² goes way beyond the jargon). Many of the responses have been one or the other. There has been little attention to the development of complimentary relationships. For example one international workshop organised by INTRAC in 2006 focused on internal mainstreaming issues and resisted the pressure from PSO to also include external mainstreaming issues.

We need to take a more open approach to mainstreaming practice, incorporating more than one perspective – seeing the issue with more than one eye.

¹¹ Human Rights and HIV/AIDS, HIV InSite Knowledge Based Chapter, 2002, S. Gruskin and D. Tarantola (<http://hivinsite.ucsf.edu/InSite?page=kb-08-01-07>).

¹² Mainstreaming HIV and AIDS in Development and Humanitarian Programmes, 2005, S. Holden (http://publications.oxfam.org.uk/oxfam/add_info/006.asp#contents).

Internal mainstreaming: a new fad?

According to earlier research¹³ Dutch CSOs, although active as funders of HIV/AIDS programmes and projects abroad were ignoring their responsibility as employers (be it HQ and field staff or experts in the field). The human resource dimension of HIV/AIDS received only scant attention in their relations with partner organisations. But by 2008 many Dutch NGOs working on HIV/AIDS or in high HIV-prevalence settings have changed their stance in a significant manner; a host of different initiatives centred on HIV/AIDS have been developed. An evaluation of the Dutch co-financing agencies¹⁴ clearly shows a lot of this energy is going into the promotion of internal mainstreaming as a strategy to support CSOs in high prevalence settings, with the support of StopAIDSNow!

But too much attention on the internal may distract CSOs and their funders from their mission – to change the lives of beneficiaries. Too much emphasis on the internal may also seriously threaten the survival of the organisation in the long term. Today mainstreaming HIV/AIDS externally into programmes appears to be an underrepresented topic (at least among some Dutch NGOs). To take a holistic approach of addressing both internal and external simultaneously is a tricky organisational process. It needs a learning by doing approach in which donors and partners alike are willing to cooperate, adjust and change.

Using multiple perspectives

Factoring HIV/AIDS into working with CSOs can never be the exclusive responsibility or domain of AIDS-focussed organisations. General development organisations, specifically those working with civil society, appear to be struggling with all kinds of demands to respond, such as: the need to demonstrate engagement with

¹³ Human Resource Management and HIV/AIDS - a study among Share-Net members, Share-net, 2004

¹⁴ Synthesis Report of Dutch CFA Programme Evaluation - MBN HIV/AIDS Evaluation, 2001-2004 (www.partos.nl/uploaded_files/Synthesis-report-HIV-AIDS-English.pdf).

HIV/AIDS, to demonstrate results and to meet funding requirements, combine focus and exploration of new methods, target groups or interventions. Three perspectives emerge for general development organisations to factor HIV/AIDS into their work:

CSOs through an HIV/AIDS lens

There is extremely little systematic and documented evidence as to the extent of devastation (apologies for crisis terminology) the HIV/AIDS pandemic is having on CSOs. Most evidence tends to be biased towards internal issues related to staff and policies in more or less formal NGO settings, as opposed to other types of CSOs. The wider impact on civil society development and organisation is not explored in high prevalence settings. A more systemic capacity building analysis is lacking¹⁵. This leads to solutions at the organisational level, but with a predominantly, limited, HRM focus.

HIV/AIDS through a programming lens

This more or less says: engage with HIV/AIDS but do it in a developmentally sound way. In other words: adapt your programmes and activities accordingly to mitigate for HIV/AIDS impact amongst your membership or target audience. While looking at HIV/AIDS through a programming lens non-engagement becomes precluded, with differing options for general development organisations versus HIV/AIDS or health focused organisations. For both it means choosing an appropriate strategy to broadening scope and/or engagement in advocacy.

Development through HIV/AIDS lens

A third route is to take a more contextual approach and look at development in a fundamentally different way. Essentially Fowler's human capital approach points at how societies may become dysfunctional as a result of

HIV/AIDS. Therefore he takes development in general as the entry point for defining a response to HIV/AIDS. This is saying that CSOs and their supporters need to 'start again with asking questions' at target group level, and strategise anew on their role and position from there on.

All three approaches have merit as they ask for a reflection on behalf of organisations wanting/ needing to engage with HIV/AIDS. As often with choices, the answer lies in the ability or competency to combine perspectives. What strikes us nevertheless is that with regard to HIV/AIDS a basic sound developmental practice is often missing, most possibly as a result of the emphasis on 'suffering' and 'need for action'. In reflection the main issues that need to be considered have to do with what we would call the application of a programmatic approach to development¹⁶. For organisations wanting to develop effective capacity building strategies for CSOs in an HIV/AIDS context, the programmatic cycle emphasises a thorough situational /contextual analysis, genuine dialogue with stakeholders, and a continuous and fresh look at ones own capabilities and inabilities.

In our view this is about explicitly changing the logic around from – what is still the usual project modus operandi – where we work from our intervention models to result to impact, to another sequence from reassessing impact down to defining what we want to achieve and then looking at our interventions. This results in a basic set of explorative questions:

- How does HIV/AIDS present itself in the context we (donors, CSOs etc) work in?
- How is it impacting those we intend to serve/what are their coping strategies/their needs?
- Who is already doing what/what are the existing relationships?

¹⁵ See The Concept of Capacity, Peter Morgan, Study on Capacity, Change and Performance, 2006, ECDPM

(<http://info.worldbank.org/etools/docs/library/232261/Morgan%20-%20Capacity%20-%20What%20is%20it%2010052006.pdf>) or PSO's conceptual framework on capacity building.

¹⁶For an extensive overview experiences and tools with regard to with programmatic approaches we refer to (<http://extranet.pso.nl/knowledgecenter/dossier.asp?dossier=8>)

- How can we use (adapt) our own mandate to assist?
- What does this imply for our work, our relationships and our own capacity?

Cherishing the insider–outsider tension

We have found the ‘insider–outsider’ model helpful to reflect on learning behaviour of development practitioners on HIV/AIDS. In general however the label HIV/AIDS ‘insider’ or expert is uncomfortable, as it are the people who are HIV infected who could possibly lay claim to being an HIV/AIDS expert; at best we are HIV/AIDS experienced. We believe that you cannot work on HIV/AIDS for a long period without being drawn in and inevitably you become a sort of activist, as the dimensions of the pandemic are so overwhelming. Adopting the term HIV/AIDS expert is a too easily assumed title that warrants more profound exploration, especially if you are HIV negative and hail from a low prevalence setting.

This is all the more so as it is important for development practitioners to learn from experience and be able to make a conscious decision between what they want to do, what they should do, and what they are able to do. How can they become competent in HIV/AIDS? How can they learn while needing to act?

Learning in Action

We feel that an approach called ‘stages of concern’ (Cora Smit¹⁷) may be helpful. It describes a staged learning in action approach which follows five distinct stages that adults who need to learn appear to follow.

- Phase 1: yourself: How do I survive as an organisation/as a person?

¹⁷ Hoe leer ik een vak? in Kennis maken, leren in gezelschap Mariël Rondeel en Sibrenne Wagenaar, Cora Smit, 2002 (<http://www.kessels-smit.nl/bronnen/literatuur/Boek%202002%20rondeel%20&%20wagenaar%20-%20kennis%20maken%20leren%20in%20gezelschap.pdf>) .

- Phase 2: your task and responsibility: what is an effective course of action or response?
- Phase 3: the other: what is important for the people/member/staff?
- Phase 4: impact: what should we do differently
- Phase 5: essence: what is the essence of my learning experience/how can I share this?

What we have noticed is that (putting it strongly) the HIV/AIDS competent (the ‘insiders’) appear to routinely utilise an information– dissemination approach which starts by presenting the basic facts on HIV and then moves on to a participatory discourse that focuses on becoming HIV competent. This is assumed to be good or for your benefit. For some reason the emphasis is on making people aware that they are as yet incompetent. The self-appointed HIV/AIDS experts then will patiently take you along the learning route that they earnestly believe to be made for you. The prescription is that you need to follow a full cure of pre-programmed knowledge that will lead to greater enlightenment. It is only after you have followed this course of being informed and made aware that you find yourself back in the competent domain.

On the contrary, the attraction of Smit’s approach is that recognising the different stages suggests that different learning arrangements and designs should be used adapted to specific situations. The starting point in every phase is a joint exploration of the work experience of the people or organisations concerned. The point here is that this joint exploration involves both the realities of the partner or CSO and the (co)funding agencies.

The phases mentioned suggest an order of progress that is based on a profoundly explorative dialogue that requires time and space for reflection. Taking the step towards genuine dialogue involves mutual exploration of the underlying assumptions and routines. At the organisational level this suggests an understanding of the organisation of its own operational context. It may mean exploring to

what extent and manner the target group (beneficiaries, members, participants) is beginning to change.

Progressing from one stage to the next is more than just time and reflection it requires developing alternative or additional actions. Such interventions need to be based on an increasing understanding of the current situation and articulating further steps. Questions that will surface might be that organisations are beginning to lose key staff due to the massive influx of HIV/AIDS funds; how do you survive as an organisation that is faced with a massive drive towards adopting an HIV/AIDS focus? For social movements or membership organisations that are not necessarily AIDS focussed, there are other questions and dilemmas concerning the move towards HIV/AIDS focussed activities. In order to ensure ownership it is essential that autonomous decision making is respected. If there is limited time or occasion for such a profound conversation, it seems inevitable that well-known dynamics of an imbalanced relationship based on control of funds will emerge.

Smit reflects that progress through the subsequent stages is the outcome of a reflective process that is owned by the person or organisation and not induced through pre-programmed knowledge. She also observes that not all people manage to make the step from phase 4 to 5, as this requires profound exploration and making the assessment of what is an essential contribution to make.

This article presents a number of frameworks for reflection and analysis to come to an inspired response. We invite readers to apply them in combination. We also struggled with their application and still struggle with translating some of the resulting analytical insights into other programmes we are involved in. That is part of our learning. We believe that, however challenging, it is worthwhile for development professionals (and the organisations they 'belong' to) working with CSOs in HIV/AIDS contexts to seriously reflect on their contribution. We hope our observations and reflections prove to

be helpful to being able to see HIV/AIDS with more than one eye. This will better enable us to tackle HIV/AIDS with perspective, vision and insight.

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